Parents Caring, Sharing, and Learning Together Online: An Exploratory Look at Informal Learning via a Health-Related Support Group in Facebook

by

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ABSTRACT

Using an adapted Straussian Grounded Theory approach, and as a participant observer, data from members of a Facebook group made up of parents and caretakers of infants or children with Gastro Esophageal Reflux Disease (GERD) were collected and analyzed. During the first exploratory phase, 31 semi-structured interviews were conducted with 25 theoretically sampled members of the group. During the second phase, 604 postings (original and comments) created by members of the online social media group, for one week, were analyzed. The study explored various dimensions of informal learning in this space. These included what learning strategies members used, what types of knowledge were encouraged and shared, how community within the group was characterized and its role in the learning space, what factors led members to join and share knowledge, and what patterns of participation existed in the group.

The findings revealed a core concept of a disconnect between group members and their medical community that drove participation in the online health-related social media group, as well as a substantive theory of learning to survive. A new framework for understanding online informal learning spaces in social media was developed and proposed. It was adapted from Wenger's Community of Practice and Gee's Affinity Spaces. Its key components include a disconnect; inherent learning processes; community and space characteristics; and types of knowledge that are encouraged and available. Findings also contributed to a better understanding of online information-seeking behaviors by introducing a new model of information-seeking within online social media groups. This model includes the stages of initiating, lurking, and browsing; requesting information; being guided by a highly knowledgeable member; reconciling; applying;

and appraising. The model is a continuous cycle with entry and exit permitted at each stage based on the learner's needs. In addition, this study's findings demonstrate that social media spaces are a viable avenue for the transferring of experience-based knowledge.

DEDICATION

This dissertation is dedicated to my family who gently prodded, supported, and cheered me on throughout this process. It is also dedicated to all those immigrant children like me who arrived not knowing a word of English, not having many worldly possessions or privileges, but who have been able to work hard and contribute to the shaping of a better, more equitable world.

Thank you to my parents, Nelly and Victor, for being brave enough to leave your home for a new land in search of better educational opportunities for your children. Without your courage and hard work, this would have not been possible. *Si se pudo*!

Thank you to Cynthia, Greg, Fernando, Cecilia, and Adrianna. Your unfailing support and belief that I could do this was a tremendous boon when the going got tough.

Thank you to Paquita. You showed me that a strong, courageous, smart woman is a force to be reckoned with.

Thank you to my husband, John. We have been through some trials by fire and have come out so much stronger. Thank you for your patience and support and for believing in me when at times I did not believe in myself. Thank you to my daughter, Isabella, for understanding when mommy had to do "homework" and had to miss family and play time. I hope you know that you can achieve anything you dream and work toward.

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To the members of the online social media group that I explored in this dissertation, you are a wonderful example of caring, strong, and courageous parents. Your willingness to learn and seek knowledge to care for your children when it seems like everything is working against you is truly noble. Thank you for letting me explore your space and learn from you. Laura and the other admins, thank you for supporting my study and being such exemplary, selfless leaders for the group. I hope one day that infant and childhood GERD is no longer a traumatic, solitary experience that countless children and parents suffer through. Thanks for showing me that working together, we can create and share knowledge, and support each other.

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LIST OF ACRONYMS

Acronym:	Full term:
BC	Because
BF	Breastfeeding
DD	Dear daughter
DR	Doctor
DS	Dear son
EP	Elimination protocol
GERD	Gastro esophageal reflux disease
GI	Gastroenterologist
H2s	Histamine 2 Blockers
HRS	Hours
LBS	Pounds
LO	Little one
MARCI	Midwest Acid Reflux Children's Institute
MGS	Milligrams
ML	Milliliters
MSPI	Milk soy protein intolerance
PED	Pediatrician
PH	Numeric scale to assess acidity or basicity
PPI	Protein pump inhibitor
RX	Prescription
SNS	Supplemental nursing system
TED	Total elimination diet
TSP	Teaspoon
TT/LT	Tongue tie/Lip tie

CHAPTER 1

INTRODUCTION

I was ecstatic when I found out about my pregnancy. Preparations leading up to the birth consumed me for nine months. I dutifully attended parenting classes and tried to follow my doctor's instructions without fail. As the end of my pregnancy approached, an unexpected cesarean did not fluster me. In fact, I was glad that my child's health and safety would be the priority. The first few days in the hospital after the birth were challenging. My newborn would not latch on and even when she did, she seemed to have trouble swallowing. Hospital staff minimized my concerns and chalked it up to technique. Upon being discharged from the hospital, my newborn continued to struggle to eat. It was as if it hurt to swallow. Her first few days home she cried all day and night. I called the doctor seeking help and was told to switch to feeding my child formula instead of breastmilk because was not gaining weight as she should. Even though my heart ached at not being able to provide my child with the immunities my breastmilk contained, I deferred to the pediatrician and switched to formula; however, a few days into the formula feeding, my newborn began projectile vomiting after meals. The force of her vomiting was so severe that the vomiting arched out several feet from my daughter's mouth as we, her parents, scrambled to find a way to soothe her. My daughter's discomfort was not limited to just vomiting. She would choke and stop breathing even when all she was doing was just laying on her back in her crib. Sleep was fleeting and crying was constant both day and night. As days became weeks, I repeatedly consulted her pediatrician only to be told that what my child was experiencing was normal and just colic. I was given suggestions that upon trial, failed to bring about any improvement in

my child's quality of life. I sought out advice from parents geographically close to me, but no one seemed to understand or have experienced what my child was going through. Sleep deprived and out of my mind with worry, I began looking online for information. Like a puzzle I had to put together, I found bits and pieces of relevant information. I struggled to reconcile what I saw occurring with my child at home and what her pediatrician was telling me. I continued searching online and found a forum where a group of parents discussed symptoms similar to my child's and discussed the diagnosis of Gastro Esophageal Reflux Disease (GERD).

I went back to my child's pediatrician with this information and asked about GERD. The doctor said some colic was normal even though my child was losing instead of gaining weight, crying constantly, and hardly ever sleeping. Everything came to a head late one night as we took our child to the emergency room of a children's hospital an hour away from our home. My child was dehydrated, weak, and needed help. At the children's hospital, my child was diagnosed with GERD. She was put on H2 blocker medication and sent home. The medication began working almost immediately and my child finally slept, ate, and seemed at peace like other infants. A few months later as she gained weight, the medication began failing and her previous symptoms came back. I consulted with a specialist this time, a pediatric gastroenterologist, who agreed with the GERD diagnosis, but did not think we needed a medication change. Once again, my child was crying for hours after each meal and unable to sleep for more than an hour at a time. Again, I began searching for answers online as I felt a complete disconnect between what I was experiencing at home and what our specialist was advising. I went back to the online forum I had visited before. This forum connected me to a Facebook group. I

explored the entire Facebook group, reading all the documents and postings even from years back. I spent time daily with other parents of children with GERD, sharing knowledge based on our life experiences, and trying to make sense of what we saw at home and what our child's pediatricians and specialists were advising during 15-minute appointments. It has been several years now, and I am still a member of this online group even though my daughter's GERD has been controlled for years. Every day I read experiences of others going through the same exact struggle I went through and witness their relief at finding a group of others who understand and who have knowledge to share.

Through this experience I realized that of all the sources of information I had consulted, the informal learning space was the most helpful in helping me learn about GERD and navigate one of the most challenging experiences of my life. This realization made me want to learn more about naturally occurring, passion-centric online spaces and the participatory informal learning that occurs in them. The following chapter discusses (a) what is known about informal learning, (b) the gap that exists within research on informal learning in online spaces, (c) the purpose and progression of the study, and (d) the limitations of the study.

Informal Learning

Although there is a robust body of research on learning, our understanding of what learning is, where it occurs, and how it functions continues to be an evolving process (Livingstone, 2001). Livingstone identified four different types of learning that differed by who controlled the learning. The first type was formal education, where an instructor decided when a learner had met a curricular outcome taken from an existing

body of knowledge. The second type was non-formal education which was characterized by the learner choosing to gain knowledge or skills by voluntarily studying with an instructor who helped further the outcomes identified by the learner. The third type was informal training where an instructor or mentor shared knowledge in a more real-life setting without a curriculum. The last type of learning-the focus of the study- was informal learning where learners, either alone or with others, acquired knowledge without an instructor or an organized curriculum. Members of the Facebook group who participated in the study met in an informal online space, shared, and acquired knowledge without any formal instructor or curriculum.

Conceptualizations of Informal Learning across Time

Although informal learning has been of interest for some time, our understanding of it has evolved across time. Focusing on the informal learning of adults in the workplace, Saul Carliner (2013) identified six distinct conceptualizations of informal learning that have occurred.

The first conceptualization of informal learning that Carliner (2013) identified occurred in the 1800s as people observed others around them in the *school of life*. Youth would learn by observing experienced adults. They would learn skills as well as morals and values held by their community. As time went on, these systems became formal apprenticeships. The second conceptualization Carliner (2013) described occurred in the 1980s and was comprised of self-directed learning, human performance interventions in the workplace, computer-based training, and a reimagining of museums as informal learning centers. The third conceptualization in the 1990s included the use of electronic performance support systems which aided employees by giving instructions, tracking

performance, and giving instant feedback. The fourth conceptualization in the late 1990s consisted of the formation of knowledge management systems in the workplace. Knowledge management systems aimed to capture, store, catalog, and make accessible tacit knowledge. During this time, computer-based training transitioned to web-based and virtual e-learning. The sixth conceptualization of informal learning emerged from the rise of social media and online social networks in the 2000s. Although Carliner and other informal learning researchers have not expounded much on this last conceptualization, it is the one that this study is focused on.

Daniel Schugurensky (2000), studying adult informal learning developed a taxonomy that focused on intentionality and consciousness. Schugurensky's taxonomy focused on three forms of informal learning: self-directed learning, incidental learning, and socialization. Having been a member of the group prior to conducting the study, I observed all three of the forms of informal learning that Schugurensky described in the group. I describe each form in greater detail in the following section.

Self-directed learning. Schugurensky (2000) described self-directed learning as learning activities taken on by people individually or as a group without help from an instructor. Self-directed learning can involve the help of an individual who can facilitate the process but does not consider themselves an instructor. Self-directed learning is knowingly undertaken and conscious because the learner knows they are learning something.

Incidental learning. Schugurensky (2000) described incidental learning as learning activities that the learner experiences without intentionally seeking them;

however, learners in an incidental learning situation are aware that they learned something.

Socialization. Schugurensky described socialization as a process that is unintentional and unconscious. In this type of informal learning or what some refer to as *tacit learning*, individuals internalize skills, values, and so on, that happen during their daily life and often do not even realize they have learned something (Schugurensky, 2000). The previous section has described differences among types of informal learning; characteristics that all forms of informal learning share are described in the next section.

Characteristics of Informal Learning

Research has shown that informal learning covers a wide variety of rich and valuable learning experiences. In fact, much of the significant knowledge that individuals use in life is acquired through informal learning situations (Schugurensky, 2000); however, researchers have found that there are some key characteristics that seem to exist across most informal learning situations no matter what their type. The key characteristics are that informal learning is shaped by the learner; informal learning is not location-specific; informal learning is unstructured; participants self-select; and informal learning is indeterminate and more of a process than an end. I describe each of these in further detail in the section below.

Shaped by the learner. Researchers found that informal learning was shaped by the learner's "choices, preferences, and intentions" (Marsick & Volpe, 1999, p. 4). It was prompted by the learner facing a challenge or trying to meet an unexpected need and not "from demands or requirements imposed from the outside" (Callanan, Cervantes, & Loomis, 2011, p. 647). According to Carliner (2013), "informal learning refers to

situations in which some combination of the process, location, purpose, and content of instruction are determined by the worker, who may or may not be conscious that an instructional event occurred" (p. 5). The learner is responsible for selecting the objectives, methods, and if they choose, also the assessment of their learning.

Not location-specific. Other early attempts at studying informal learning were based on where the learning occurred. Vygotsky (1962) stated that informal learning consisted of *everyday concepts* garnered through lived experiences rather than *scientific concepts* taught in a formal classroom. Many prior researchers thought that formal learning happened in formal classrooms of institutions of learning whereas informal learning occurred outside of these institutions; however, more recent research shows that informal learning is not location-specific and can happen anywhere (Callanan et al., 2011) as is the case of online informal online learning space that is the focus of this study.

Unstructured and self-selected. Researchers also examined how informal learning events were organized. In contrast, formal learning usually involved an instructor who followed an established curriculum consisting of objectives, content, assessments, and some type of credit or reward afforded by the sponsoring institution. Informal learning was "predominantly unstructured, experiential, and non-institutional" (Marsick & Volpe, 1999, p. 4); however, over time, this dichotomy started blurring as in the case of asynchronous e-learning tutorials or mentoring programs or lunch and learns which required formal coordination but were considered informal learning because learners self-selected to participate (Carliner, 2013).

Indeterminate and a process of becoming. Hager (2006) examined multiple types of in-person informal learning situations and found that informal learning is indeterminate. Its end cannot be pre-specified because this type of learning is highly contextual and based on the learner. Learning of this type is more of a process than a product. Informal learning happens as life presents needs and opportunities to learn. As Hager (2006) stated, "learning is about ongoing becoming rather than about attaining a particular state as a preparation for something else" (p. 238).

Although research on informal learning has been happening for several decades, there has not been much research on informal learning within newer spaces like social media. The research that exists has focused mainly on the informal learning that occurs in museums and in the workplace as discussed in the next sections. Exploring this available literature informs the study despite it not being focused on informal learning within social media.

Informal Learning in Museums

Research on adult learning in museums has focused on the training of staff and volunteers and informal learning of visitors. Dudzinska-Przesmitzki and Grenier (2008) conducted a literature review of museum research and found that most of the research focused on how museum visitors affected their own learning through personal agendas (including individual motivation and learning strategies), prior knowledge, and attitudes. The studies also focused on how museums influenced the learning of adult visitors through exhibit design efforts. Overall, Dudzinska-Przesmitzki and Grenier (2008) found that the existing literature was limited and demonstrated "a lack of methodological rigor" (p. 14). They also mentioned two large research limitations: (a) much of the existing

literature on adult learning in museum studies was not theory informed or theory generating and (b) there was an absence of adult education and learning theory within museum studies. According to the researchers when referring to research on informal learning in museums, "Our review found a dearth of empirical work that explored experiential, self-directed, or free-choice learning process using established adult education theory" (Dudzinska-Przesmitzki & Grenier, 2008, p. 19). While the dearth described had to do with informal learning in museums, I believe it also extends to research on informal learning in social media spaces. Therefore, the aim of this present study was to develop—if not a formal theory—at least a substantive theory, as well as examine the informal learning that occurred considering learning theory. Research about informal learning that did attempt to draw from adult learning theory and employed rigorous methodology was research regarding informal learning in the workplace which are described next.

Informal Learning in the Workplace

Much of the literature on informal learning in the workplace has focused on the incidental and socialization type of learning that occurs as employees go about their business of working. The research has found that informal learning in the workplace occurs through observation, social interaction, and problem-solving (Dale & Bell, 1999; Garrick, 1998; Marsick & Watkins, 1990). Communities of Practice (COPs) are a conceptualization of informal learning in the workplace that has been studied extensively and is pertinent to the present study. I discuss this in further detail in the next chapter.

Like COPs, online social media groups are formed around a common concern or passion and involve the sharing of knowledge and collaborative meaning creation.

Following is a review of the research that has been conducted on informal learning within online social media.

Informal Learning in Online Social Media

There was one relevant study found on informal learning occurring within online social media groups. It was relevant to the present study because it focused on the knowledge-sharing and acquiring processes in online social networks. Heo and Lee (2013) used an Activity Theory framework to examine informal learning processes occurring in a blog, *Naver*, and a social network, *Cyworld*. By examining the types of division of labor within these spaces, Heo and Lee (2013) identified three dimensions of learning that occurred in social media: an *acquisition process*, a *reflection process*, and a *practice-based community process*. The first dimension, or learning as an acquisition process, included learners who sought and gained information from others in a passive role. The second dimension included learners who were more active in dealing with knowledge by creating meaning and reflecting on that meaning. The third dimension or learning as a practice-based community described learners who created and increased their knowledge by interacting with others. Heo and Lee concluded that the third dimension of learning was the type that best utilizes the capabilities of Web 2.0 sites.

Other studies have looked at workplace and non-workplace-related informal learning occurring within social media utilizing the COPs theoretical framework. These studies are described in the next section.

Informal Learning in Workplace-related Online Communities of Practice within Online Social Media

A few dissertations (Davis, 2010; Dolan, 2013; Smock, 2012) and a research article (Mak, 2013) were found that specifically explore online communities of practice (OCOPs) within social media. Dolan (2013) focused on the use of Facebook, LinkedIn, and Twitter in the workplace to help foster workplace learning, building engagement and COPs. Dolan shared that even though he could not make any statistically significant inferences, he found evidence "that indicated that social networking sites were contributing factors in informal learning within an organization, and that they were useful in building networks and engagement among employees" (Dolan, 2013, p. iii). In addition, he concluded that although social networking sites in his study site met several of the criteria of COPs, they did not promote significant, long-term interactions between members and therefore could not be considered true COPs. Dolan's conclusions were limited by a very small sample size.

In her dissertation, Davis (2010) explored connectedness or sense of community and professional development in an OCOP within LinkedIn. Davis focused on the use of OCOPs for ancillary learning by workplace training and learning professionals. Davis also examined the transfer of learning from the social networking site to workplace practices and professional development. She used a mixed method, sequential, quantitative data priority approach in her study. Davis began by administering a web-based survey, Rovai's (2002) Classroom Community Scale, followed by semi-structured interviews, and an analysis of network members' postings. Davis found that there was a statistically significant correlation between connectedness or sense of community and

learning. Connectedness explained 46% of the variance in means. Davis also found that most of those she interviewed self-identified as lurkers or those who seldom post message, but that they observed and read messages posted by others. She cited legitimate peripheral participation (LPP) as a key component of OCOPs. She theorized that these individuals might not have benefitted from their membership in the group as much as those who had posted.

In the single journal article found on OCOPs within social media, Mak (2013) examined how work place socialization can be achieved through Facebook status updates. Mak (2013) used the COP theoretical lens and discourse analysis method to analyze over 60 status updates made by a new employee and his co-workers over a period of five months. He found that chitchatting in status updates helped employees understand workplace norms and engage in workplace socialization. Mak concluded that examining chitchatting in status updates could provide insight into the process of transitioning from a new member or employee to a full member or employee of a team. Most of the limited literature available on OCOPs within social media discussed earlier has focused on workplace learning. In the next section, I discuss OCOPs occurring in social media that were not work-place related.

Informal Learning in Non-Workplace-related Online Communities of Practice within Online Social Media

One dissertation was found that examined OCOPs within social media in a non-workplace-related context. Smock (2012) focused on the use of Flickr as a COP in a non-workplace context and was the study that was most closely aligned to what was explored in the current study. Smock's (2012) focus was on exploring group membership, activity,

learning strategies, and how expertise is shared within Flickr. He used the COP theoretical lens to examine his findings in a two-phase mixed methods approach. The first phase consisted of semi-structured interviews with 21 users of Flicker. The interviews focused on how participants learned about photography through their use of the online social network. Smock used the COP lens to examine the social network's activities. The second phase of his study consisted of an online survey of 200 Flicker users that investigated three forms of participation which were photography posting, commenting, and discussion board postings. Through regression analysis, Smock found that user expertise, exhibited by answering of questions and providing additional materials, predicted a certain type of Flickr COP participation like commenting and sharing knowledge. Smock found that personality traits predicted commenting and asking questions and that participants used two types of learning strategies, solitary and interactive. New members in Smock's study engaged in solitary learning to increase their knowledge and skill and then progressed to more interactive type of learning activities. As a member of the group prior to conducting the study, I observed individuals engaging in both solitary and interactive type learning. Like Smock, I wanted to understand what type of learning participants engaged in and why.

Research Gap in Informal Learning Occurring in Online Spaces

Most of the research that has explored informal learning has focused on in-person physical settings, like museums or the workplace. As discussed above, there is very limited research on the informal learning that occurs within online spaces and especially within social media groups. Facebook has emerged as one of the most popular and lasting types of social media. Therefore, one would assume that there is a better chance of

research on informal learning being conducted in Facebook than other social media spaces; however, Manca and Ranieri's (2013) critical review of the research on Facebook shows that none of the 50 studies that they found focused on the informal learning processes that occurred within social media. In fact, they noted that research on Facebook's potential to bridge formal and informal education is rare and needed (Manca & Ranieri, 2013). Other researchers like Greenhow (2011) concur with these findings and have encouraged further research into the informal learning occurring within popular social media as it can inform the creation and design of formal technology mediated spaces. Searches for studies post 2013 also demonstrate the still-limited research on informal learning in social media.

The present study attempted to contribute to the limited body of research about non-workplace-related informal learning that occurs within groups found in online social media sites. Specifically, this study advances understanding of the online informal learning behaviors of parents or guardians of children with GERD. This study could improve educational practices by offering insights into the learning that occurs within social media which may, in turn, help to inform policy regarding use of online social media within academic settings.

Purpose of the Study

The purpose of this study was to qualitatively explore the informal learning experiences of members of an online social media group hosted by Facebook. Using an adapted (Charmaz, 2000; Corbin & Strauss, 2008; Glaser & Strauss, 1967) grounded theory approach, and as a participant observer, I collected and analyzed data from members of a Facebook group made up of parents and caretakers of infants or children

with GERD. The following guiding questions were used to explore the informal learning that participants experienced:

1. According to participants, what learning strategies do participants use to gain knowledge in this online social media group?
2. According to participants, what factors influence activity in this online social media group?
3. According to participants, what types of knowledge exist in this online social media group?
4. According to participants, what patterns of participation exist in this online social media group?
5. How do participants characterize "community" in this online social media group?

Progression of the Study

I used an adapted (Charmaz, 2000; Corbin & Strauss, 2008; Glaser & Strauss, 1967) Grounded Theory methodology to explore informal learning in an online social media group. Consistent with this approach, the study used (a) theoretical sampling, (b) constant comparison, (c) memo-ing, (d) multiple phases of coding, (e) the use of gerunds in coding and results, (f) concurrent data collection and analysis, (g) member-checking, (h) attempted central theory formation, and (i) triangulation. The data for the current study were collected in two phases. During the first exploratory phase, I conducted semi-structured interviews with theoretically sampled members of the group. In keeping with Grounded Theory, I analyzed data soon after they were collected which further informed the next data collection round. During the second phase, postings (i.e., original and

comments) created by members of the online social media group were analyzed. Using the two data sources served to validate the study findings through triangulation.

Limitations of the Study

One significant limitation of this study was its narrowness. It explored one online social media group, focused on one topic, and examined one type of social media, Facebook, at one point in time. Hence, the results are inherently not generalizable to a larger audience. A second limitation was that I conducted this study as a participant observer. I was a member of the group that I studied for several years before conducting the study, therefore I came into the study with inherent assumptions; however, as described in Chapter 2, I have purposefully employed strategies for enhancing the rigor of the present study throughout the data collection and data analysis processes.

Chapter Summary

In summary, the present study explores informal learning in an online social media group hosted by a social media site using an adapted grounded theory approach. It presents the development of an emergent conceptualization of how informal learning occurs in an online social media group through the use of various Grounded Theory methods and by examining two types of data. The current study makes an important contribution to the literature because it provides a conceptualization for this new phenomenon for which there is a significant research gap.

The following chapters are organized as follows. Chapter 2 introduces the four theoretical approaches underlying the current study. The chapter discusses each of the following approaches in detail: (a) social learning theory, (b) COPs, (c) affinity spaces, and (d) social cognitive factors. Chapter 3 explored the adapted Grounded Theory

methodology that served as the underpinning for the present study. Chapter 4 summarizes the study's findings in a way that is consistent with the use of Grounded Theory by describing themes, their core categories, and the non-core categories that led to them. Chapter 5 presents the substantive theory generated by the associations between the core concepts as well as new models that resulted from the findings. In addition, this chapter explores the contributions the present study makes to the literature as well as implication for policy, and areas of future research.

CHAPTER 2

CONCEPTUAL FRAMEWORK

In this chapter, I describe the study's conceptual framework which centers around the idea that learning is social. As Corso, Giacobbe, and Martini (2009) stated "learning is a social fact, fostered by involvement and participation in a practice" (p. 75). The next chapter will describe the hybrid approach I took to grounded theory in greater detail, but I wanted to explain why I used a conceptual framework in this study. Although classic grounded theory (Glaser & Strauss, 1967) does not encourage the use of a conceptional framework prior to data collection, Straussian grounded theory (Strauss & Corbin, 1998) does because Strauss and Corbin believe it increases the researcher's theoretical sensitivity. As my aim for this study was to develop a theory, I felt a conceptual framework as well as a review of the literature would be appropriate for this study.

The first section of the chapter begins by examining social learning theory which is an integral part of informal learning situations. The second section of the chapter explores the communities of practice theoretical framework which helped form the guiding questions of this study. The third section explores the Affinity Spaces framework which offers an updated understanding of communities of practice (COPs).

Social Learning Theory

At the outset of the study, I believed that much of what occurs within online social media groups could be understood through the lens of social learning theory. Although the focus of extant literature has centered on in-person settings (Bandura, 1986), the findings of that literature can still help elucidate the learning processes that

occur in online social learning settings like the Facebook group explored in the current study. I discuss three of Bandura's key findings that were pertinent to this study below.

Reciprocal Causation and Personal Agency

Bandura (1986) framed human learning as a three-way interaction between environmental variables, person variables, and behavioral variables. Environmental variables included available learning opportunities as well as response-reinforcement. Person variables included pre-existing abilities and beliefs. Behavioral variables were specific actions the learner took in a situation. Bandura (2006) believed that learners had personal agency which they used to seek out environments that met their needs. He proposed that learners were not passive participants of their environments.

Expectations and Self-efficacy

Going further than behaviorists on response-reinforcement contingencies, social learning theorists proposed that learners were aware of existing contingencies and had expectations for future ones. Bandura (1977) explained that learners' beliefs about contingencies were based on their own experiences and the consequences they had seen other people around them experience. Taking this idea further, Bandura (1986) proposed that not only did learners have expectations about the consequences for certain behaviors, but they also had efficacy expectations. In other words, they developed beliefs as to whether they themselves could be successful at certain activities. These self-efficacy beliefs prompted certain behaviors, as learners were more likely to engage in activities in which they felt confident that they would be successful. Other researchers showed that learners who have high self-efficacy for a task achieve that task at higher levels as they set higher goals for themselves, put in more effort, and are not deterred as easily by

obstacles (Pajares, 1996; Zimmerman, Bandura, & Martinez-Pons, 1992). Factors that prior researchers thought to affect self-efficacy include prior success/failure by the learner, messages from others, perceptions of what support is available in each environment, observations of how successful others are, and whether the activity is carried out as a group (Bandura, 1997).

Modeling

A third important principle of social learning theory that Bandera put forth was modeling or demonstrating a behavior for another learner or imitating another's behavior. Bandura (1977) found that models could be live or symbolic, but learners tended to emulate those models that they perceived to be capable and influential. For successful modeling to occur, the learner needed to attend to key aspects of the modeled behavior as well as what had been observed. They also had to have a desire to reproduce the behavior and the ability to physically and cognitively reproduce it. Bandura thought it was best that the learner receive feedback after performance (Bandura, 1986; Schunk, 1981). I revisit Bandura's three key findings of reciprocal causation and personal agency, expectations and self-efficacy, and modeling in Chapter 5 in the context of the present study's findings.

Much like social learning theory, the COP framework is a conceptualization of informal learning that had been studied extensively and is pertinent to the current study. Like COPs, online social media groups are formed around a common concern or passion and involve the sharing of knowledge and collaborative meaning creation. The following section reviews the COPs framework in greater detail.

Communities of Practice

The concept of communities of practice has been around since the early 1990s when Wenger and Lave conducted in-person research at the Institute for Research on Learning (Wenger, 1998, 2000). Later on, additional researchers added to the understanding of in-person communities of practice, but all concluded that a community has a significant role in bringing about "knowledge creation and sharing that allows its members to learn and develop their competencies" (Corso et al., 2009, p. 75).

Lave and Wenger's work positioned informal learning as a group process that occurred between individuals in communities of practice rather than within a single individual (Lave & Wenger, 1991). Through various knowledge-sharing activities, members became a COP (Wenger, McDermott, & Snyder, 2002). Early on, Wenger (1998) listed 14 identifying characteristics of COPs that help differentiate them from other group associations:

1. Sustained mutual relationships;
2. Shared ways of engaging in doing things together;
3. Rapid flow of information and innovation;
4. Absence of introductory preambles;
5. Very quick setup of a problem to be discussed;
6. Substantial overlap in participants' description of who belongs;
7. Knowing what others know, what they can do, and how they can contribute to an enterprise;
8. Mutually defining identities;
9. The ability to assess the appropriateness of actions and products;

10. Specific tools, representations, and other artifacts;
11. Local lore, shared stories, inside jokes, knowing laughter;
12. Jargon and shortcuts to communication as well as the ease of producing new ones;
13. Certain styles recognized as displaying membership;
14. A shared discourse reflecting a certain perspective of the world. (p. 125-126)

Further research found that COPs formed around a common concern or passion and were comprised of people "who deepen their knowledge and expertise in this area by interacting on an ongoing basis" (Wenger et al., 2002, p. 4). Wenger explained that members of these communities met because they found value in the interaction as they learned together by sharing information, helped each other solve problems, thought about common issues, and created tools for shared understanding. Over time, they developed a unique perspective on their topic as well as a body of common knowledge, practices, and approaches. They also nurtured personal relationships and established ways of interacting. They may even have established a common sense of identity (Wenger et al., 2002). Most of the literature on COPs has focused on in-person COPs. A few researchers have explored OCOPs as the following section discusses.

Online Communities of Practice

The limited research that exists on OCOPs has mainly focused on their role in the enterprise learning strategies of corporations (Ardichvili, 2008; Johnson, 2001). Previous research on OCOPs has explored what motivates members to share knowledge (Lin et al., 2009) including factors such as trust, self-efficacy, expectations, (Hsu, Ju, Yen, & Chang,

2007) and social capital (Chiu, Hsu, & Wang, 2006; Hall & Graham, 2004). Lin, Hung, and Chen (2009) investigated what factors determined members' knowledge-sharing behavior within workplace-related OCOPs, or *professional virtual communities*. They developed an integrated model to explain the associations between contextual factors, members' perceptions of knowledge-sharing, knowledge-sharing behavior, and community loyalty. They found that (a) reciprocity-built trust in OCOPs or had an indirect positive effect on knowledge-sharing; (b) self-efficacy, perceptions of relative advantage, and perceptions regarding compatibility did have a significant and positive effect on knowledge-sharing behavior; and (c) knowledge-sharing influenced community loyalty and led to sustainability of OCOPs (Lin et al., 2009, p. 936).

In their study, Hsu et al. (2007) examined the factors that foster or hinder knowledge-sharing behavior in OCOPs. They used a social cognitive theory-based model to investigate factors like self-efficacy, expectations for personal influences, and trust. They found that (a) self-efficacy had both a direct and indirect effect on knowledge-sharing behavior; (b) personal outcome expectation, the belief that relationships with others could be improved by sharing knowledge, had a significant influence on knowledge-sharing behavior; and (c) community-related outcome expectations had no significant influence on knowledge-sharing behavior. These researchers and others identified several fundamental social cognitive factors that influence knowledge-sharing in online groups which are discussed in the next sections.

Knowledge-sharing factors. Learning in a community is inextricably linked to participating in that community. Participants learn as they interact. For example, they engage in cognitive restructuring by having their ideas challenged by other members'

ideas that are different from their own, in a process that leads participants to update their mental models and knowledge (Neufeld, Fan, & Wan, 2013). Participation occurs by interaction and knowledge-sharing. Of the social cognitive factors that appear in the literature on OCOP, the ones that apply most directly to the current study are sense of community, interpersonal trust, self-efficacy and social awareness, and community identity. I discuss these factors in greater detail below.

Sense of community. The amount of support that members feel within a group is an important part of knowledge-sharing. Members who feel that they are part of a group are motivated to cooperate and share ideas and information (Brickson, 2000; Triandis, 1995, 2001; Tseng & Kuo, 2010; Wagner, 1995).

Interpersonal trust. Several researchers (Lewicki & Bunker, 1996; Tseng & Kuo, 2010) investigating communities that engage in knowledge-sharing have found that trust is essential to knowledge-sharing. If members feel that they can rely on others' promises, they will more likely maintain long-term relationships with them because they know they can rely on them for cooperation and sharing of knowledge (Madhok, 1995). Interpersonal trust plays an even bigger role in online communities in which members do not see each other or interact in person, but still share information and experiences (Greenfield & Campbell, 2006).

Self-efficacy and social awareness. Bandura (1997) discussed how important self-efficacy was to learning. He felt that being able to assess one's own abilities to execute behaviors effectively was essential in the learning process. It is also an important factor in self-regulation of motivation and performance (Gist & Mitchell, 1992). When community members feel they can observe and learn from others and can demonstrate

knowledge to others, they are more prone to share knowledge with other members (Kang, Lee, & Kim, 2017). Furthermore, being aware of what others know or do not know-social awareness-also aids members in their assessment of their abilities and the merits of knowledge-sharing with an expectation of reciprocity.

Community identity. Community identity has also been identified as a factor that affects knowledge-sharing (Neufeld et al., 2013). Wenger, McDermott, and Snyder (2002) identified three essential components that must be present in a COP: domain, community, and practice. Neufeld et al. (2013) further expanded on these components by connecting them to three group behaviors indicative of those involved in a COP: shared repertoire, joint enterprise, and mutual engagement. They further broke down shared repertoire into the historical, social, and physical resources shared by participants in a COP such as stories, organizational memories, technologies used, and terminologies/shared languages that were created or adopted (Neufeld et al., 2013). They identified joint enterprise as the maintaining of a common identity formed by a set of pursued interests that narrow the group's focus and delineates what they participate in and avoid. Neufeld et al. (2013) defined mutual engagement as the extent to which members of the COP interact and the evidence of that, such as communication activities and knowledge-sharing as well as interpersonal interactions for problem-solving.

Many popular online social media groups such as the one in this study, can be considered OCOPs when viewed through the COPs theoretical lens. Online social networks are formed by a group of people around a shared concern, problem, or passion. Through ongoing interactions, these groups become further established and develop tools, communications, and other learning strategies. The technological tools inherent in online

community spaces, such as calendars, discussion areas, and archives also help support the learning processes (Wong, Kwan, & Leung, 2011). In addition, as online social networks have text-based conversations that are captured in discussion threads, the meaning making process of informal learning that occurs within them is even easier to study than the informal learning which occurs within in-person COPs (Ziegler, 2014). As Ziegler (2014) stated, "This public visibility makes peer-initiated online communities a venue for exploring the meaning-making process of informal group learning" (p. 64).

Though COPs theory provided a useful framework for exploring social learning within groups, its focus on in-person groups with long-term membership limits its applicability when studying online social media groups. Gee (2004) introduced the affinity spaces theoretical framework to describe spaces that do not fit perfectly into the COP framework. The Affinity Spaces framework is described in the next section.

Affinity Spaces

In 2004, Gee introduced the framework of affinity spaces. He proposed that although people learn by apprenticing themselves to a community that shares practices, as communities of practice framework proposes, there may be limitations to the application of this framework. For example, the communities of practice framework can allude to close personal ties between members, which is a characteristic that may not fit all of these types of social learning settings as some groups are composed of relative strangers, as is the case of the group examined by the present study. Gee also pointed out that COP framework had been used to describe such a wide array of types of social forms that it may have lost its relevancy.

Whereas the word *community* connotes membership by a group of people, a better paradigm may be to think of *spaces* where social interactions occur. This new way of classifying social forms allows for more flexibility and applicability (Gee, 2004). The idea of *space* is not limited to physical space but is extended to *virtual spaces* such as individuals playing chess via email or mail. Gee (2004) went further to discuss a specific type of space called *affinity space* where individuals connected around a shared interest that they had an affinity for. There are 11 features of an affinity space as follows:

1. The first feature is that individuals interact with each other in terms of a common endeavor that is not based on age, race, class, gender, or disability.
2. Newbies and masters and everyone else share common space. Novices and experts are not differentiated. They share a common space and each individual decides how much he or she wants to participate and learn. Even lurkers, those who choose to only read, are accommodated.
3. Some portals are strong generators. Individuals who participate in the "portal" or shared space are able to generate new signs and relationships for the original generator or common endeavor.
4. Content organization is transformed by interactional organization. The content and organization of the common endeavor is significantly altered by the work that goes in the "portals" or shared spaces.
5. Both intensive and extensive knowledge is encouraged. The shared space allows for the development and sharing of both specialized

knowledge (intensive) and general, broader knowledge (extensive knowledge) by individuals who participate in it.

6. Both individual and distributed knowledge are encouraged. Individuals who participate in the shared space are supported in developing and displaying individual knowledge that they hold but are also able to learn to use and contribute to distributed knowledge. Distributed knowledge can be found in other people, materials in the space, or "mediating devices" such as tools, artifacts, and technologies (Gee, 2004, p. 86). Individuals are supported in working together so that their individual knowledge become part of a greater, shared knowledge.
7. Dispersed knowledge is encouraged. The shared space allows for individuals to bring in knowledge and skills from other sources outside of the space itself. This dispersed knowledge is valued and encouraged.
8. Tacit knowledge is encouraged and honored. Knowledge that is internal to individuals is respected and encouraged even if it cannot be fully articulated and was gained only by hands on experience. Individuals have opportunities to articulate this tacit knowledge via postings.
9. There are many different forms and routes to participation. Individuals in the shared space can participate at different levels from being

lurkers to being more vocal, central participants. Individuals at the various levels are allowed and respected.

10. There are lots of different routes to status. Individuals in the space can obtain a high status or respected role, if they wish, in different ways.
11. Leadership is porous, and leaders are resources. The creators or leaders of the space are not rigidly on top of a hierarchy. They do not command, but rather facilitate. Other individuals in the space are allowed to create and lead not just the creators. (Gee, 2004)

More recent researchers conducting studies on affinity spaces, such as Curwood, Magnified, and Lammers (2013), have argued for an update to Gee's (2004) categorization and propose the following defining features of affinity spaces:

- A common endeavor is primary
- Participation is self-directed, multifaceted, and dynamic
- Portals are often multimodal
- Affinity spaces provide a passionate, public audience for content
- Socializing plays an important role in affinity space participation.
- Leadership roles vary within and among portals
- Knowledge is distributed across the entire affinity space
- Many portals place a high value on cataloguing content and documenting practices
- Affinity spaces encompass a variety of media-specific and social networking portals

Chapter Summary

Although much work remains to be done to better understand informal learning spaces, the theoretical framework of social learning, communities of practice, and affinity spaces, described above, provides a foundation for the present study. I revisit these theories in the final chapter to discuss what the findings suggested as relates to these theoretical frameworks. In the next chapter I describe the adapted grounded theory methodology that was used to conduct the present study.

CHAPTER 3

METHODOLOGY

In this chapter, I introduce the epistemological and philosophical foundation for this study. Subsequent to this description is a discussion of grounded theory methodology and why it was appropriate for this study. I then present the research design, including a description of the online social media group in general and then a more specific description of participants and procedures involved in the two phases of the study. For Phase 1, this includes a rationale for the initial selection of participants, recruitment, informed consent, confidentiality, and a sample of semi-structured interview questions, as well as a detailed description of data analysis including theoretical sampling, constant comparison, analytic memo-writing, coding (i.e., open, axial, selective), and theoretical saturation. For Phase 2, this includes selection of participants, recruitment of participants, and data analysis. The chapter concludes with a discussion of my views and biases as a researcher, and the validity and reliability of the study.

Epistemological and Philosophical Foundation

Although the epistemological and philosophical foundation of grounded theory methods continues to be examined and debated (Birks & Mills, 2015), for the purposes of this study, I share the epistemological and philosophical foundations that are most commonly attributed to grounded theory and how those have affected the present study.

Pragmatism and Interactionism

One of the influential Pragmatist authors, Dewey, perfectly captured three key pragmatist beliefs that the present study is based on. The first is that knowledge arises through the acting and interacting of individuals (Corbin & Strauss, 2008). Thus, even if

an individual discovers something as an individual, it is as a result of previous socializations or interactions with others. The second is that a problematic circumstance that the individual cannot solve by reacting in their automatic way or by habit, is the catalyst for the knowledge inquiry they begin (Dewey, 1929). A third is that knowledge and the actions it propels work in tandem.

> Knowledge leads to useful actions, and action sets problems to be thought about, resolved, and thus is converted into new knowledge. In a continuously changing world, generating one contingency after another, this interplay of practice and inquiry is also continual. (Corbin & Strauss, 2008, p. 5)

In this study, the assumption is that members of the group that was explored interacted and co-created knowledge. Their interactions were not a one-time occurrence, but rather an accumulation of interactions and processes that occurred within and outside of the online social media group when they applied knowledge they had gained to their lives. In addition, the group itself and the activity within it is thought to be a result of individuals who encountered a foreign situation or problem, GERD diagnosis for their infants, that they had limited knowledge about, and thus embarked on a journey of inquiry. Last, as members of the group, applied or took action based on the knowledge they gained, it became knowledge which they continued to refine by inquiry and action.

Relativist Ontological Position

Strauss and Corbin (1994, 2008) wrote that the world was complex, and change occurred continually therefore knowledge was also evolving. They believed in a "multiplicity of perspectives and truth" (Mills, Bonner, & Francis, 2006, p. 28). This

aligns with the beliefs of the present study, that understanding of GERD is an evolving process and that the online social media group explored in the study was engaged in a continuous exploration and reframing of life with an infant or child diagnosed or exhibiting symptoms of GERD. The following section describes the grounded theory methods that were adopted as a result of the epistemological and ontological beliefs I had coming into the study.

Grounded Theory Methods

I selected an adapted grounded theory approach to guide the various stages of this study. I felt this approach was appropriate for various reasons. The first was that the goal of this approach is to generate a theory for a process which participants experience. It is inductive by its very nature. The generated theory is *grounded* in the data that participants who have experienced the process share with the researcher (Creswell, 2013). It is especially helpful when trying to understand new phenomena. The goal of this study was to understand the *new* phenomenon of informal learning that occurred within an online social media group from the perspective of those who participated in the group. Second, this approach is appropriate when studying human action, social processes, and social interaction (Annells, 1997). Having been a member of the Facebook group for several years, I experienced gaining knowledge within the group as a highly social process composed of social interactions. Third, Grounded Theory is well suited for studying "social problems or situations to which people must adapt" (Cooney, 2010, p. 25). The members of the online social media group explored in this study were brought together by an unexpected situation (Schreiber, 2001), Coping and learning about GERD their children were experiencing and through the group they were able to share

knowledge to help them adapt. The following section describes some of the history of grounded theory methodology and what grounded theory methods the present study undertook.

History of Grounded Theory

Grounded theory was developed by Barney Glaser and Anselm Strauss in their seminal work entitled, *The Discovery of Grounded Theory* (Glaser & Strauss, 1967). Their work outlined the main techniques of grounded theory including theoretical sampling and constant comparison. Strauss and Corbin (1990) subsequently published additional material which delved into how they thought researchers should approach data analysis. Glaser did not agree with Strauss and Corbin's take on grounded theory methodology (Glaser & Holton, 2004), and thus two types of grounded theory emerged: classic grounded theory, espoused by Glaser, and qualitative grounded theory or straussian grounded theory, espoused by Strauss and Corbin. Other types of grounded theory subsequently also emerged, with the two most well-known being constructivist grounded theory (Charmaz, 2014) and feminist grounded theory (Wuest, 1995). In this study, I employed portions of three types of grounded theory methodology mentioned above, classical grounded theory, qualitative grounded theory, and constructivist grounded theory. In the following section, I discuss how this was done.

Use of Classic and Qualitative Grounded Theory

Elements expounded in classic grounded theory, such as theoretical sampling, memo-ing, and constant comparison, were used throughout this study. Several aspects of Strauss and Corbin's approach, qualitative grounded theory, were also used in this study. One aspect is the postmodern belief that knowledge is co-created and relative. My aim

with this study was to explore the co-construction of knowledge engaged in by a group of people and thus the phenomenon itself is highly postmodern.

A second aspect that qualitative grounded theory espouses is the consideration of the macro conditions surrounding a phenomenon which was important for this study. The group being studied formed spontaneously out of a shared interest and conditions related to that interest, external to the group itself, and continued to grow. Thus, I thought that examining the broader contextual factors that existed around this group was key to understanding learning within this group.

Third, Strauss and Corbin stressed the value of validation, the act of comparing concepts against data by techniques such as member-checking and data checking (Corbin & Strauss, 2008), an aspect which Glaser's grounded theory did not include. This type of validation helped me to accurately understand the phenomena I studied.

Fourth, I used several of Strauss and Corbin's techniques for comparison such as far-out comparisons and the flip-flop technique. Fifth, I used Strauss and Corbin's (1998) suggestions that literature can increase theoretical sensitivity and be useful throughout the research process. As opposed to Glasser who felt that there was no need to review any literature because it would inhibit or constrain analysis (Glaser, 1992). Sixth, I used Strauss and Corbin (1998) method of writing a story about the analysis that was the final conceptualization of the central core category. I share this story in the final chapter of this study.

Strauss and Corbin's (1990) use of preconceived categories (e.g., causes, consequences, conditions), which appeared in their first two editions of their works on methodology and has been less emphasized in more current editions, to analyze emergent

categories felt like it would force findings and so I did not use them. Instead I relied on classic grounded theory's continued insistence on having the data be the result of discovery. I created categories as they emerged from the data and did not try to analyze them with preconceived categories as identified by Strauss and Corbin.

Use of Constructivist Grounded Theory

Although, I did not feel that all the tenets of constructive grounded theory would be applicable to this study, I did feel that a few would be useful. The first is the idea that the interaction between a researcher and participants produces data and thus memos should include the researcher's reactions to interactions with participants. Several of the memos produced in this study are a reflection of my interactions with participants and affected theoretical sampling actions. Second, is the use of gerunds to connote a sense of action (Charmaz, 2000). I used gerunds throughout the study both to code data and to report findings in the final chapters of this study. Using gerunds, I believe forced me to look for underlying actions and to get to a more analytical level of coding versus just being descriptive.

Study Design

The present study was a two-phase qualitative exploration of informal learning in an online social media group hosted by Facebook. I took a qualitative approach to this study because of the newness of the topic of informal learning within online social media group. In addition, qualitative methods are well suited to the field of e-learning in education because the factors and influences surrounding this field are not entirely measurable by quantitative methods (Cox, 2013).

The participants for the two phases of the study came from one online social media group hosted by Facebook. I was a member of several online social media groups that could have been selected for this study; however, I had been a member of this online social media group for several years. In that time, I had developed relationships with the administrator and members of the group which I thought would facilitate the recruitment of participants and give me needed insight into the group and its processes. For example, by having been a member of the group, I knew the various types of subgroups that existed. This knowledge aided in the initial sampling structure.

In keeping with the nature of social media, the online social media group's composition and size was fluid and ever-increasing. It increased its number of members on an almost daily basis. It was composed of 822 members on July 11, 2015; 1,232 members on January 26, 2016; 2,200 on September 2, 2016; and 3,144 on January 30, 2017. A month's worth of activity in this social network shows that on average 9 original messages and 87 comments are posted per day and 71 original messages and 673 comments are posted per week on the social network's wall. This study presented a snapshot of the functioning of the group during the length of the research (2015-2016).

The social media group that this study focused on is a closed group that individuals can only join if approved by the group's administrators. When this study first began, the social medial group's purpose, as posted on the *about* section of the network, was to share advice for the care of *GERDlings* (i.e., infants with GERD) from the *true experts*, their caretakers. During this study, an additional disclaimer was added to the description of the group encouraging members to always seek medical advice and guidance from a medical professional. A pinned post or posting that was always visible at

the top of the page's feed, was also added. The post welcomed members and asked them to post an introduction of themselves and answer 15 questions about their child's reflux condition. It advised members that other members are not medical experts and would be sharing what they have learned through their personal experiences. It also encouraged members to not take anyone else's postings at face value and to do their own research and questioning so that they would be the best, most informed advocates for their child. The purpose of the group also changed to work along with a companion website to help babies/infants/children with acid reflux or various food intolerances/allergies. New members were required to write an introductory post, allow tagging and messaging in their account settings, and could not block administrators.

The social media group's members were spread across the world with a majority coming from the United States. According to the group leaders, there are some differences in age, ethnicity, primary language, marital status, educational level, and socio-economic status (SES) among members; however, members were primarily female, white, living in the United States, with a post-high school degree. Before commencing the study, I obtained permission from the group's administrators to recruit participants for the study from the social media group's membership (Appendix A). The administrator also gave permission and allowed the announcement of this study to remain *pinned* until enough participants were obtained. The University Institutional Review Board approved exempt status for this study (Appendix B).

Study Phase 1

An adapted mostly Straussian Grounded Theory methodology was used because there had been little prior research on informal learning within social media groups. The

first phase of the study consisted of interviews with group members carried out in the tradition of Grounded Theory which seeks to understand a phenomenon from the participants' point of view. Inherent in the grounded methodology and adopted for this study, was the idea that data collection and data analysis needed to occur concurrently and inform each other. Figure 1 shows a bird's-eye-view of which actions were taking place during this phase of the study. The following section describes the selection and recruitment of participants, and data analysis methods for the first phase of the study.

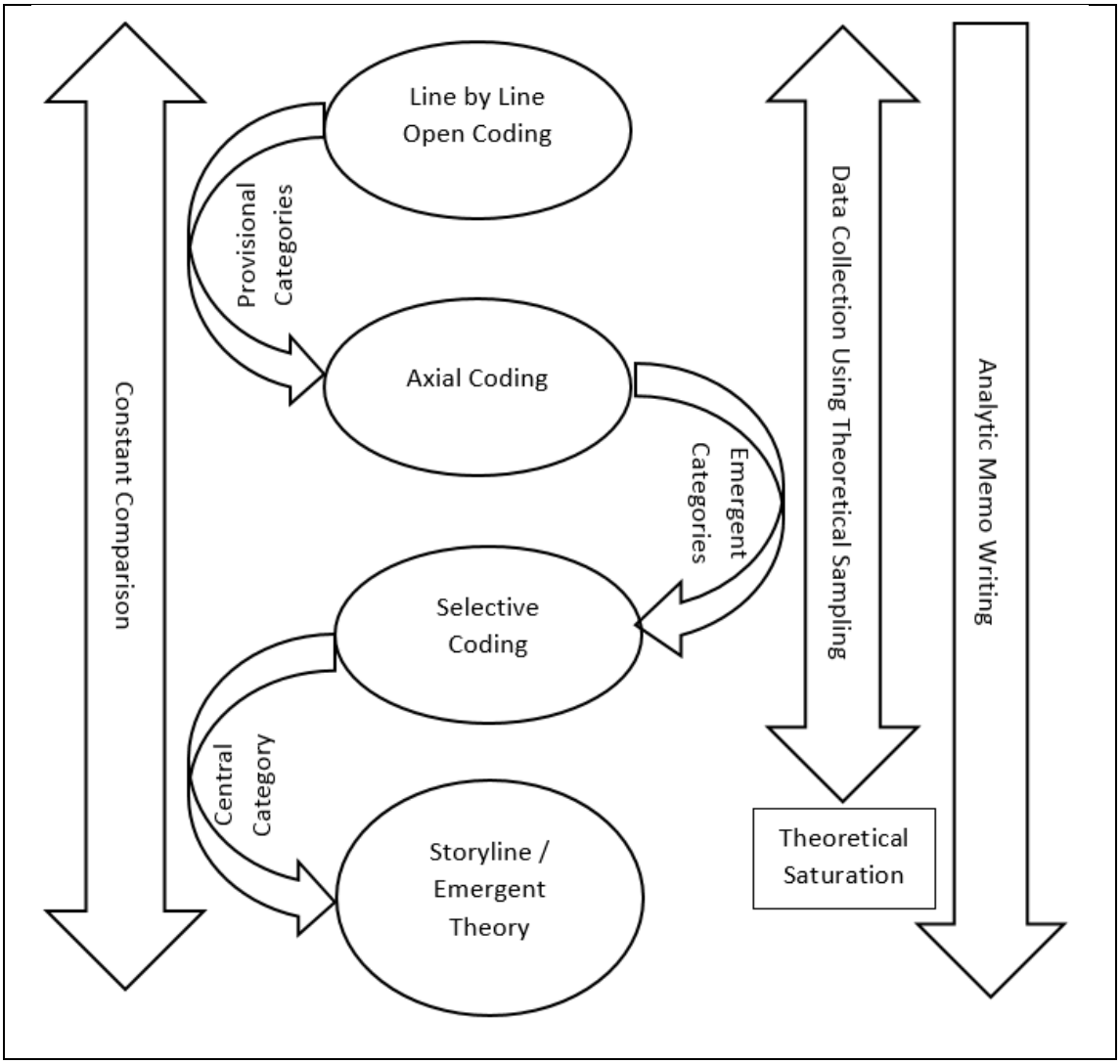

Figure 1. Phase 1 data collection and data analysis.

Selection of Participants

I selected interview participants prior to the data collection for Phase 1, using quota selection (Goetz & LeCompte, 1984). I identified major subgroups that represented certain characteristics, as described below, and then recruited participants from each subgroup. Based on observations I made while participating as a member of the online social media group for several years and the categories that were used in previous research on informal learning within online social media groups (Davis, 2010; Smock, 2012), the following subgroups were used to initially select participants:

1. Frequency of posting
    a. *Frequent*: Members who posted to the social media group's wall (i.e., original message or comment) approximately one or more times a day
    b. *Average*: Members who posted to the social media group's wall (i.e., original message or comment) approximately a few times a week
    c. *Infrequent*: Members who posted to the social media group's wall (i.e., original message or comment) approximately a few times per month
    d. *Peripheral*: Members who never posted to the social media group's wall
2. Length of membership
    a. *Newbies*: Those individuals who were members of the social media group for less than one year

b. *Continuing Members*: Those individuals who were members of the online social media group for one to two years

c. *Long-term*: Those individuals who were members of the social media group for more than two years

Recruitment of Participants

I recruited participants by posting an informational statement about the study on the online social media group's wall. The administrator for the group pinned my statement to the top of the message feed area. Group members who were interested in participating in the study were taken to a webpage outside the group where they were able to read the informed consent statement and if interested, answer a short questionnaire. The informed consent statement included the purpose for the study, study procedures, ways to obtain more study information, and the process for submitting concerns or complaints. The message also informed participants that those who completed an interview would receive a $20 Amazon.com gift card as a show of appreciation for their time (Appendix C). The short questionnaire included the following questions:

- Have you read the informed consent material above, do you acknowledge you are at least 18 years old, and that you voluntarily agree to participate in the study? (an answer of "yes" branched to the rest of the questionnaire)
- What pseudonym would you like to use for the interview?
- What are the best time/days for you participate in an interview?
- What time zone are you in?

- How long have you been a member of this Facebook group?
- How often do you post on the wall of this Facebook group?
- What is an email you can be reached at to set up the interview?

Questionnaire responses helped to determine if participants belonged to any of the subgroups initially targeted. I emailed group members who were selected to be initial participants with several options for interview times. The pseudonym they selected on their initial intake questionnaire was used throughout the study to protect their privacy. On the day of the interview, participants called into a conference line (toll-free number) and upon giving their permission, their interviews were recorded. Interviews were then transcribed. In keeping with the grounded theory approach, interview transcripts were open coded and analyzed within a couple days after transcription. Memos were written after each interview to further the analytical process. Questions that emerged on memos guided further interviews of the same participant or led to the selection of new participants for interviews in keeping with theoretical sampling procedures.

The initial semi-structured interview protocol included closed and open-ended questions concerning participants' activities as members of the online social media group. I reviewed literature on COPs, Facebook, informal learning, social learning, knowledge-sharing, and affinity spaces for theoretical sensitivity prior to data collection (Gee, 2004; Heo & Lee, 2013; Junco, 2012; Kirschner & Karpinksi, 2010). This review aided in the development of initial interview questions. The interview protocol also included demographic questions including gender, highest level of education, frequency of postings, and length of membership in the social network. The following is a sample of

the initial interview questions organized by the research question to which they are related; the full set of questions can be found in Appendix D.

Sample question for Guiding Question 1. According to participants, what learning strategies do participants use to gain knowledge in this online social media group?

17. How do the members of this social network share their knowledge about infant reflux (i.e., knowledge-sharing behavior; Neufeld et al., 2013; Tseng & Kuo, 2010)?

Sample question for Guiding Question 2. According to participants, what factors influence activity in this online social media group?

21. How do you feel about asking questions of the members of this social network (i.e., interpersonal trust and COPs; Chai, Das, & Rao, 2011; Rovai, Wighting, & Lucking, 2004; Tseng & Kuo, 2010)?

Sample question for Guiding Question 3. According to participants, what types of knowledge exists in this online social media group?

12. What knowledge regarding infant reflux have you gained by being a member of this social network (i.e., cognitive learning; Neufeld et al., 2013)?

Sample question for Guiding Question 4. According to participants, what patterns of participation exist in this online social media group?

8. What motivates you to participate in this social network and to remain a member?

Sample question for Guiding Question 5. According to participants, how do participants characterize *community* in this social media group?

24. What types of connections exist between the members of this social network (i.e., sense of community; Neufeld et al., 2013; Rovai et al., 2004; Tseng & Kuo, 2010; Wenger, 2000)?
25. How do members of this social network support each other (i.e., sense of community; Neufeld et al., 2013; Rovai et al., 2004; Tseng & Kuo, 2010; Wenger, 2000)?

In keeping with Grounded Theory methodology, I followed up on additional topics as participants raised them. At the end of the interviews, I gave participants the option to add any additional information not asked during the interview which they felt was pertinent to the phenomenon being studied. Participants were also asked if they could be contacted via email for any follow-up questions. In accordance with theoretical sampling, five initial participants were interviewed more than once to further flesh out concepts and to develop core categories and new participants were interviewed that could provide further insight into the concept.

Data Analysis

I used NVivo qualitative content analysis software as a tool to facilitate the analytic process. There were several Grounded Theory methodologies that I used throughout the various phases of the study. These include theoretical sampling, constant comparison, and analytic memo-writing. I describe each of these ground theory processes in greater detail below.

Theoretical sampling. Theoretical sampling is an integral part of Grounded Theory methodology. Theoretical sampling is a process for making sampling decisions throughout the research process as gaps surface. This study used theoretical sampling throughout the study. Data analysis began as soon as I transcribed the interviews. As data were being coded and categorized and gaps were identified, additional participants who could contribute further evidence in various areas were selected (Glaser & Strauss, 1967). For example, upon hearing participants in several interviews reference a certain member as being very knowledgeable and willing to help others, I interviewed that participant. Another example occurred later, once the theoretical concepts were developed. The data showed that knowledge-sharing and participation was affected by the stage of reflux the participant's child was in. Thus, eight new participants whose children were at various stages of reflux were recruited and interviewed to add new evidence to the developing concepts.

I continued utilizing theoretical sampling until I determined that saturation had been achieved, at which point I stopped data collection. Theoretical saturation, as detailed later in this chapter, was achieved when new incidents did not reveal any new information relating to the themes, core categories, or subcategories (Corbin & Strauss, 2008). Additionally, during axial coding, I interviewed some initial participants a second time to further investigate aspects of the emerging theories. Table 1 contains a breakdown of the participants who were interviewed. Participants were chosen because they represented one of the theoretical sampling categories despite meeting other categories as well. For example, *Interview Participant 1* had a child in the post GERD period although

she was also someone whose frequency of posting was average or a few times per week and was a long-term member.

Table 1

Theoretical Sampling Participant Characteristics

Frequency of Posting		Length of Membership		Phase of GERD		Role in Group		Total
Description	*n*	Description	*n*	Description (*n*)	*n*	Description	*n*	*n*
Frequent (1 or more per day)	2	*Newbies* (less than a year)	2	*Beginning*	2	*Administrators*	3	
Average (a few times per week)	2	*Continuing* (1-2 years)	2	*Middle*	2			
Infrequent (a few times per month)	2	*Long-term* (2 years or more)	2	*Post GERD*	2			
Peripheral (never)	2			*Recurring* (2)	2			
						Number of participants		*N* = 25
						Follow-up interviews		6
						Total Number of Interviews		31

Note. GERD = gastro esophageal reflux disease.

Constant comparison. An important aspect of Grounded Theory methodology is the process of comparing data throughout the data collection and data analysis process (Glaser & Strauss, 1967). I engaged in constant comparison throughout both data collection and analysis. For example, during data analysis, as new incidents were labeled with an existing code, these incidents were compared with previous texts which were labeled the same way. I also used specific comparison techniques recommend by Strauss including flip-flopping, systematic comparisons, far-out comparisons, and waving the red flag (Strauss & Corbin, 1998). Flip-flop comparisons involved seeking out participants that were the opposite extreme on a dimension in question. For example, I interviewed caretakers who had no medical background and then sought out those with extensive medical training and experience providing medical care. Both had children with GERD and were seeking help within the group, but one came in with no prior medical knowledge and the other was a nurse.

Systematic comparisons involved asking *what-if* questions to explore all the dimensions of an emergent concept (Gibbs, 2008). Far-out comparisons involved comparing elements of a concept with the most different example of that concept that shares the same characteristics (Gibbs, 2008). For example, I interviewed participants who were very active in the group. They logged-in multiple times of day and posted information. I then sought out and interviewed members who also logged-in daily, but were *lurkers* or those who had not ever posted. Waving the red flag comparisons involved being alert to phrases like *never* or *always* and exploring further when participants used those phrases and considering if the opposite of their phrase is true (Gibbs, 2008). For example, several participants mentioned never seeing any conflict or

drama in the group. I explored this idea further and found that although there were few instances of conflict there were some that did occur. I then sought out and interviewed participants who had experienced conflict in the group.

Analytic memo-writing. A central aspect of the Grounded Theory approach is also the creation of memos throughout the entire process of data collection and data analysis. In this study, I created memos throughout the data collection and data analysis process. Analytic memos regarding personal relationships to the study, definitions of codes, possible connections, possible emergent patterns, emergent categories, and so on, were kept throughout the coding process. For example, during the open coding phase, I created memos for each new code that was created. In addition, during the process of constant comparison, when a new incident was compared to an existing incident and the comparison led to the creation of a new code, a memo was written to capture thoughts on the new code. In addition, I wrote memos regarding which codes should be elevated to categories and thereafter which categories were core categories and would become part of any possible emergent theory. I also wrote memos for any code that was merged or eliminated because it was not pertinent to the goals of the study. A sample memo is included below; participant code names were removed:

DOCTORS BEING DISMISSIVE

[Participant pseudonym] mentioned that she felt her doctor did not do enough to help her child because he/she thought reflux was normal and her child was just colicky especially as her child was gaining weight. She states however that she knew that assumption was incorrect as her first child had also been a spitter,but did not exhibit any of the symptoms her second child did. She could compare her two children and realize that even though spitting can be normal and not painful for some babies like her first child, it can be a sign of a more serious problem and be quite painful for infants like her second child. Have other members of the

group experienced this type of dismissive response from doctors? Why do doctors have this response when it comes to infant reflux? Why is a baby being in pain o.k. and not needing of treatment?

FEELING THAT DOCTORS ARE BLOWING YOU OFF OR RUSHING YOU OUT - DOCTORS BEING DISMISSIVE

[Participant pseudonym] mentions how difficult it was with her first child and feeling that her child's doctors were not really listening to her. Even though her child was not gaining weight or sleeping, the doctors did not seem overly concerned. She also felt they were rushing her out of their office as fast as they could. Have other members had similar experiences and is that why they have sought out alternate sources of support and knowledge? Is this discontent with medical care the strongest motivator for participation?

[Participant pseudonym] describes her experience with getting medical for her child. She states that she first went to a nurse practitioner who she felt she had to constantly push even though her infant was not gaining weight and dropping off the weight chart. The nurse practitioner seemed to not take her seriously despite her child displaying many troubling symptoms. She then went to another doctor who she felt showed more concern and referred her to a pediatric gastroenterologist. Is this experience of not receiving help when a child is displaying multiple issues what leads members to joining the group and seeking medical advice there?

Decision to collapse two similar nodes:
**Feeling that Doctors Are Blowing You Off or Rushing You*
**Doctors Being Dismissive*

"Doctors being dismissive seems to be more all-encompassing. Participants report doctors rushing them, blowing them off, saying their child has normal or common case of colic and nothing serious. It seems like there are multiple reasons why participants feel their child's doctor is being dismissive. Are there other reasons why they feel this way?

Coding. In keeping with the Grounded Theory methodology, the data analysis process began soon after interviews were completed and transcribed. There were three stages of coding: open coding, axial coding, and selective coding. I describe actions taken during each stage below.

Open coding. The analysis began with open coding. During open coding, I analyzed the text of transcripts line by line. This line by line coding forced a close analysis of what participants were saying and the creation of codes that were grounded in participant responses rather than any preconceived notions I may have had coming into the study (Gibbs, 2008). I did not come into the study with a code list, but rather developed one based on what participants shared. Using a Constructivist Grounded Theory method (Charmaz, 2014), I used gerunds to code and analyze so that there was a sense of action and the idea that participants were conveying being part of a process. An example of this would be the core category of "encouraging external knowledge" which subsumed the subcategories of "identifying related learning spaces" and "sharing research articles created outside the group." Codes were then compared/contrasted and organized into provisional categories. I used tables and hierarchies to assist in organizing codes and categories. Theoretical sampling and constant comparison continued throughout open coding to further flesh out codes.

Axial coding. During the axial coding stage, I refined and further developed categories by looking at various elements that considered dimensions suggested by Strauss and Corbin (1998) like causal conditions, phenomena, strategies, context, intervening conditions, actions/interactions, and but were not defined by them. To aid me in the analytic process, I created visual representations of the categories and their interconnectedness, such as concept maps and Venn diagrams. See Figure 2 for a sample concept map. Theoretical sampling and constant comparison continued throughout axial coding to find any additional evidences or dimensions of the categories. The end result of this stage of coding was a re-organization of codes by associations to each other.

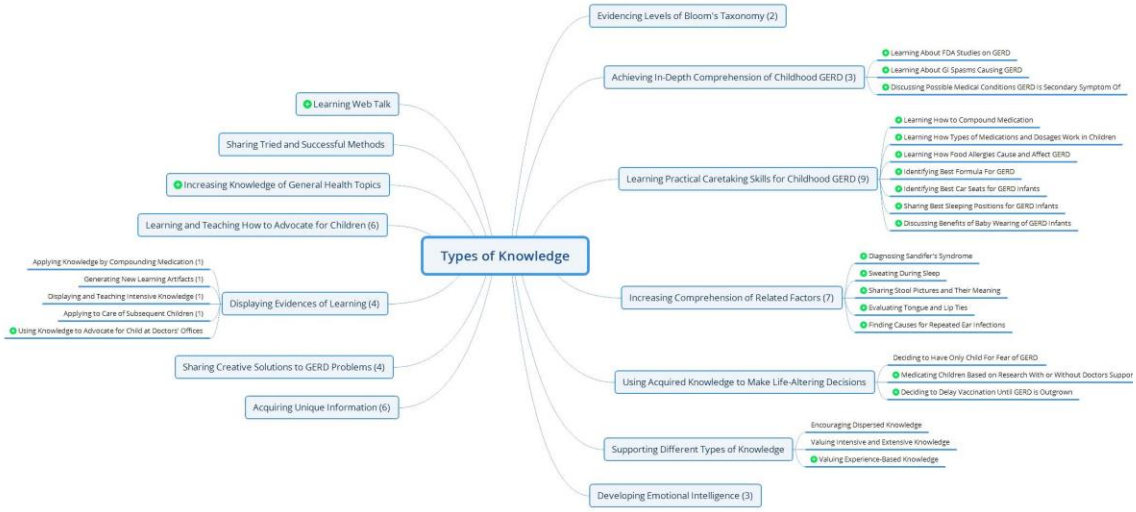

Figure 2. Sample concept map.

Selective coding. In the third phase of coding, selective coding, I examined associations between core categories and themes until I was able to identify the central concept or variable that best explained the participants' experiences and was relevant to all other categories that were identified. Upon identifying this core concept, memos were revisited and sorted to create a storyline. During this process, I went back to the field and interviewed six participants a second time to add insight to my understanding of the central core concept. This process continued until theoretical saturation was reached and the central core concept was sufficiently developed and could be written about in a story format. I then reviewed available literature that could help situate the study's findings. These are shared in Chapter 5 of the present study.

Theoretical saturation. Theoretical saturation was achieved when new incidents did not reveal any new information relating to the core categories or subcategories (Corbin & Strauss, 2008). I stopped collecting data once I was confident that the core category and associated categories could explain all the possibilities of the data once

reexamined with these concepts in mind. I was also confident that new participants that were interviewed did not add any new data as their responses were already incorporated into the existing axial coding scheme and storyline.

Study Phase 2

Sample Size

Participants who were involved in the second phase of the study were also members of the social media group described above. Looking at a month's worth of activity in this social media group during December 2014, I found that on average, nine original messages and 87 comments were posted per day and 71 original messages and 673 comments were posted per week. Original postings were typically three to four sentences and comments were one to two sentences long. Given the level of activity of this social media group, I collected and analyzed one week of original messages and comments to provide a complete, but manageable number of postings.

Recruitment of Participants

In addition to the pinned post for Phase 1, I posted a message on the online social network wall that disclosed my presence as a researcher and acknowledged my role as data gatherer. I specifically told members of the social network that I would be looking at one week's worth of postings. The message specified the week that the postings would be collected. The message let members know that any identifiable information on the postings would be removed before data were analyzed and that names would be replaced with participant numbers. It also advised members of the social media group that if they did not want their postings to be analyzed, they could opt out by clicking on the link provided with the message or by contacting the researcher through the Facebook

messaging system or by email. Seven of the members clicked on the link and provided their Facebook usernames and asked to have their postings excluded from the study. The messages posted on the wall by these members were excluded from the data set as well as any comments they made in response to other members' postings. See Appendix E to view the recruiting message in its entirety.

Postings

Postings were downloaded from the Facebook group through a combination of an add-on application from NVivo software and copying and pasting. The postings or comments from those who did not want to participate in this phase of the study were removed from the data set. All other postings were imported into NVivo software for analysis. These imports preserved the sequence and timing of postings.

Much like Phase 1, different phases of coding were occurring concurrently with constant comparison and analytic memo-writing; however, unlike the first phase, data collection was done at the beginning and not throughout the phase. Figure 3 illustrates this difference.

Figure 3. Phase 2 data collection and data analysis.

Data Analysis

The posting and comments that appeared on the online social media group's wall during the selected one-week window were analyzed using Grounded Theory methodology. I coded each post line by line. Open, axial, and selective coding was conducted on the postings and comments. The coding hierarchy developed during Phase 1 of the study was used as a coding framework during the open coding for Phase 2;

however, constant comparison was carried out and new codes that did not appear during Phase 1 were created as needed and codes that did not appear during Phase 2 were deleted. To allow for triangulation, axial and selective coding of the postings and comments was conducted independently of data analysis for data collected during Phase 1 of the study. Analytic memos regarding personal relationships to the study, definitions of codes, possible connections, possible emergent patterns, emergent categories, and so on, were kept throughout the coding process for Phase 2 of the study. Although the previous describes the methods that were used in the study, in the next section I discuss views and biases and the validity and reliability of the study.

Researcher's Views and Biases

As described in the background section of the previous chapter, I was a member of the online social media group explored in this study for several years. I therefore had some inherent preconceptions regarding the processes occurring within the group before beginning the study. Having joined the group due to my own daughter's health issues and having found many answers to questions I had about her care, I believed that learning was possible by participating in the group. In as much as is possible, I tried to set aside any preconceptions I had about the group's processes and followed the steps of grounded theory methodology so that the findings were grounded in the voices of the group members and not my own assumptions.

Validity and Reliability

To ensure the validity and reliability of this grounded theory study, I took several steps at various stages of the study (Sprenkle & Piercy, 2005) to increase the credibility and trustworthiness of the study as described below.

Disclosure

To safeguard against threats to external reliability, I took steps to disclose my background as it related to the study during every stage of the study. To be transparent, I also took steps in this chapter to detail initial criteria for selecting participants, the coding procedures, and development of categories and theories.

Data Collection

I transcribed all interviews verbatim. Once completed, I checked the transcripts against the audio recordings for accuracy. Whenever I identified a gap or unclear segment while transcribing, I contacted the participants to clarify what they wanted to convey.

Data Analysis

I analyzed the transcripts in the first phase of the study as soon as possible after the interviews were transcribed. This allowed me to write memos with ideas fresh in my mind. To further promote internal reliability, I emailed figures depicting emergent themes and core categories to participants in the study to conduct member-checking. Participants were asked if they felt that the analysis accurately reflected their experiences. Any feedback from participants became part of the analysis process.

Triangulation

To promote internal validity, this study utilized multiple data sources or attempted to triangulate the data. Interviews were conducted with member of the online social media group and member's postings within the online social media group's wall were analyzed. Each data source type was analyzed separately to be able to compare and contrast findings.

Theoretical Sampling and Constant Comparison

Although the aim of grounded theory methodology is not to be able to generalize across populations, the theoretical sampling and constant comparison process does allow for some external validity. Trying to apply constant comparison methods, I had to consider all the facets and dimensions of theoretical concepts across participants before I felt confident that data collection or theoretical saturation was reached. When I found a gap in understanding I tried to remedy it in the next round of theoretical sampling. This happened even in the final stages of the study as the storyline was created. Negative cases or cases that contradicted what the majority of participants had experienced were incorporated by adapting the story so it allowed for their inclusion. Thus, the study findings were based on many different types of comparisons.

Chapter Summary

In this chapter, I defined a rationale for using grounded theory methodology as well as the components and origins of the grounded theory methods that were used in the study. I described the social media group that was sampled in as much detail as was available. Then I described each of the two phases of the study, including the recruitment and selection of participants, data collection, and data analysis for each phase. The next chapter contains the results for both phases of the study, postings and interviews. The results for the two phases were interwoven together and presented by theme and core categories mirroring the grounded theory methodology used in the study. Chapter 5 re-integrates themes and core concepts into a central core concept, presented in the central story.

CHAPTER 4

RESULTS

The purpose of this adapted Grounded Theory study was to explore the informal learning experiences of members of an online social media network group made up of parents and caretakers of infants or children with GERD. To fulfill this purpose, I attempted to answer the following guiding questions:

1. According to participants, what learning strategies do participants use to gain knowledge in this online social media group?
2. According to participants, what factors influence activity in this online social media group?
3. According to participants, what types of knowledge exist in this online social media group?
4. According to participants, what patterns of participation exist in this online social media group?
5. How do participants characterize "community" in this online social media group?

In this chapter, I share the major findings of this study. I discuss each aspect of the learning experience as reported by participants. Findings are listed by themes and then by the core categories that made up the themes. In the tradition of Grounded Theory, the themes emerged from the data shared by participants in the study. As described in the previous chapter, data were coded using gerunds, many in vivo, to connote action or a process. To stay as true to the data as possible, gerunds were kept *as-is* in the results.

In addition, even though data were gathered in two different phases (i.e., interviews and postings), I report results as an aggregate. Initially I thought that the two phases would bring about distinct enough results to warrant being reported separately, but upon analysis the themes emerging from the postings echo many of the themes that emerged during interviews. Thus, to avoid redundancy, I reported these jointly.

The chapter begins with a review of the size and characteristics of the participant sample for each phase. I then present demographic data for each phase and study findings by theme and core category. The artificial separation of data into themes creates an occasional repetition as each theme is discussed; however, Chapter 5 revisits the data and integrates all the themes.

Description of Sample

Phase 1

For Phase 1, 31 interviews were conducted with 25 unique participants. Figure 3, first shared in the previous chapter describes the characteristics of the interviewees.

Phase 2

As was explained in the methodology section of this dissertation, due to the high level of activity and membership in the group only activity during one specific week of postings was collected for analysis. During the selected week, 53 original threads were collected and analyzed. There was a total of 604 postings, original postings and responses, which were collected and analyzed during this phase.

Demographic Data

Phase 1

The following figures describe the demographic data and aggregate the group-level activity that was collected during the interview phase of the study. These data are being reported here to provide context for a discussion of their signification and integration with themes in the next chapter.

Level of education. Figure 4 lists the level of education that interview participants reported during phase I of the study. A majority of interview participants (92%) obtained a degree higher than a high school diploma, and about half (48%) had obtained a Master's degree or Doctoral degree.

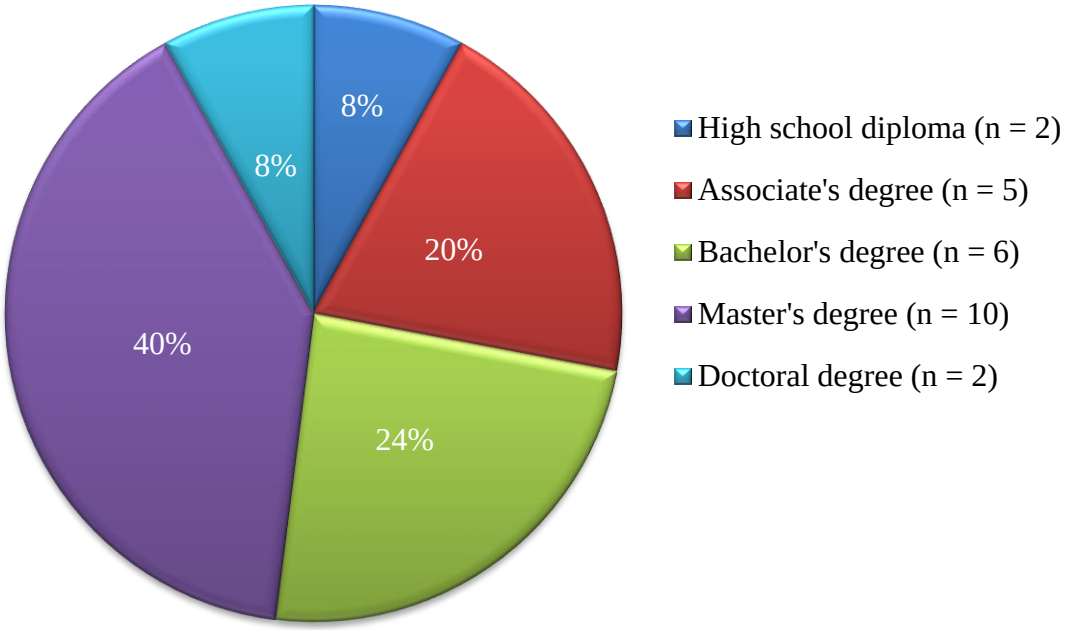

Figure 4. Interview participants' level of education (*N* = 25).

Medical background. One of the perceptions I had as a member of the group after reading postings, was that many of the highly knowledgeable members had medical

training. I had this perception due to the complexity and breadth of their answers when speaking about GERD medications. During the study, as Figure 5 shows, I found that out of the total number of interviewees, only 12% had some kind of medical training. The majority or 88% had no medical training.

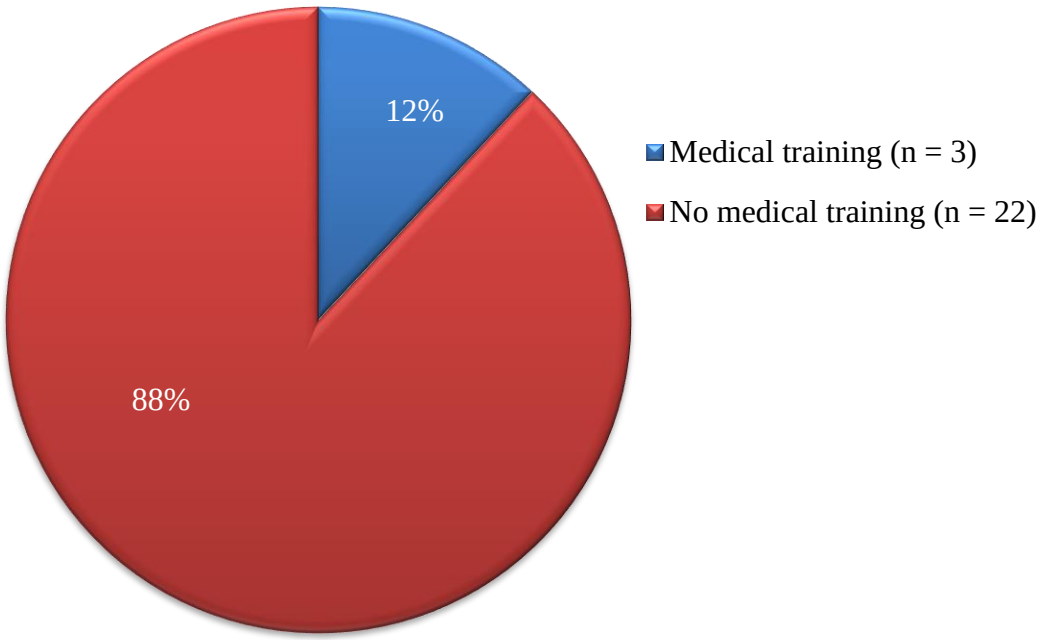

Figure 5. Interview participants' medical training (*N* = 25).

Posting versus logging-in. Figure 6 shows two types of frequency. It shows how many of the interviewees posted on the wall and also how frequently they logged into the group to just read postings. These frequencies were self-reported by interviewees during Phase I of the study. The categories were defined in this manner for posting frequency:

- *Frequent*: Members who posted to the social media group's wall (i.e., original message or comment) approximately one or more times a day
- *Average*: Members who posted to the social media group's wall (i.e., original message or comment) approximately a few times a week

- *Infrequent*: Members who posted to the social media group's wall (i.e., original message or comment) approximately a few times per month
- *Peripheral*: Members who never posted to the social media group's wall

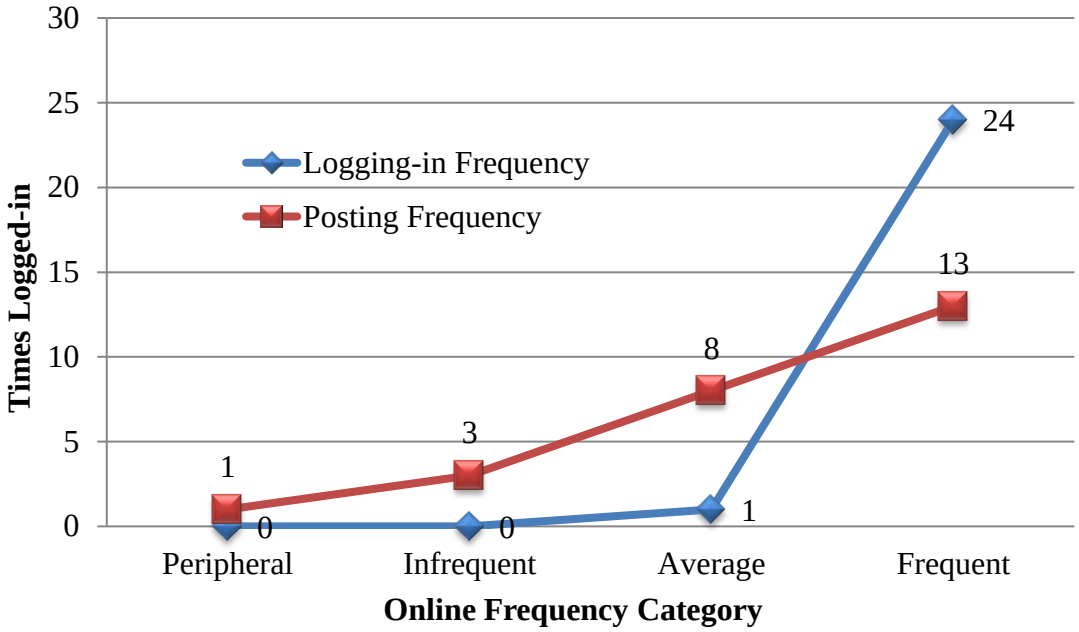

Figure 6. Interview participants' logging-in and posting frequencies (*N* = 25).

The categories were defined in this manner for logging-in frequency:

- *Frequent*: Members who logged into the social media group one or more times a day
- *Average*: Members who logged into the social media group approximately a few times a week
- *Infrequent*: Members who logged into the social media group approximately a few times per month

- *Peripheral*: Members who logged into the social media group every few months

Figure 6 shows that although a majority of participants (96%) logged into the group frequently, only half (52%) posted frequently, and a third (32%) posted an average amount. Thus, some of the participants engaged in peripheral participation, or lurking behavior (Davis, 2010).

Length of membership. To conduct initial quota sampling, interview participants were asked how long they had been members of the online social media group. Figure 7 shows the breakdown of participants into Newbies, Continuing Members, and Long-term Members. Newbies were members of the group for less than one year. Less than half of the participants (48%) were members for less than a year. Continuing members were members from between one to two years. About a quarter of participants (24%) were continuing members. Long-term members were members for longer than two years. About another quarter of members (28%) were long-term members. Two had been members for six years, two had been members for five years, two had been members for two years, and one had been a member for one year. Although initial selection of participants led to a more equal distribution of length of membership subsequent theoretical sampling led to selection based on stage of reflux and frequency of posting, which resulted in more newbies or shorter length of membership as they were participants that tended to be in the most active stage of reflux and highest frequency in posting.

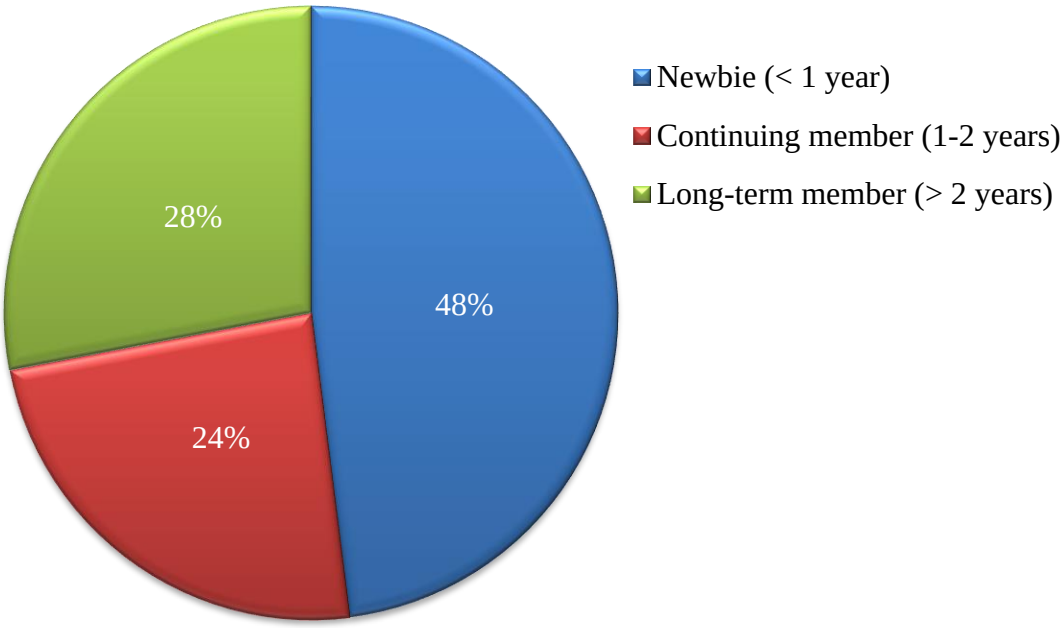

Figure 7. Interview participants' membership longevity in the group (N = 25).

Phase 2

Number of responses per posting. Figure 8 describes the number of responses original postings received. Of the 53 original posting threads, 11 received 3-5 responses, whereas only one original posting thread received 51 or more responses.

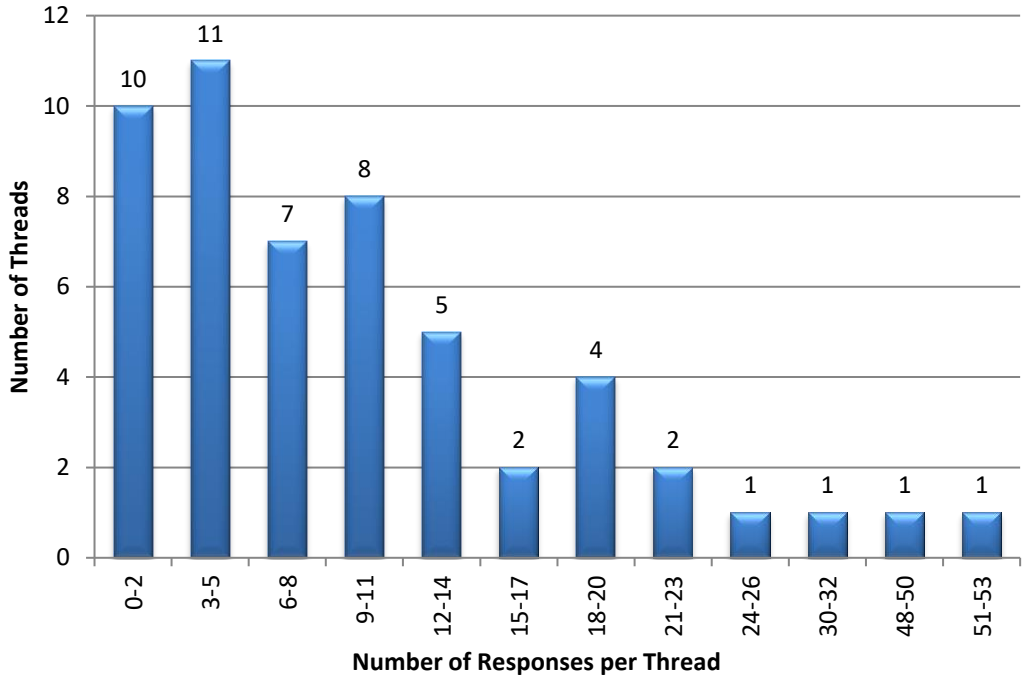

Figure 8. Responses per posting thread (*N* = 53).

Response time. Figure 9 shows how long it took for an original post to receive a response. The majority, 42 of 53, received a response within the first hour after the original message was posted. The rest received responses within five to six hours after they were posted. Only two original postings received no response at all. The association of response time to level of participation is discussed in the last chapter.

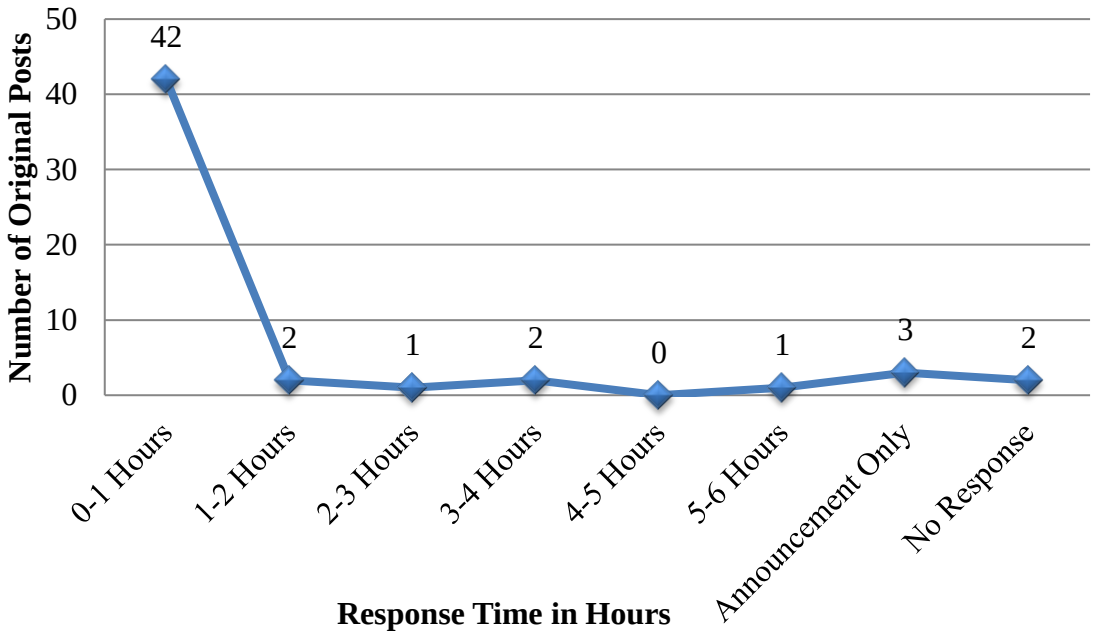

Figure 9. Response times per original post (*N* = 53).

Postings by time of day. Figure 10 shows what time of day postings that were analyzed were posted. The time was held constant to the researcher's time zone, mountain standard time. The highest number, 87, were posted between 4:00-6:00a.m. in the morning. Other high numbers of postings were posted between 6:00a.m. and 2:00p.m. There seems to be significant drop between 2:00p.m. and 4:00p.m. were only 42 questions were posted. It seems to pick up again slightly and then experience another drop off at 10:00p.m. until about 4:00a.m.

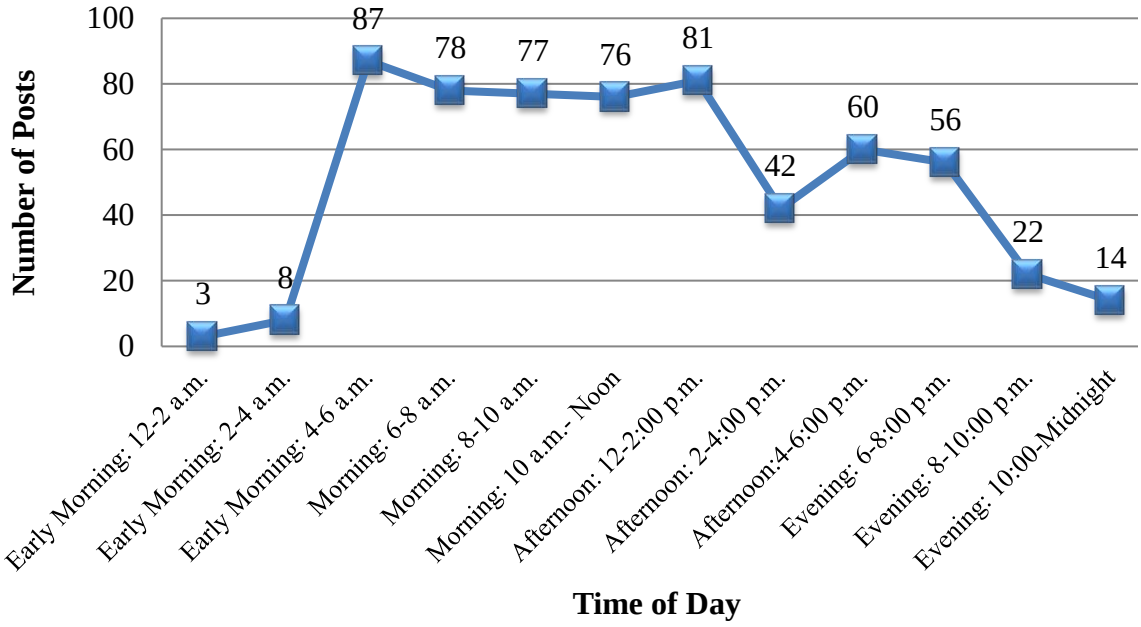

Figure 10. Original and response postings by time of day (*N* = 604).

Posting by day of week. Figure 11 shows what day postings that were analyzed where posted on the group's wall. The highest number of postings went up on Saturday followed by Monday, Sunday, Thursday, Tuesday, Wednesday, and Friday.

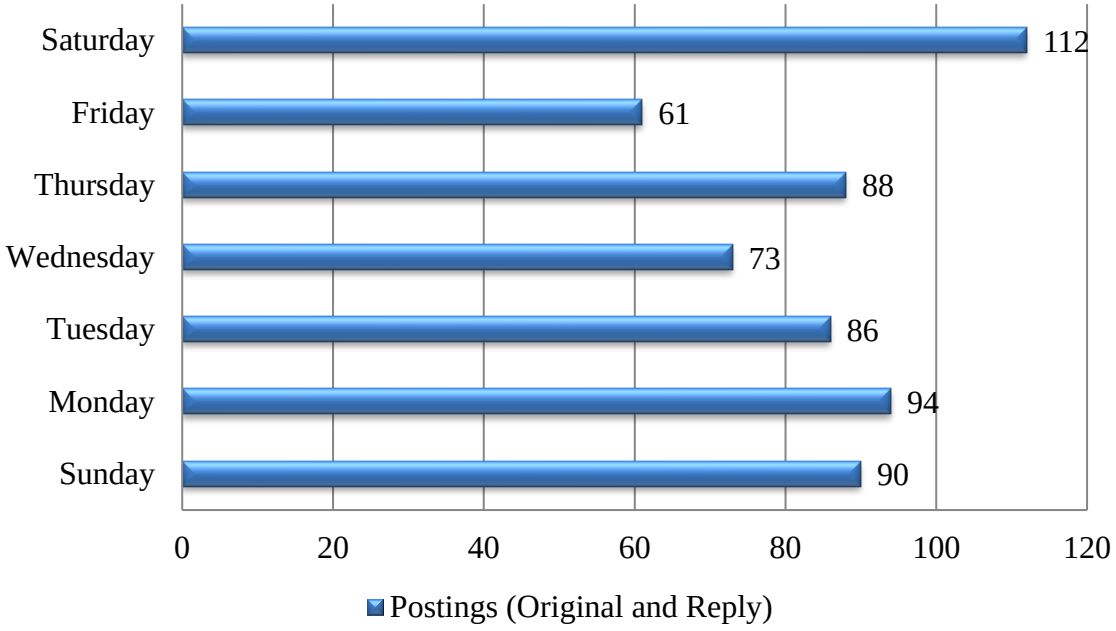

Figure 11. Postings by day of week (*N* = 604).

Relevance of responses. Figure 12 depicts the relevance of responses to the original post. For most postings that were analyzed, 47 out of 53, a relevant comment came with the first response.

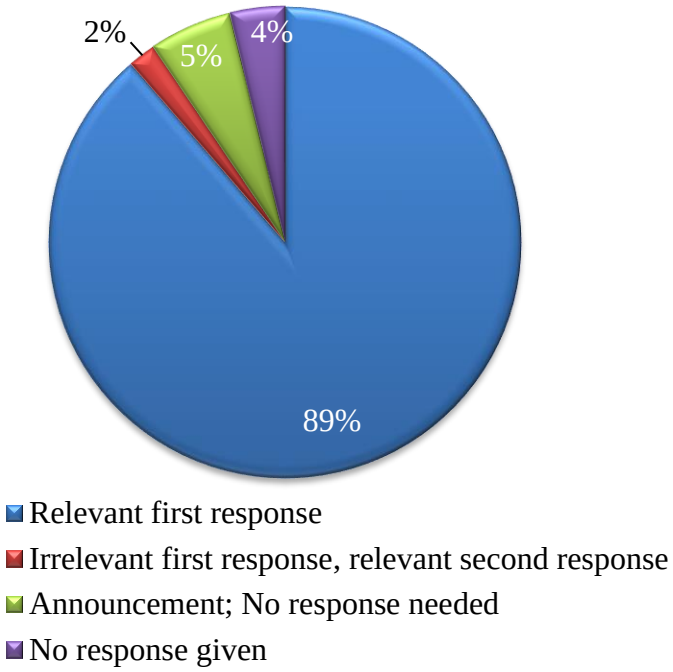

Figure 12. Relevance of first and second responses to original postings (*N* = 53).

Following are two examples of what is meant by a relevant reply within the first response. The response is on topic and offers an answer based on experience or research that is relevant to the question being asked in the original posting.

Original Post (1:20 PM 2/26/15):

> *Posting Participant 5*: Rash Question - My LO has a rash on her face. Some drs are saying its due to food intolerance/sensitivity & others are saying its yeast/bacterial/etc. because its only on the face. If it were food related, it would be over the entire body. Anyone have any experience w/ this? Poops were green

for a few days, then brown & yesterday we had a seedy yellow:-)

Response Post 1 (1:39 PM 2/26/15):

Posting Participant 68: DS only had his mspi rash on his face :(

Response Post 2 (1:57 PM 2/26/15):

Posting Participant 18: DD has hers only on face. Poop starts green and progresses to seedy yellow once all dairy is out of her system.

Original Post (6:46 AM 2/21/15):

Posting Participant 17: I've had my 4mo on [brand name] probiotics for a few weeks now and she was on [formula name] before that. She still goes almost a week without <pooping frown emoticon> she tries at times and gets nothing, and she's very gassy. I give her pear juice with her [Medicine Name] for reflux. Anything else I can do to help her poop?

Response Post 1 (6:55 AM 2/21/15):

Posting Participant 85: My daughter had horrible issues. We started on [Name of Laxative] daily (.5-1 tsp), but I hated the thought of all that medicine. I purchased (Brand Name)] probiotics and started with the recommended 1/4 tsp daily. She turned into a pooping machine. I adjusted the dose and even skipped days, so she wouldn't poop too much. She is now

> pooping on her own. So maybe she has grown out of it or the extra fluid she consumes with water had helped. Not sure. Good luck.

The next section begins the presentation of findings that resulted by guiding question.

Guiding Question 1

Guiding Question 1 posed the following: According to participants, what learning strategies did group members (parents and caretakers of infants and children with GERD) use to gain knowledge in this online social media group? Members of the group that was studied, discussed, and engaged in various learning strategies to acquire knowledge about infant and childhood GERD. As is the nature of Grounded Theory, during the selective coding phase, categories that best explained the participants experience and were relevant to all other categories for this guiding question became core categories and later themes. The themes that emerged from the data within this section were these:

1. *Theme I*: Participants engaged in distinct information-seeking behaviors in non-linear patterns.
2. *Theme II*: Members followed a clear process of skills acquisition or steps to go from newbie to an experienced member.
3. *Theme III*: Members learned by applying acquired knowledge gained through participation in the group to the care of their child.

Theme I

Theme I of Guiding Question 1 was *participants engaged in distinct information-seeking behaviors in non-linear patterns.* Participants who were interviewed discussed several distinct information-seeking behaviors they engaged in to learn about infant or

childhood GERD while participating in the group. Behaviors that were classified as information-seeking were initiating; browsing; requesting information; lurking or learning vicariously; evaluating information; applying; and monitoring.

Information-seeking behaviors garnered from the two phases of the study, interviews and postings, are listed in Table 2. The information-seeking behaviors that were most mentioned by interview participants were evaluating information, initiating, requesting information, and being guided through knowledge acquisition by a highly knowledgeable member. I discuss each of these behaviors in greater detail in the sections that follow the table. I present the most frequently-occurring categories of responses from participants related to information-seeking behaviors below.

Table 2

Types of Information-Seeking Behaviors that were Mentioned in Interviews and Postings

Information-Seeking Behavior	No. Referenced in Interviews	No. Referenced in Postings
Evaluating information	75	79
Initiating	38	17
Requesting information	19	67
Being guided through information-seeking by a highly knowledgeable member (usually group leader)	0	68
Lurking or learning vicariously	17	1
Browsing	14	6
Applying	11	53
Monitoring	6	0
Total	180	291

Note. Total refers to the number of instances these behaviors were mentioned in interviews and postings.

Core Category I. Core Category I of Theme I was *evaluating information acquired within the group.* As Table 2 showed, there were 75 references in interviews and 79 references in postings to some type of evaluation process that members of the group went through upon acquiring information from other members in the group. The evaluation processes and their sub-processes are listed in Table 3.

As can be seen in Table 3, some members of the group discussed acting on information gained from the members of the group without evaluating the information. Reasons for not evaluating information included feeling sheer desperation and urgency at wanting to help their children, feeling the child was older and as much care was not needed, and feeling that the decisions were so minor that they did not require evaluation; however, the majority of those interviewed discussed going through one or several processes of evaluation before applying information gained from the group. I describe each of these processes in greater detail below in order of the most mentioned to the least.

Table 3

Processes and Sub-Processes that Participants Mentioned Using to Evaluate Information Gained through the Group.

Processes	Sub-Processes	Interviews	Postings
Reconciling	Reconciling information from group with own prior knowledge	4	19
	Comparing similar experiences	7	27
	Reconciling information from doctors and information from group	5	7
	Asking follow-up questions	2	12
	Assessing own knowledge level on a topic		2
	Total	18	67
Verifying	Verifying with medical providers	10	3
	Comparing with published research	7	1
	Doing web research on responses given by group	6	2
	Running information by spouse or other family members	2	1
	Verifying back with the group		2
	Total	25	9
Judging trustworthiness of knowledge sharer	Watching track record of giving advice to other members	4	
	Judging based on own previous interactions with knowledge sharer	4	
	Trusting knowledge based on length of membership	3	
	Judging based on language shared in posting	3	
	Determining what perspective knowledge sharer is coming from	1	
	Exploring knowledge sharer's Facebook profile Interviews	1	
	Judging based on stage of GERD knowledge sharer is in	1	
	Judging based on perceived education level of knowledge sharer	1	
	Trusting those with a medical background	1	
	Total	19	
Acting without evaluating information	Not vetting minor decisions	4	
	Running with information out of desperation and urgency	2	
	Not finding experienced members matching situation	1	
	Not vetting when child is older	1	
	Total	8	
Trusting ideas that multiple members validate		4	3

Note. Numbers given in the table refer to the number of instances these behaviors were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

The evaluation process that seemed to be of primary importance to many members was to reconcile knowledge gained from the group with their own experiences and prior knowledge whether it was based on what medical providers had told me or their own research. This may have also involved asking follow-up questions of the group and comparing similar experiences with group members. Once reconciled, members decided whether to apply the information to the care of their child or not. A quotation that represented this process was this:

> *Interview Participant 7*: I'm part of the self-help page for the navy base and I find a lot of times I get concerned about some of the medical questions that people ask on the group and I have concerns about the way people who aren't in the medical field answer those questions because I feel like they're giving a lot of really bad and dangerous advice. Certainly when I'm researching stuff on the Internet and if I'm part of a Facebook page, I'm always looking to make sure that the advice there makes sense with my training and I have really been, I hate to say I have been surprised but it's been nice to see that everyone who is commenting on the page (group) and the information that's being provided seems to be good advice and sound advice. That made me more confident about using the page for advice.

A posting that represented reconciling was the following.:

> *Interview Participant 11*: At that point you know if it applies to me like a particular advice or suggestion, I have to determine whether or not I feel comfortable with it myself and whether or not I feel like it would be safer

> or beneficial for my son. If I do, then let's say it requires me getting a probiotic or medicine I will figure out what would be the best place to get it. So, it's kind of just that process of determining whether this information applies to me and whether I feel comfortable and safe applying it to my son. Sometimes the answer is yes and sometimes the answer is no.

The second most cited process was verifying the information other members shared through different methods such as comparing with published research; verifying with medical providers both general and specialists; verifying with a spouse or family members; verifying with information available on other sites on the Internet; and verifying back with the group. Several members mentioned seeking out articles in peer-reviewed journals. A quotation that represented this process was the following:

> *Interview Participant 1*: I'm a huge Doubting Thomas, so I definitely wanted to confirm it in some other source before I actually did it, although not that I would doubt anyone, just for my own peace of mind, but absolutely. I'd see if I'd find whatever information, whether it was a peer-reviewed study or a published article.

Several members also discussed taking the information to their medical providers and obtaining their opinion on it. A quotation that represented this process was this:

> *Interview Participant 2*: I got that information from some member on the site, that she was recommended. I of course confirmed it with my pediatric GI at a subsequent visit I had with him. He said, "Oh yeah, that's definitely the right way to go, you're doing the right thing." So that was invaluable information, for sure.

The third evaluation process that seemed like a key process was judging the trustworthiness of the individual sharing information. Members did this by evaluating the information the group member(s) shared with others, judging the individual based on the length of their membership in the group, judging the individual based on their own previous interactions with the individual, judging based on the type of language used in the person's posting, judging based on the person's social media profile, judging based on what sources the person gives to back up what they state, and judging based on what stage of GERD the person's baby is in. A quotation that is representative of judging the worthiness of a knowledge sharer was this one:

> *Interview Participant 5*: Well because I'm on there frequently enough so I kind of get a feeling of who the people on there that know something about something and that you see posting frequently and that they seem educated based on their responses and you kind of get a feel for, I guess if their posting... and that's why I don't ever use that information to completely make a decision but you kind of glean who's a little bit more trustworthy and more educated about certain things.

The fourth evaluation process mentioned by members of the group was to identify and trust the ideas that the greatest number of members validated either by sharing the same idea or by showing support for the idea. A quotation that represented this category was, "You see a lot of moms coming together to share information. Especially when many moms are validating the same ideas, then it's worth spending time to listen to" (Interview Participant 6).

Core Category II. Core Category II of Theme I was *initiating information-seeking*. A second behavior that was referenced in 38 different instances during member interviews and 66 instances in postings was the way in which members began their information-seeking and how they identified the group as an information source of interest. The ways participants initiated their information-seeking is described in Figure 13.

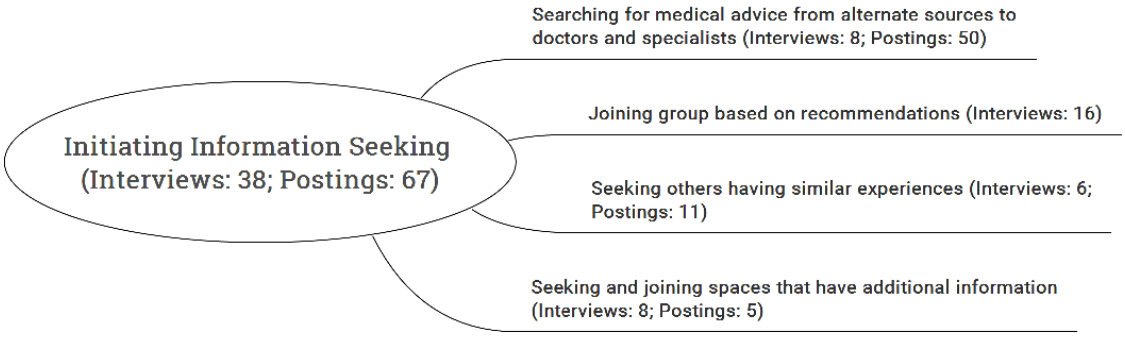

Figure 13. Frequencies of interview responses and postings for information-seeking. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

There were eight instances in interviews where participants discussed joining the group because they were searching for medical advice from an alternate source to doctors and specialists that they felt were not helpful. Fifty members whose postings were analyzed sought medical advice on the group's wall as an alternate source to doctors and specialists. A quotation that was representative of this type of information-seeking was this:

> *Interview Participant 11*: Parents even though they are told not to, will Google and look up their kid's symptoms and a lot of times there is that kind of mother's intuition where the doctor may say it's just this or do that

> and you kind of just know that there is something else going on with your child and it's not o.k. So, I think that disconnect kind of drives people to look elsewhere because a lot times I think professionals make it seem simple or that there really is no answer or options. For some people that is just not good enough and so they go to groups like this and look for other options and look for people that will give them other options.

There were 16 instances where members who were interviewed discussed joining the group based on recommendations from individuals or groups they had turned to for information first. A quotation that illustrates this is the following:

> *Interview Participant 17*: I was ... I don't know how it technically started, but I was a member of another forum. A moderator had started a forum and I was a member there for a very long time. I can't quite remember how it got started, but I'm pretty certain it was pointed out to me via another member. They said, "Hey, why don't you come join this? Our forum is now under construction, and people are going over here." So, I believe that's what led me to join this on Facebook.

There were six instances in interviews and 11 instances in postings where participants described initiating their information-seeking and joining the group as an information source because they were seeking others with similar experiences. A posting representative of this idea was the following:

> *Posting Participant 2*: Did any of you struggle with a baby who just didn't want to eat? A friend's baby has been struggling to stay on the curve (3%

> weight) so she started EP so she could measure ounces. She's already milk and soy free. Her daughter just doesn't seem to have an appetite. Ideas???

There were eight instances where members who were interviewed and eight messages that were posted that mentioned searching the Internet for learning spaces where they could obtain any additional information on GERD. The following was a quotation that was representative of this category:

> *Interview Participant 8*: Basically, first I searched on the Internet. I Googled about it. Basically, I had an elder son also. He also had reflux. But at that particular point of time, four and a half years back, back in 2010, I really didn't know that these kinds of groups existed. At that particular time, it was not very common. We used to use. So, at that point of time I did not know how to handle my baby because he had severe reflux. This time it is a lot easier because what really happened to me is that I searched Google and found a lot of sites that had lost of information about GERD, so I went to all those sites and then I thought this is what this new baby is having. Then I searched on Facebook because I know now everything is on Facebook there are all kinds of groups for everything on Facebook. So, I found a couple of them and joined them. After joining these groups, I have not gone back to search Google for anything because anything can be answered there.

Core Category III. Core Category III of Theme I was *requesting information*. Participants used different methods to request information from other members of the group. Table 4 shows the different methods that were mentioned 37 times in interviews

70 times in postings. I discuss the methods participants utilized to initiate information-seeking below.

Table 4

Methods Participants Mentioned Using to Request Information

Methods for Requesting Information	No. Referenced in Interviews	No. Referenced in Postings
Asking questions on the group's wall	24	52
Contacting members individually	10	1
Asking follow-up questions of group	0	6
Bumping for more information	2	5
Commenting on someone else's postings to ask questions	1	6
Total	37	70

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings.

As seen in Table 4, the most often mentioned and observed method for requesting information within the group was posting to the group's wall. Facebook technology made the group's wall central to the group's site. In addition, the group's rules requested that all new members answer a series of questions and post an introduction to the group's wall upon joining. This mandatory introduction compelled most members to ask questions and request information through the group's wall.

Another method participants used for requesting information was contacting other members individually through personal messaging technology. This method was mentioned 10 times in interviews and one posting. As Interview Participant 15 stated, "whenever I put a few things up people would send me a message instead of posting information on the threads, they will send a message. I have interacted with a few people back and forth just to get some ideas and share tactics."

A third method that became apparent when analyzing group postings was individuals asking follow-up questions of the group once they had received initial responses. Participants would obtain information, then come back, and report what happened and request more information from the group. The posting below was representative of this method of requesting information:

> *Posting Participant 17*: Looking at the diet link you sent the other day thanks. Is the change in consistency cause for concern? What is ppi? Sorry for my lack of knowledge! Found ppi in the files <smile emoticon>. Are those easier on her system than something like [Medicine Name]?

Another method participants that were interviewed mentioned was bumping for information which is where they post a comment of *bumping* or *bumping for more information* to keep the thread at the top of the feed, so all members will see and hopefully post more comments. This method was mentioned twice in interviews and five times in postings. A last method of requesting information was to comment on someone else's post to ask a question. Asking questions of the group on a thread started by someone else was mentioned by participants in one interview and observed in six postings.

Core Category IV. Core Category IV of Theme I was *being guided through information-seeking process by a highly knowledgeable member, usually group leader*. One information-seeking behavior that was not discussed by interview participants but was apparent in 68 different instances from analyzing the group's postings was that new learners were guided through their information-seeking process personally by members who were long-term and had achieved a certain level of knowledge. Almost every thread

that was analyzed showed that after a participant asked their initial question, a highly knowledgeable member asked follow-up questions, suggested resources, or a course of action. The highly knowledgeable member also went beyond just answering the initial question, they connected the learner to other members by tagging other members that were highly knowledgeable in the topic that was broached and connected them to relevant resources. The highly knowledgeable member also stayed on the thread answering the new learner's follow-up questions and facilitating their learning process to the end of that thread. Following is a discussion thread that shows this with Posting Participant 4 being the highly knowledgeable and a group leader:

> *Posting Participant 5*: Even though my LO's [Medicine Name] has no flavoring & the pharmacy told me it was good for 30 days, should I get a new batch in 14 days?
>
> *Posting Participant 4*: I would if you can :-)
>
> *Posting Participant 4*: What % sodium bicarbonate?
>
> *Posting Participant 5*: I'm not sure. I threw the information sheet away after the pharmacist ticked me off! My LO isn't eating as much the last 2 days & I'm thinking it may be due to the meds losing their effectiveness. Will the pharmacy let me refill early?
>
> *Posting Participant 4*: If you pay out of pocket? Bring in rest of bottle for them to take/trade so they don't think you're over dosing? Is dose high enough? Give beads in the meantime?

Posting Participant 5: I think we pd $10... Her dose was increased 2 weeks ago. She's 3 mo & weights 5.61 kg. (Image of child's medication)

Posting Participant 15: Good luck my doctor and pharmacists told me that it lasts for 30 days (which it does not)

Posting Participant 4: 1.5 x 5.61 = 8.4 a dose. You've got 5.4 a dose and it's just 2 doses not three...

What follows is another thread demonstrating the same process involving a highly knowledgeable member, Posting Participant 4. Here, the highly knowledgeable is guiding a new learner, Posting Participant 59, asking the new learner follow-up questions, answering questions, and tagging another highly knowledgeable member, Posting Participant 9, who can help.

Looking for any advice. My daughter has mspi and severe reflux. We just switched from [Medication Name] to compounded [different Medicine Name]. It seemed like she was doing better until half way through the second week she started with bad gas pain and screaming at bottles again. We have had a ultrasound for pyloric stenosis that was negitive and have upper GI on Wed and possibly a ph probe after that. She is 3 mo and 10.12 lbs currently on 2 mg per ml [Medicine Name] 2.5 ml 2x a day. She is also back to spitting up constantly even hrs after a feed.

Posting Participant 4: welcome! These questions will help everyone get started to help you <smile emoticon> Questions baby's age? Three (3) Months weight? Skin? Rashes? Eczema? Meds? Which ones? What

doses of meds? How long on meds? [Medication name] How administered/what form? Liquid. FROM WHERE? How many mgs/ml? Look at bottle of meds <smile emoticon>. How are poops? What are they like? (If breastfeeding: normal yellow/mustardy seedy Breastfed baby poop?) Green? Foamy like shaving cream? Stringy like the inside of a banana peel? Like cottage cheese? Jelly? Slick & slimy? Like coffee grinds? Soft like peanut butter? Painful, foul-smelling Gas? Struggle to poop & when it comes out it's soft?

Posting Participant 21: Is your compounded [Medication Name] flavored? The pharmacy compounded meds are notoriously unstable and it could be that the med is no longer strong enough. Are you keeping it refrigerated?

Posting Participant 5: We too started experiencing reflux symptoms again around day 12 of compounded meds (unflavored). Today I got a new Rx for only a 14-day supply, picking it up tomorrow. Hoping that was the problem.

Posting Participant 59: Yes, they added grape flavor. It has been consistently refrigerated.

Posting Participant 4: Hot off the press! This tells about the different 'forms' of ppis, compounded (like yours) is included <smile emoticon> http://[website address]

Posting Participant 4: [*Posting Participant 9*'s Name]

Posting Participant 9: Sorry. I was wading through notifications. <wink emoticon> 10 weeks is a long time. If you are serious about re-lactating, I would start with renting a hospital-grade pump and power-pumping (pumping every 2-3 hours). You can also take something called "[natural supplement]" by [company], eat lactation cookies, take fenugreek, etc., but creating demand (pumping) is the most important. I recommend the [Website Name] website and FB group [Facebook Group Name]. The other side is will baby get back to latching? There are some tools you can use, including suck training (finger-feeding), SNS, and bottles that mimic breastfeeding (the only one I know of is the [Bottle Brand Name] bottle with it's [*sic*] double nipple system). Let me know if you'd like to talk more about latch issues. Personally, I wouldn't try too hard at latching until you first know baby has milk to receive at the breast. http://[website address] (FYI: My experience: I almost lost my supply due to TT/LT until intervention at three weeks (pumping, suck training, SNS). Recovered supply with powerpumping and galactagogues, finally got baby latching at 3 months old.)

Posting Participant 59: My baby has mspi so I'm going to need to be on total elimination diet to make sure my milk would be ok for her. So, should I try getting supply back then start the diet or would it make it harder to get my supply back by while on the diet? That's the part that gets me her stool is free from blood right now and I'm scared of messing that up.

Posting Participant 9: Do you mean free from visible blood, or tested negative for blood? What about mucous? Green color? Well, you'd want to start the elim diet now so when you get a supply, you are well on your way to a "hypoallergenic" supply. Getting enough calories can be tricky, but it is doable. Some relatively safe foods are good for supply, like oatmeal. Are you just dairy/soy-free, or total elimination diet?

Posting Participant 59: When we were nursing we didn't realize there was a problem until we seen visible blood. It took a while for it to clear up after we started [Formula Name] but as of a few weeks ago she was testing negative for blood. Her poop on [Formula Name] is green runny and still has like golden mucus in it. Our GI told us this was normal on [Formula Name] but I've heard different things on this. We have been on [Formula Name] for about 7 weeks now.

Posting Participant 4: Her baby's on [Formula Name] bcse her ped - well, don't get me started I wrote a SCATHING review about him!!#%!!%! So she might just need the TED; it's hard to tell... [*Posting Participant 59*'s Name] 1 you can either do the TED or 'just' cut out all milk and soy protein, even 'hidden' as in ingredients...

Posting Participant 59: She had a reaction to soy formula and [Formula Name] so I'm not sure where we would need to start I assumed total elimination then slowly add in milk and soy free products and watch

for reaction? The ped didn't give us a choice and had said she was lactose intolerant at the time.

Posting Participant 9: I am heartbroken that you were given such ignorant information. <frown emoticon>

Posting Participant 59: Yeah I have 3 others kids and she was the first I had decided to nurse and it was disappointing. [Baby's Name] is also our rainbow baby after losing her sister last year at 19 weeks pregnant so this has been a total roller coaster none of our other kids had these problems.

Posting Participant 4: There're links to Ted info/how-to on the bf reflux pg on [website address]

Posting Participant 4: {{{{hugs}}}}

Core Category V. Core Category V of Theme I was *lurking or learning vicariously*. Comments made in 17 instances by interview participants and one posting participant described engaging in what is considered *lurking* behavior. Lurking in the present study is defined as being a member of the group, posting infrequently, but reading postings frequently. A quotation that represents this concept is as follows:

Interview Participant 15: To be honest I wouldn't say I have participated a lot because I am still learning and trying to understand. I read a lot of what goes on. I read a lot of the questions and how people respond to them and I get ideas and I definitely get understandings from that.

Although only 17 interviewees stated they lurked, a comparison of the self-reported frequency of logging into the group by all interviewees and their self-reported frequency

of posting (Figure 6) shows that most of those interviewed spend a significant amount of time logged into the group without posting and thus they were lurking.

Theme II

The second theme centered on findings that *members followed a clear process of knowledge acquisition or stages to go from newbie to a highly knowledgeable member*. Postings that were analyzed from the group's walls also showed evidence of these stages of the process of skills and knowledge acquisition. Figure 14 shows the individual stages that are part of this process which included *questioning*, *asking*, *receiving*, *reconciling*, *applying*, and *sharing knowledge*. I based these stages on findings depicted in Table 5.

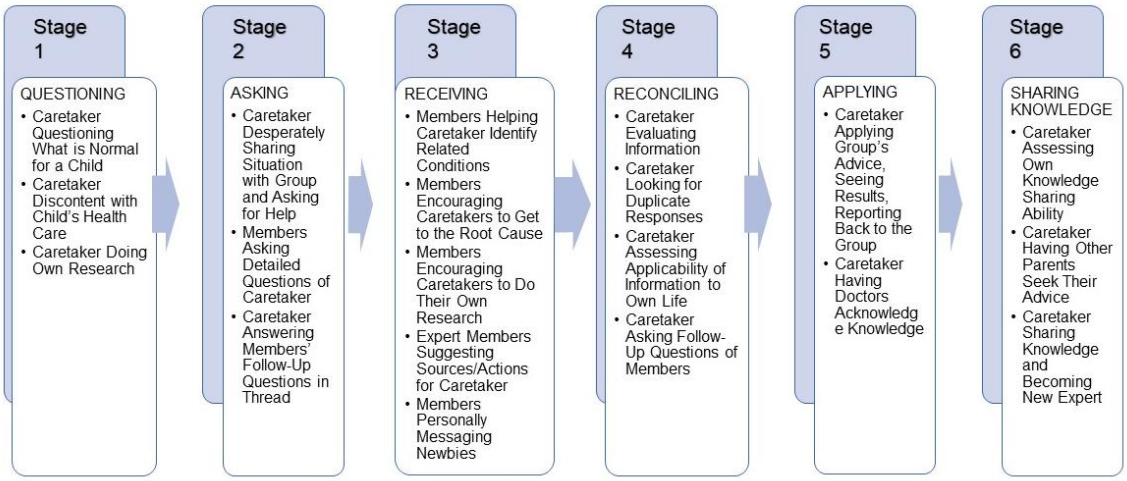

Figure 14. Stages from newbie to highly knowledgeable member as reported by study participants.

Table 5 shows how each stage was conceived and made up of several minor codes that rose from participant interviews and postings. For *questioning* this included the minor codes of the caretaker questioning what is normal for their child; the caretaker being discontent with their child's health care; caretaker doing their own research. For

asking this included the minor codes of the caretaker desperately sharing their situation and asking for help from group members; members asking detailed questions of caretaker; and the caretaker answering members' follow-up questions in the thread.

Table 5

Steps to Go from Newbie to Highly Knowledgeable Member within the Group

Steps	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
Questioning		
Caretaker questioning what is normal for child	3	4
Caretaker discontent with child's medical care	1	5
Caretaker doing own research	2	3
Asking		
Caretaker desperately sharing situation with group and asking for help	6	11
Members asking detailed questions of caretaker		
Child's feeding questions		5
Diagnostics tests questions		4
Caretaker's breastfeeding		1
Child's age and weight questions	1	1
Pediatrician's course of treatment questions	1	3
Previous treatment questions		8
Caretaker's diet questions		3
Child's stool questions		6
Child's related symptoms questions		6
Medication questions		12
How medication was compounded questions	5	
Main concern questions	2	1
Caretaker answering members' follow-up questions in thread	0	37
Receiving		
Members helping caretaker identify related conditions	0	2
Members encouraging caretakers to get to the root cause	0	5
Members encouraging caretakers to do their own research	5	11
Highly knowledgeable members suggesting sources/actions for caretaker	1	16
Members personally messaging newbies	0	5
Reconciling		
Caretaker evaluating information	75	77
Caretaker looking for duplicate responses	3	1
Caretaker assessing applicability of information to own life	2	19
Caretaker asking follow-up questions of members	0	12
Sharing knowledge		
Caretaker applying group's advice, seeing results, reporting back to the group	8	14
Caretaker having doctors acknowledge knowledge	6	1
Caretaker having other parents seek their advice	1	0
Caretaker sharing knowledge and becoming new highly knowledgeable member	1	1
Total	44	279

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings.

For *receiving*, this included the minor codes of members helping the caretaker identify related conditions; members encouraging caretakers to get to the root cause of the problem; members encouraging the caretaker to do their own research; highly knowledgeable member's suggestion sources or actions for caretaker to take; and members personally messaging newbies. For *reconciling*, this included the minor codes of the caretaker evaluating information; the caretaker looking for duplicating responses; the caretaker assessing the applicability of the information in their own life; and the caretaker asking follow-up questions of the members. For *applying*, this included the minor codes of the caretaker applying the group's advice, seeing results, and reporting back to the group; and the caretaker having doctors acknowledge their knowledge.

For the last stage of *sharing knowledge* this included the minor codes of the caretaker assessing their own knowledge-sharing ability; the caretaker having other parents seek their advice. These stages were of course not always followed sequentially nor completed during a specified period of time.

Theme III

In Theme III, members learned by applying acquired knowledge to the care of their GERD child. Interviews and postings showed that members of the group applied knowledge they gained in the group in different ways. Table 6 shows the ways in which knowledge was applied, and how often these were referenced in interviews and in postings that were analyzed. These applications included using acquired knowledge to advocate for their child, applying the their knowledge to the care of their current and subsequent children diagnosed with GERD, applying their knowledge by compounding their own medication, generating new learning artifacts for the group, using their

knowledge to change their diet when breastfeeding, using their knowledge to discern misconceptions their pediatricians or specialists had, using their knowledge to inform medical practice, using their acquired knowledge to explore natural treatment or design a new treatment, and using their acquired knowledge to control the direction of their learning both inside and outside of the group.

Table 6

Application of Acquired Knowledge

Applications	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
Using acquired knowledge to advocate for child	33	4
Applying knowledge to care of subsequent children diagnosed with GERD	18	1
Applying knowledge by compounding medication	14	10
Generating new learning artifacts	9	3
Applying advice and changing diet	0	8
Discerning misconceptions pediatricians and gastroenterologists have	7	3
Group experience-based knowledge informing practicing medical profession	3	0
Trying natural treatments recommended by other members	0	3
Acquiring options to design own child's treatment	1	1
Controlling direction of learning	1	0
Total	86	33

Note. Numbers given in the table refer to the number of instances these applications were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

As can be seen in Table 6, the two applications of knowledge that were most mentioned by participants were members using their acquired knowledge to advocate for

their child and applying the acquired knowledge to the care of their subsequent children. I discuss these two applications in greater detail below.

Members of the group used knowledge they gained through participating in the group to advocate for the care of their child especially when meeting with medical professionals. For example, Interview Participant 11 commented that "other people will come on and tell them not to take it as a final answer and that if they are not satisfied with their doctors to go find someone else." Interview Participant 19 also discussed using the knowledge gained through the group to advocate for her child with her child's doctor:

> *Interview Participant 19*: I actually used quite a bit of that information to take into my doctor. I can't remember the links that they had, but I do remember going into the files and printing off quite a few of the files. My daughter seemed to be the worst at night, and I remember printing off a file in there, something about why babies make more stomach acid at night, and different treatments. There were a couple of studies, I think, on different kinds of treatment and medications that had been used. I really want to do what's ... I remember being very concerned about it. I want to do what's scientifically based, I don't want to be guessing. The files and the websites were helpful because I could see what's current research, what's not, and I could take that stuff into my doctor and discuss that with him.

A posting participant that expressed the same sentiment stated the following:

> *Posting Participant 96*: I just want to share and help others advocate for their babies and know that feeling this way is horrible but expected.

The second most referenced application of knowledge participants gained through the group is to better care for their subsequent children with GERD. The following statement by Interview Participant 3 is representative of this application of knowledge:

> My other two kids had reflux and I was so much better able to deal with it, empower ourselves. My sister's kid has had reflux. I can't tell you the number of people who have been able to find solutions to their problems because of the information I've gleaned. It's been incredible.

A posting that is representative of this type of application of knowledge is below:

> *Posting Participant 99*: We had a similar story but being a second-time mom refused to settle for what drs were saying and got the right meds and formula by 4 months and had a new baby. Recently at 16 months increased meds and omg what an appetite increase too.

Guiding Question 2

Guiding Question 2 posed the following: What factors influenced group members' activity in this online social media group? There were many factors that participants mentioned as influencing their activity within the online social media group. In the tradition of Grounded Theory methodology, these factors went through several rounds of coding and analysis and were grouped together into core categories and themes. The themes that emerged from the data within this section were these:

1. *Theme I*: There were factors that were important to participants prior to joining the group that led them to join.
2. *Theme II*: There were factors that were important to participants that led to their continued membership in the group.

3. *Theme III*: An overarching factor that was important to group membership and participation was a disconnect between caretakers and medical professionals.

These three themes and the corresponding categories are shared in the following section.

Theme I

Theme I of Guiding Question 2 made note of findings that there were factors that were important to participants prior to joining the group that led them to join. Upon analysis, it was evident that there were factors that were mentioned as being important prior to joining the group which were different from factors that were discussed as being important and affecting continued membership and participation in the group. The following chart depicts the factors that participants stated were important prior to joining the group. These included GERD being a complex medical and emotional issue; existing characteristics of the group or learning space; seeking emotional support; feeling high level of desperation; seeking practical knowledge based on experience; existing characteristics of the individual learner; and the child's GERD being severe.

Table 7

Factors that were Important to Participants Prior to Joining the Group

Factors	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
GERD Being a Complex Medical and Emotional Issue	61	82
Existing Characteristics of the Group or Informal Learning Space	73	0
Seeking Emotional Support	58	15
Feeling High Level of Desperation	23	9
Seeking Practical Knowledge Based on Experience	20	11
Existing characteristics of the Individual or Learner	17	0
Child's GERD Being Severe	3	13
Total	255	130

Note. Numbers given in the table refer to the number of instances these applications were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Core Category I. Core Category I of Theme I was *GERD being a complex medical and emotional issue*. Participants discussed various factors that collectively depicted the complexity of GERD 61 times in interviews and 82 times in postings. The complexity of this issue made finding information, emotional support, and day-to-day living with GERD very difficult. Figure 15 lists all the aspects participants mentioned that make GERD a complex medical issue along with the number of instances participants mentioned each aspect in interviews and postings.

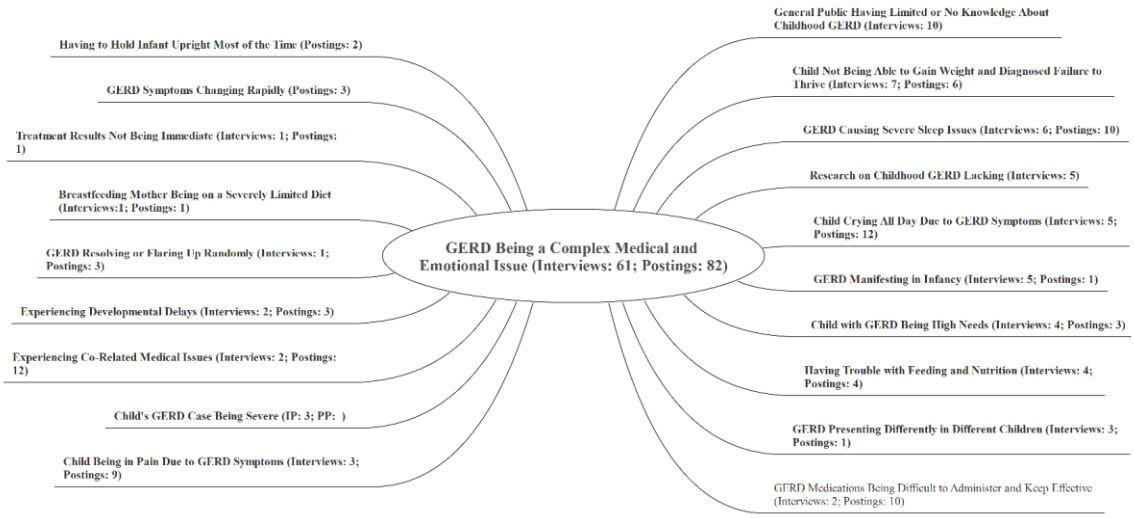

Figure 15. Frequencies of interview responses and postings for gastro esophageal reflux disease as a complex medical issue. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Quotations that were representative of these challenging aspects of GERD were these:

> *Posting Participant 96* (Crying): The screams of my baby were something I had never experienced before and over time they eventually became the screams of me, the screams inside my head as I held my wailing baby, the screams exploding from me as my husband held our baby.

> *Posting Participant 11* (Co-related gastrointestinal issues, medications being difficult to administer): He would not take it... he would gag on it and spit it out... no matter what I did <frown emoticon> I even mixed it with some formula... but he would not finish the bottle... just to get him to take it I had to put a ton of formula with it... and then he eventually stated refusing all his feeds... that's why I went with the mint [Medication Name].. he likes his [Medication Name]. He first got a rash in his chin,

which I thought was from drool about 4 or 5 days after I made the mint [Medication Name] batch then I noticed it was spreading to his torso... the ped said he had a yeast rash in his diaper area… which I didn't notice. But he had the red ring <frown emoticon> which he has always had... I thought it was from his poop sticking to him. But he had horrible smelly has and diapers from the start… but they got really green, runny and mucus after a week of [Medication Name].

Interview Participant 17 (Severe sleep issues): And the other thing was he stopped sleeping. That was very difficult. It's hard enough with a newborn. I mean, all moms are exhausted when they have newborns. I can't take away from that, that's everybody. This was different. He wasn't sleeping any more than 40-minute stretches, and sometimes that would go on for every six hours. I mean, to me, I thought the baby had insomnia, because he was not sleeping. And I remember bringing that to the attention of my doctor and saying, "This can't be normal." And I remember her saying to me, "Well, some babies just don't nap." And I said, "Oh no, I'm not talking about napping. I'm talking around the clock."

Posting Participant 75 (Developmental delays): She never learned how to chew. Sounds weird but common in babies with reflux. Therapy is to teach her to chew so she can eat solids without choking.

Posting Participant 59 (Child being in pain): Ok that's a little more than we have been giving her hopefully it will get us through. I hate seeing my happy baby in pain constantly.

Like the challenging aspects of GERD being a motivating force for seeking and joining the group, the characteristics of the group or learning space it provides were important factors for new group members.

Core Category II. Core Category II of Theme I was *characteristics of the group or learning space being present*. Interview participants discussed certain characteristics of the group that made participants want to join the group 73 times in interviews. Figure 16 depicts what these characteristics were and how many times they were mentioned in both interviews and postings.

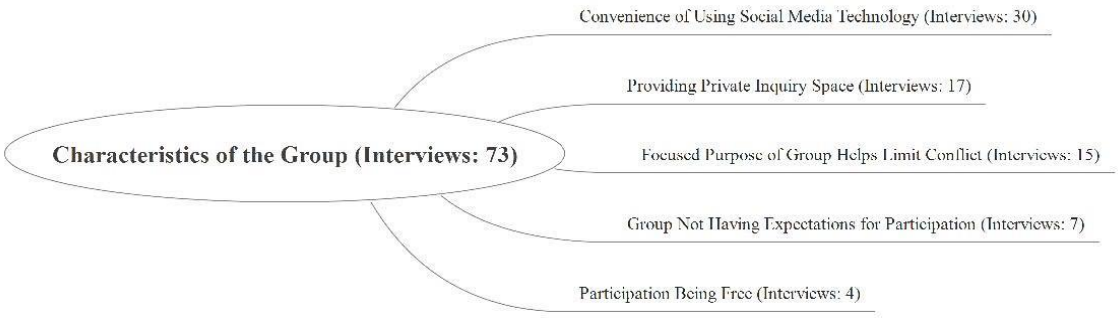

Figure 16. Frequencies of interview responses and postings for group characteristics that motivated participants to join. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

Quotations that were representative of this category are listed below. The first quotation is regarding the convenience of using social media technology, the way it provided a private inquiry space, and the group not having expectations for participation:

> *Interview Participant 15*: It's the sense that no one else on Facebook knows that I am asking questions and stuff like that. You can sit on the sidelines and read. You don't have to actively participate all the time.

The next quotation describes the impact of the group's focused purpose on the group.

> *Interview Participant 11*: It is a community and within that community there is a central theme and that might be reflux or having a child with Down's syndrome. It is that one thing that kind of connects people and I think having that connection kind of makes the group more cohesive. If it was just people that have infants you would deal with a lot more generalities or less helpful posts, but since there is something specific like reflux I think it is more helpful. It is more cohesive and more helpful.

Along with the difficult nature of GERD and the characteristics of the group, participants mentioned seeking emotional support as a significant factor.

Core Category III. Core Category III of Theme I was *seeking emotional support*. Participants mentioned the seeking of various types of support as motivation for joining the group 58 times in interviews and 15 times in postings. Figure 17 depicts the types of emotional support that they described seeking.

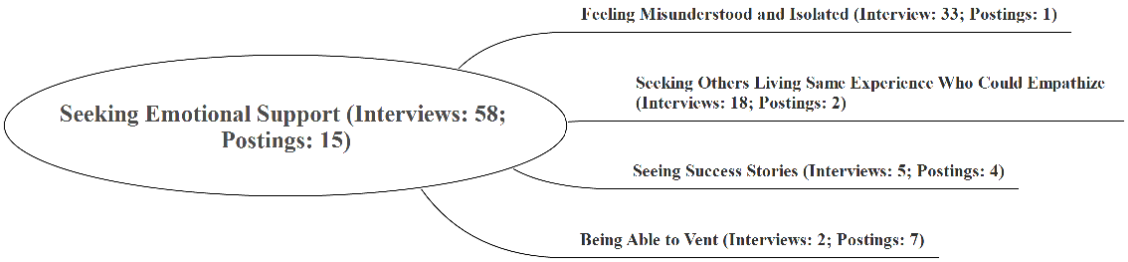

Figure 17. Frequencies of interview responses and postings for emotional support types. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

A quotation that was representative of this factor was Interview Participant 10's statement regarding joining the group because she was seeking information, but also emotional support.

> Seeking more information. Also it's [*sic*] support. Somebody who actually understands what you're going through and doesn't just say well it's a laundry problem. Because while yes I did and do still do a lot of laundry, it's not easy when you have to care for a child or in my case two children who will not stop screaming and puking.

The next quotation that is representative of this factor is regarding seeking others who are living the same experience and can empathize:

> *Interview Participant 19*: I think it was helpful, like I said, I was looking for other moms' experiences that had had similar experiences or support, that could offer support or, I guess, sympathy or empathy.

The next quotation also highlights participant's need to not feel alone or misunderstand:

> *Interview Participant 12*: I think there is an emotional support there. Like you know your baby has been up all night crying and you haven't gotten

> any rest…you know through the group that there are other people in the group who are going through the same thing. Shows you are not alone.

Participants mentioning seeking emotional support also mentioned feeling a high level of desperation as are explored in the next section.

Core Category IV. Core Category IV of Theme I was *feeling high level of desperation*. Participants discussed feeling getting to a point where they were feeling a high level of desperation at seeing their child in pain and not obtaining any relief. They mentioned these feelings as being a major catalyst for searching for information online and eventually joining the group. Interview participants mentioned this sense of desperation 23 times in interviews and nine postings. Quotations representative of this core category are the following:

> *Interview Participant 6*: We felt like we didn't have time to waste. He had always been … he always struggled so much. He didn't pass seven pounds until he was over three weeks old. He was not gaining, he was not eating, he was screaming, he had barely learned how to nurse, at three months old. We needed to find a solution fast and we didn't have time to wait for doctors to schedule us for appointments and to treat things casually. That is a very emotionally devastating feeling when you cannot feed your baby, you can't calm your baby and you can't keep your baby from hurting.

The next two quotations further describe the type of desperation that participants expressed:

> *Interview Participant 2*: I mean the desperation in the sense that you want your child to feel better, you have no idea what to do, that you put your

faith in, your doctor, your pediatrician or whatever, GI doctor you've seen one or whatever and this is the same situation with my daughter. I took everything they said at like 100%. You have to…you know, my daughter was on the killer dose, looking back at everything and on compounded prevacid and when she wasn't gaining weight, she was looking weak and was failure to thrive. She wouldn't sleep and it was two years of this. Because she was on it over the age two. I didn't know anything about disability issues or about dosing or about MARCI kids dosing. I took everything that my pediatrician and my GI said to, as the gospel. There really wasn't any sort of support anywhere else at the time.

Interview Participant 16: It definitely feels like we could only get through it if we took it moment by moment because when we would, we would have serious breakdowns when we just thought, "Oh my God, is our lives going to be like this all the time? Is there really ever going to be an end to this?" It has this power over his entire young, short life, so it's totally true that's why you go ... You are, you're like, "Well I'm going to search for berries in the forest then because we're not going to starve." I'm going to figure it out whether I just have to sit here in front of the computer and just Google 100 different search terms until I find some information, which is essentially how we found our solution, literally just like desperation.

Another key factor for joining the group according to participants was their desire to obtain practical knowledge based on experience instead of fact-based medical information. The next section explores this factor further.

Core Category V. Core Category V of Theme I was *seeking practical knowledge based on experience*. Participants mentioned the seeking of practical knowledge based on experience and not facts as a reason for joining the group 20 times in interviews and 11 times in postings. Following is a quotation that was representative of participants' seeking of practical knowledge.

> *Interview Participant 20*: I think with this group in particular, I think the strength of the group is obviously the shared experience. The real-life experience, the real-world application of trying different medications and doses and formulas and then certainly in some cases, even referring people to doctors in certain areas that have proven themselves to be good in dealing with the problem.

The next quotation compares the type of information a participant obtained from doctors and why it was lacking.

> *Interview Participant 22*: My doctor was supportive, but he also wasn't part of my everyday life. He wasn't someone I'd talk to on a daily basis and he wasn't really somebody that I could say ... Well, I mean, I guess I did tell him, "You know, I'm struggling with lack of sleep," but I think doctors are there to answer from a medical perspective, your medical questions. Other mom's, I think, have a different, of course, perspective because they're in it. They're in the thick of it, and they're having that

> same experience or they've had that same experience, and so they know how frustrating it is. They know how frustrating it is when people keep telling you, "Just keep breastfeeding, just keep breastfeeding," or another thing I heard a lot was, "Oh, reflux is really over-diagnosed nowadays. You know, most kids that are diagnosed with reflux don't really have it." Your doctor can tell you, "You know, here's the medication you should try. Here's some dietary things you can try," but you're not going to text your doctor at 2:00 in the afternoon and say, "I'm really having a bad day. My baby won't quit crying, um, you know, and I just tried to feed her some applesauce and she like gagged on it." You're not going to call your doctor and tell him those kind of minutia, day to day things that are happening. No matter how supportive they are, they aren't you're sounding board, they aren't your friend. When you're in a group like that, when you post something like that, you're posting to a group of other moms that are going through that same thing or have gone through that same thing, so they get it. They aren't just going to tell you, "Here, try this medication or here's something else you could do differently." They're going to say, "I've been there and I've been through it, and these are the things that helped me. These are the things that helped my baby.

Like the factors that were important prior to joining, there were different factors that participants mentioned as being important during their membership in the group. These are discussed in the next section.

Theme II

Within Theme II, there were different factors that were important to participants that led to their continued membership in the group. Table 8 depicts the factors that participants stated were important during membership in the group. These factors included the experience-based knowledge found in the group; caring for an infant/child with GERD being a difficult experience; strong leadership being present 24/7; participant wanting to find solutions fast 24/7; group and learning space having limitations; family support for participation; and having time for participation. In the next sections, I discuss the key factors or core categories that participants discussed regarding factors important during membership as depicted in Table 8.

Table 8

Factors Leading to Continued Membership in the Group

Factors During Membership	No Instances Referenced in Interviews	No. Instances Referenced in Postings
Experience-based knowledge found in the group	65	8
Caring for an infant/child with GERD as a difficult experience	42	56
Strong leadership being present 24/7	19	3
Wanting to find solutions fast 24/7	15	7
Group and learning space having limitations	13	0
Family support for participation	9	1
Having time to participate	4	0
Total	167	75

Note. Numbers given in the table refer to the number of instances these applications were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Core Category I. Core Category I of Theme II of Guiding Question 2 was *knowledge found in the group is validated, deep, and easy to understand*. Participants discussed the knowledge that they found in the group as being one of the factors for why they remained in the group 65 times in interviews and eight times in postings. Figure 18 lists various aspects of the knowledge that participants mentioned was present in the group. These included accessing a worldwide membership and a broad knowledge base; receiving validated, experience-based information, consistently receiving elaborate responses quickly; and knowledge that is clear and easy to understand.

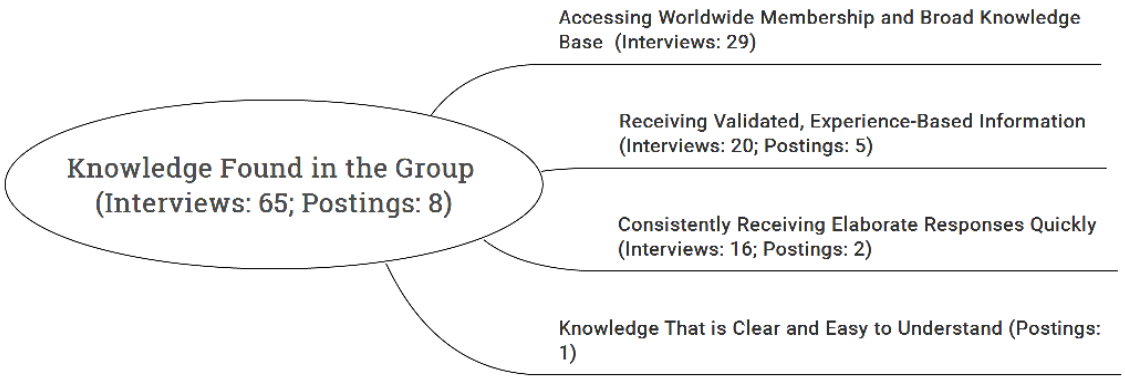

Figure 18. Frequencies of interview responses and postings for group knowledge as a membership factor. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

Following is a quotation from a participant that speaks to receiving elaborate responses quickly from the group:

> *Interview Participant 11*: I would say that in the group there is usually a very good response. I would say that at least two people respond and if not, I have had maybe 10 or 12 different people respond to a single question. So it is one of those groups that you know if you post something at least someone is going to get back to you and answer the question as

> best they can or maybe tag someone else that can answer the question. You know when you post even though it's like 5:00 in the morning, you've got other people that are also awake and even though it is 5:00 in the morning, they respond as well within a timely manner.

The next quotation is from an interview participant that discusses receiving validated, experience-based information from the group and accessing a worldwide membership and broad knowledge base that can speak to many different issues:

> *Interview Participant 22*: Yes! Yes, it's more practical and also more tried and tested. Whereas although the doctor knows…every child is different and there is more a wealth of experience. There is more wealth of knowledge within the group because there's so many people and everyone's experienced something different. What may work for one child will definitely not work on another, but because the group is so big you could have 50 parents who all went through the same thing and had something work for their child. No pediatrician is ever going to know that because it is something that…you know parents will try anything where doctors won't.

Similarly, to GERD being a complex medical and emotional issue being one of the factors that was important prior to joining, caring for an infant or child with GERD being a challenging even traumatic experience is a factor that is of primary importance to continued membership in the group. I discuss this in the next section.

Core Category II. Core Category II of Theme II was *caring for an infant/child with GERD being a challenging experience*. One of the factors that participants discussed

as affecting their choice to continually participate and seek knowledge in the group was how difficult of an experience caring for an infant/child with GERD was. This concept was mentioned 42 times in interviews and 56 times in postings. Figure 19 depicts aspects of caring for an infant or child with GERD that make it a difficult experience which include caretakers being exhausted from stress and sleep deprivation; seeing child experiencing distressing symptoms; GERD experience leading to depression or post-traumatic stress disorder; feeling helpless at not being able to comfort child; having children with multiple special needs; having multiple children with special needs; caretakers being accused of not caring properly for a child; and the cost of GERD medication and specialized formula being taxing on family.

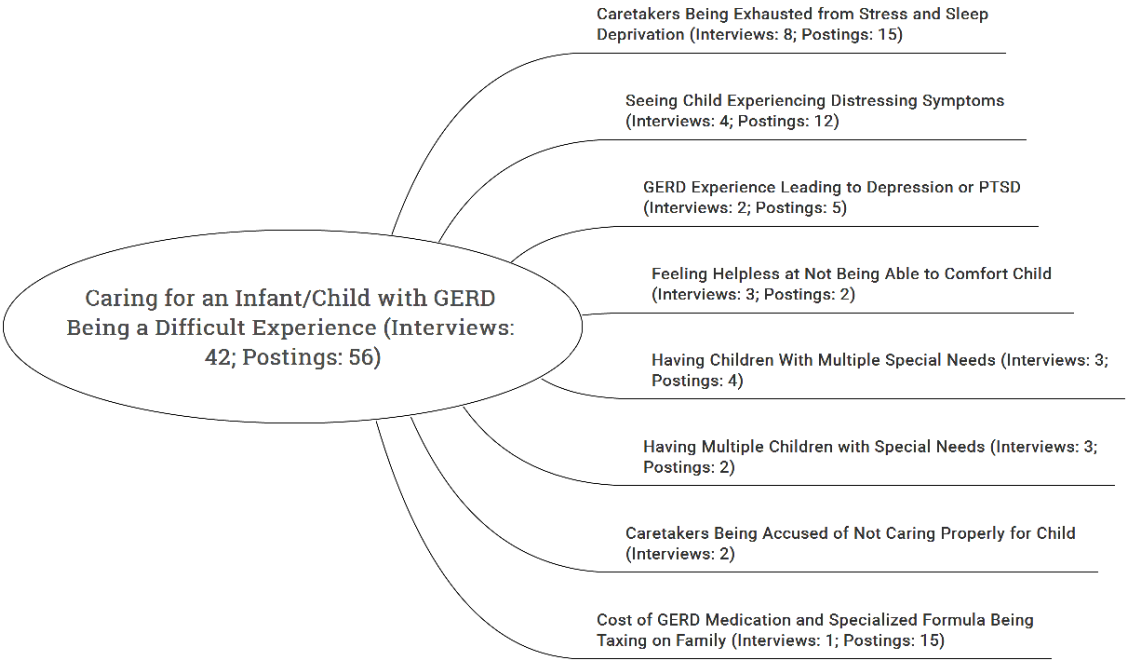

Figure 19. Frequencies of interview responses and postings for difficulty caring for an infant/child with gastro esophageal reflux disease. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Quotations that were representative of this category are shared in the next section. In the first two quotations participants described the sleep deprivation GERD causes for the entire family:

> *Interview Participant 21*: We didn't sleep, which is a huge stressor, biologically, on your body, on anyone's body. Whether you're dealing with a baby or not, you can only go with sleep deprivation for so long. I remember I had a Fitbit at the time, and it was telling me I was averaging like two to three hours of sleep every night.

> *Interview Participant 14*: When it is reflux it's definitely maddening. You don't sleep. They think that when you are up with a newborn, you don't sleep and you don't, but at least they start to grow out of it and they sleep more and more and you start to get your sanity back. But with a refluxer, everything sets it off. Vaccines sets it off. Teething sets it off. You know just being sick sets it off. Off nights sets it off. You know you are constantly worried that with every single scream at night, you're going to be up for an hour and half trying to soothe your kids and putting them back down to sleep.

The next quotation speaks to the challenge of seeing one's child experiencing distressing symptoms and feeling helpless at not being able to comfort one's own child.

> *Interview Participant 20*: Mm…it's hard. It's exhausting. Um…it's horrible to watch them go through so much pain and not be able to do anything about it. Um…or feel like you can't do anything about it.

> Um…it's just….sorry…we're still going through it. I am just so exhausted. It's exhausting mentally and physically draining.

The next two quotations described the effect the experience of caring for a child with GERD has on the caretaker sometimes leading to depression, anxiety, or post-traumatic stress disorder.

> *Posting Participant 43*: So I spent the whole day in my bedroom, hanging out with the 2 year old, not taking care of the smallest lo. My husband has taken care of him for the past 24+ hours. My anxiety and depression is horrible. I am getting panicked just caring for him😒 I just peeked at him, sleeping in his seat, and I feel like I've abandoned him☹ No nursing and now he barely seen his momma today. I hate this stuff so much.

> *Posting Participant 29*: Hugs momma! I've so been there. I had such anxiety about feeding my son bc it was such a battle. I felt like I was torturing him. I had to pass him off to my husband and take a breather more times than I can count.

Core Category III. Core Category III of Theme II was *strong leadership being present 24/7*. Participants described the strong leadership that was present in the group as being a factor in their continuing membership 19 times in interviews and three times in postings. They discussed the various duties the leaders provide in the group and how leaders make the group effective. Figure 20 depicts the duties and characteristics that participants attributed to the group leaders.

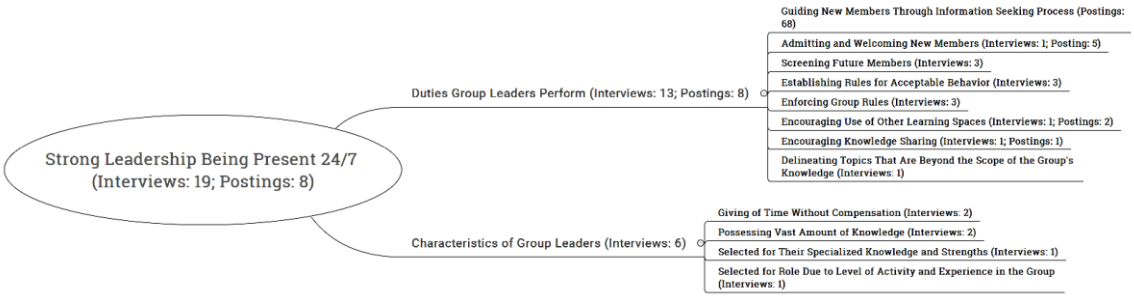

Figure 20. Frequencies of interview responses and postings for duties and characteristics of group leaders. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

I present quotations below that were representative of the strong leadership being present 24/7 in the group. The first quotation speaks to group leaders screening future members:

> *Interview Participant 1*: I would say the moderator, I forget her name ...she obviously does a very good job of whoever she allows into our group, she keeps out any spammers or anybody who's not there to be there for the purpose of discussing infant reflux I guess.

In the following quotation the participant discusses their duties as a group leader including enforcing group rules, establishing rules for group behavior.

> *Interview Participant 24*: I see the role of moderator as making sure - Again, this current and past - just making sure that people are ... People's posts are being addressed. Answered. I guess the role of the moderator would be keeping the peace. Again, there's not been like heated discussion, but if there was, it would be saying, "Well, we all have to ..." You know? Just be kind of peacekeeper or making sure people aren't writing slanderous, harmful things, which is not happening in this group.

In the following quotation, a group leader describes how leaders are selected for their specialized knowledge and strengths.

> *Interview Participant 25*: And there definitely ... different moderators have their different strengths. So like, one is really good with medications one is really good at navigating the Canada health care system, one is really good at navigating the Australian health care system, one is really good with allergies, one's really good with everything and severe cases and less severe cases. So one thing when we did try to choose the moderators to help us, they were people who had a vast amount of personal experience and extreme situations that made them very knowledgeable.

Core Category IV. Core Category IV of Theme II was *wanting to find solutions fast 24/7*. Another factor that participants mentioned was important to their ongoing membership in the group was being able to ask questions of the group and find solutions any time of day or night on the group within a short time frame. It was mentioned 15 times in interviews and seven times in postings. Quotations that were representative of this category were these:

> *Interview Participant 22*: It's not easily available whereas this is like a question and answer, you can go out there and say hey, I live in this area. Who do you see for your child's GI? Who do you avoid? You're able to get an answer.

> *Interview Participant 10*: Between being able to get an answer quickly to your question especially because half the time these questions come up in

the middle of the night when you cannot get a hold of a doctor. You cannot get a hold of somebody else. You got this group and they're pretty much there around the clock.

Interview Participant 11: Um…the convenience of it. If I am encountering something I can just go to my phone and type it up. Within less than a minute I will get a quick response. The convenience and quick response is one of the top things.

Core Category V. Core Category V of Theme II was *group and learning space having limitations*. Participants mentioned the limitations of the group and the learning space it afforded 13 times in interviews. Figure 21 depicts the limitations they felt the group or learning space had.

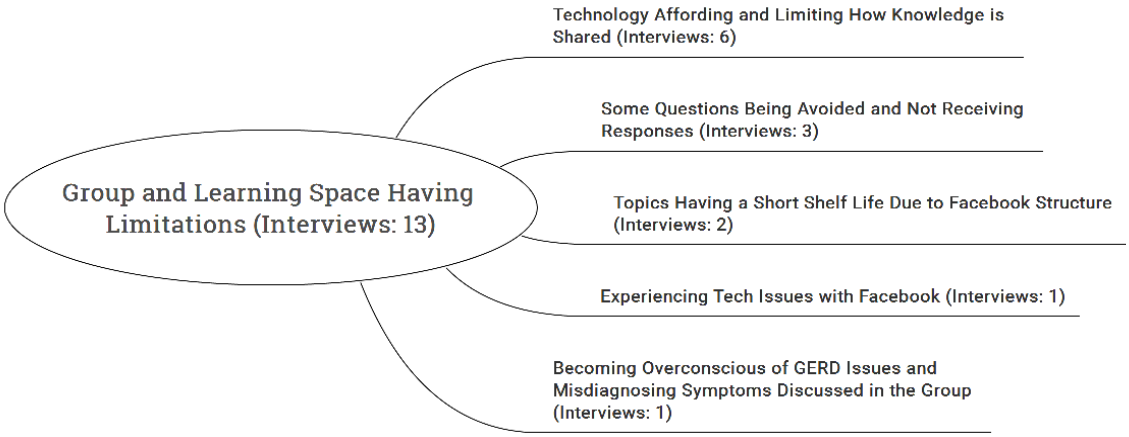

Figure 21. Frequencies of interview responses and postings for group and learning space limitations. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

Quotations where participants spoke of the limitations of the technology the group uses were these:

> *Interview Participant 20*: In a way, that's the frustration of ... It feels like when I posted to these kinds of forums, groups, it has a very limited shelf life. Sometimes I've been able to utilize search terms, for instance, like you can search through all of the messages in that group with key words, but certainly as someone who has posted something, it's like if people don't see it in the first couple days, that post doesn't really have any traction.

> *Interview Participant 4*: The reason why I like having the website is because I feel like that's where I store things. In Facebook, it's a vertical scroll. Everything gets lost in a vertical scroll and you know it is tiring to keep typing the same thing over and over.

Theme III

Theme III in Guiding Question 2 was an overarching factor that led to group membership and participation. The factor was a disconnect between caretakers and medical professionals. The following Table 9 depicts the dimensions of this disconnect that participants discussed. These included doctors not being knowledgeable about infant and childhood GERD; caretakers and doctors having a combative relationship; doctors being ineffective; and having knowledgeable and helpful medical professionals.

Table 9

Dimensions of Disconnect between Caretakers and Medical Professionals

Dimensions	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
Doctors not being knowledgeable about infant and childhood GERD	54	16
Caretakers and doctors having a combative relationship	30	35
Doctors being ineffective	45	16
Having knowledgeable and helpful medical professionals	10	1
Total	139	68

Note: Numbers given in the table refer to the number of instances these behaviors were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

The Core Category in Theme III under Guiding Question 2 was *doctors not being knowledgeable about infant and childhood GERD*. As shown in Table 9, participants discussed ways in which medical professionals demonstrated a lack of knowledge regarding infant and childhood GERD 54 times in interviews and 16 times in postings. The ways doctors demonstrated a lack of knowledge included diagnosing GERD as colic or not needing treatment because it was normal; doctors being unfamiliar with GERD medications for children; doctors not understanding related factors or taking a more holistic approach; doctors not relating because they have no personal experience with GERD; and doctors not being aware of non-prescription treatments. Figure 22 lists these ways.

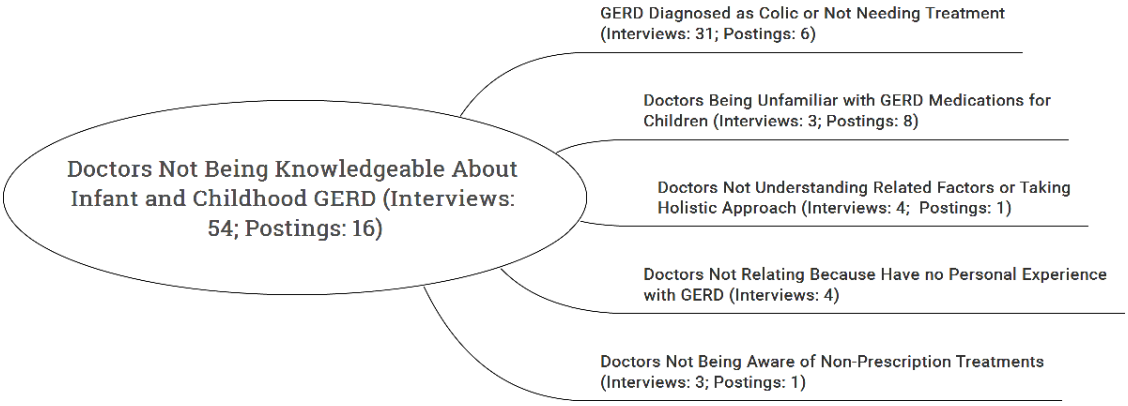

Figure 22. Frequencies of interview responses and postings for doctors' lack of knowledge about infant/childhood gastro esophageal reflux disease. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Quotations that were representative of what participants stated regarding doctors thinking the symptoms of GERD were normal and not needing treatment were the following:

> *Interview Participant 15*: So, I did not know what was wrong with him and he was sort of…he was fine for the first couple of week after we brought him home. Although he was spitting up. I kept saying to them in the hospital because he had been taken to the hospital two days after he was born because of breathing issues. He kept spitting up and spitting up. I kept telling them that the spitting up is not normal for a newborn, not this much. They were like "no, no, it is fine. It is just regular spit up". So I was like o.k. whatever. So after it had been about four weeks. I had called my pediatrician and I said that something is not right because he is screaming all day. And then he's like it's nothing. But when he is waking up screaming for three hours at night. And it is not colic because you know the difference. Anyway, he said well you need to take him to the ER. So

> we took him to the ER and they did checks like an ultrasound and an X-ray and they said he had reflux. They automatically gave us [Medication Name] so they diagnosed him as reflux in the hospital, in the ER. Then sent us home.

> *Posting Participant 85*: I went in and told the ped all his symptoms and basically demanded help, she was skeptical and said a lot of people just don't want to accept they have unhappy babies which was such an ignorant thing to say (clearly never went back to her).

A quotation that is representative of doctors being unfamiliar with dosing and medication for infants and children with GERD was the following:

> *Interview Participant 12*: I would say that given some of the newer research that a lot of doctors have some knowledge, but it is somewhat limited. I know a lot of the doctors I have talked to have been very strict about not using certain medications and some are not familiar with other medications.

Two quotations that were representative of doctors-not-understanding related factors or taking a holistic approach were the following:

> *Interview Participant 4*: Oh. No, my doctors did not know about the elimination diet. Or they didn't ... They didn't know or care. I mean, not that they didn't care, but it wasn't like ... It was never mentioned to me from them. I'm very lucky that no doctor told me to stop breastfeeding;

however, like I said, this has been 11 years now and doctors are still telling mothers to stop breastfeeding. It just pisses me off.

Interview Participant 16: The remedy that I researched and sort of has actually been effective, which is probiotics, totally benign, all natural, but it's very important to get the right probiotic and that's a whole journey of research in and of itself. All of that, we had to figure out on our own, and do our own research, and basically ask our own questions. I felt like the medical community never offered that ... Ironically, our GI specialist, is a professor and she's telling me, "Oh, I'm doing a paper on probiotics," I'm like, I don't understand why you didn't talk to me about that and talk to me about that option.

Guiding Question 3

Guiding Question 3 posed the question, what types of knowledge existed in this online social media group? Participants discussed several types of knowledge that were shared and acquired through participation in the group. In the tradition of Grounded Theory methodology, these aspects regarding knowledge in the group went through several rounds of coding and analysis and were grouped together into core categories and then themes. The themes that emerged from the data within this section were

1. *Theme I*: The type of knowledge that was most acquired in the group was knowledge about practical, day to day living with GERD.
2. *Theme II*: Participants gained additional knowledge they had not intentionally sought through participation in the group.

3. *Theme III*: There are factors of differing importance that affect knowledge-sharing in the group.

These three themes and the corresponding categories are shared in the following section.

Theme I

Theme I under Guiding Question 3 was the type of knowledge that was most acquired in the group was knowledge about practical, day to day living with GERD. Participants mentioned that knowledge to help them care for their infant or child with GERD on a day to day basis was the most important and most acquired type of knowledge gained through participation in the group. As Interview Participant 22 stated, "A lot of questions do still revolve around GERD/reflux, but they revolve around life with GERD/reflux as opposed to necessarily just a medical question."

Participants often cited this practical type of knowledge as not being available through doctors or other professionals, but only being available from other individuals living the same experience of having a child with GERD. Table 10 shows the 47 types of knowledge participants stated they gained through participation in the group both in interviews and postings.

Table 10

Types of Knowledge Acquired through Participation in the Group

Types of Knowledge	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
GERD medications and dosages for infants/children	27	26
Getting to the root cause of GERD	20	2
Sleep positions/positioning devices for infants with GERD	14	6
Learning how to compound medication	10	13
Identifying best formula type for infants with GERD	9	10
Learning about secondary effects of GERD	6	1
Understanding elimination diets	5	15
Linking GERD flares to vaccines/teething/ear infections	5	4
Identifying symptoms of GERD in infants/children	5	6
Finding natural treatments for GERD symptoms	4	18
Discovering methods for thickening milk	4	20
Connections between GERD conditions and stool types	3	6
Evaluating tongue and lip ties and connections to GERD	3	3
Finding an effective pediatric gastroenterologist	3	6
Learning about the degradation of GERD medications	3	8
Finding alternatives to cow's milk	2	0
Learning about the best types of bottles and nipples to use	2	0
Solid foods best tolerated by infants with GERD	2	1
Identifying best car seats for infants with GERD	2	0
Combining treatments to find relief for child	2	1
Learning how to wean child off GERD medicines	1	2
Learning about acid rebounds due to changes in treatment	1	0
Learning about FDA studies on GERD in children	1	0
Which GERD treatments could aggravate GERD	1	0
Handling feeding aversion and dream feeding	0	14
Learning about allergy symptoms	0	13
Learning about GERD diagnostic tests	0	5
Identifying ways to increase weight gain and nutrition	0	2
Uncontrolled GERD hospitalization/severe consequences	0	6
Learning when to wean child off medicine	0	2
Best over-the-counter medications for GERD	0	6
Learning about drooling and use of pacifiers	0	2
Dealing with constipation and gassiness caused by GERD	0	12
Exploring spit-up types and what they mean	0	7
Sharing tips for getting child to take medication	0	9
Learning how to prevent GERD in next child	0	1
Identifying related medical specialists to consult	0	5
Learning about community resources that could help	0	1
Examining ingredients in medicines and formula	0	8
Skin issues related to GERD or GERD medication	0	4
Weaning and trying new food/formula/other treatments	0	8
Learning about effects of medication	0	11
Defining terminology related to GERD	0	1
Identifying safe foods for child	0	6
Understanding how to time medication and feeding	0	3
Learning how to advocate for child	0	11
Sharing saving tips for medication	0	3
Total	133	288

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

The top 10 types of knowledge included learning how types of GERD medications and dosages work in infants and children; learning how to get to the root cause of GERD; learning best positions for sleep and best positioning devices; learning how to compound medication; identifying the best formula type for infants with GERD; learning about the secondary effects of GERD; learning how to do the elimination diet if breastfeeding; analyzing the associations between GERD flares and vaccines, teething, and ear infections; learning how to identify symptoms of GERD in infants and children; finding natural treatments for GERD symptoms; discovering methods for thickening milk; and learning about stools and what conditions to which different types are connected.

Core Category I. Core Category I under Theme I was *learning how types of GERD medications and dosages work in infants and children*. As Table 10 shows, one of the knowledge topics that participants mentioned the most was learning about GERD medications and how they work in infant and children's bodies as opposed to that of adults. A second aspect of this topic was how dosages should be administered and spaced out for infants and children versus the one dosage adults take. These topics were mentioned 27 times in interviews and 26 in postings. Quotations representative of this core category include the following:

> *Interview Participant 7*: Yeah I definitely learned more about how H2's and the PPIs kinetically work in the body and why certain medications and dosages worked with infants and definitely how much quicker those medications are metabolized in children.

Interview Participant 10: Well, basically I was trying to find out the appropriate dosing for PPI because what we were doing wasn't working and trying to find out what other, how other people have, what their experiences were with different PPIs. Knowing that yes, my children were going to react however they were going to react per their individual systems to whatever medication they were on. We had reached the point where it wasn't working at all.

Interview Participant 13: The big difference I noticed was in the information about medication. Like dosages. I got all of that information from the Facebook page. I didn't even know the difference between an H2 medication and a PPI blocker. I learned all of that from this site.

Core Category II. Core Category II of Theme I was *learning how to get to the root cause of GERD*. One of the knowledge topics that participants brought up 20 times in interviews and two in postings was how to get to the root cause of GERD. GERD is often associated with allergies or physical abnormalities and thus knowing the root cause is very important in being able to find the appropriate treatment. Participants mentioned having tried many treatments with their children that were not working and seeking knowledge in the group from other parents who may have been through the same experiences. They stated that the group often helped them get to the root cause of their child's GERD whereas their doctors were mainly interested in just resolving the symptoms. Quotations representative of this core category include the following:

Interview Participant 15: Yes, that is a big thing. I stopped eating dairy which I saw really helped. I didn't think for a minute that they would have been associated so that is definitely something that has helped immensely, and I only found out about it through the group. You know that it could be an issue. A big thing. We suspected it might be MSPI so I went on a complete diet to try to rule that out. Well, a huge thing that I learned in the group – like I said – was the root cause.

Interview Participant 11: I posted questions regarding my son's GERD such as the possibilities for why there might be GERD such as food intolerances and usually that is connected to if the child has milk protein intolerance or any other kind of allergy or intolerance that can create GERD.

Interview Participant 8: Yes, because the one thing I have experienced you know is that my son he also has food allergies and he also has GERD so he can't really drink milk. As soon as he has milk he starts choking and gagging and he can't sleep at all. The best thing what I have learned through this group is the MSPI. You know milk soy protein allergy and if you are breastfeeding what really helps because you know when I started breastfeeding my baby he had blood in his poop. My doctor said it's fine and it doesn't matter, but this group taught me o.k. if you have a baby that is really allergic then you have to cut down on certain foods.

Core Category III. Core Category III of Theme I was *learning best positions for sleep and best positioning devices for GERD infants*. A third knowledge topic that came up often was learning what the best position for an infant with GERD was. It came up 14 times in interviews and six times in postings. As many infants with GERD have difficulty sleeping because of the way GERD works, it is a topic that affects participants across the board. Many doctors advocate for elevating an infant while they feed and sleep, but they do not go into the details of how to do this. Participants stated that through the group they were able to identify the best ways to elevate an infant and even the best positioning devices for infants with GERD. This topic is an excellent example of the practical knowledge that participants described as being a reason for joining and staying in the group. Quotations representative of this core category include the following:

> *Interview Participant 5*: If anything I feel like everyone is super helpful as far as offering the support, just knowing that there's other people going through it and being able to give different ideas of even like for sleeping, I mean the doctors will say, "Oh keep them propped, you should have a pillow up there," but sometimes that just doesn't work and so people get creative and they think of different ways of doing things and then they can share that with people that are struggling. So I feel like that sometimes is the most helpful information because it's one thing to be given a kind of medicine by your doctor but I think to make your day to day life so much easier these people have lots of knowledge about that kind of stuff that I think is really helpful for people.

> *Interview Participant 10*: Things like wedges or various types of bibs that might catch a little bit more is what you learn through the group. For instance, with a GERD baby (I know you know this, obviously being part of the group) you wouldn't lay the baby down flat on its back to trim its toenails, so you come up with alternate ways such as like a rock and play or something like that where the baby could be seated and you could do that.

Core Category IV. Core Category IV of Theme I was *learning how to compound medication*. A fourth knowledge topic that several participants discussed having acquired in the group was learning how to compound medication. It was mentioned 10 times in interviews and 13 times in postings. Members shared information regarding research done by [University Name] on GERD dosing for infants and children. Then several members took the instructions from that research and taught each other how to compound over the counter GERD medication in an immediate release type of medication that their infants could consume based on that university's recommendations for their child's age and weight. Typical medication sold over the counter or even by prescription requires that those taking it not eat for an hour before taking the medicine which is difficult for infants or parents to time. Thus creating an immediate release version is critical for many parents. In addition, some members found that compounding their own medication weekly allows the solution to retain its composition better versus the pharmacy's compounding which is done on a monthly basis. Quotations representative of this core category include the following:

> *Interview Participant 7*: I've started compounding my own medicine for him. I got that sort of recipe for that through the group. I think probably for me seeing that others are doing their own compounding at home and getting information from them about what they've used and the fact that they've used it safely and successfully in their own kids.

> *Interview Participant 6*: We just said we are starting a PPI and we are going to do this on our own. We did as much research as we could through the group. I didn't want to just blindly say, "Okay you mix this and this." I wanted to know how it works behind the scenes so I asked a lot of questions about the buffer. Why do you mix the two? Well you mix the two so that you have only half a buffer which will be a baking soda. You'll have enough buffer but at the same time it won't be causing the chemical reaction the baby stomach. They vomit like a volcano when you mix an acid and a base, the volcano starts. I wanted to know exactly why do you need a buffer, what is immediate release versus delayed release, what's going on to make this happen.

In addition to learning about topics that had to do with day to day living with GERD, participants also discussed knowledge they gained without seeking it out or even realizing they had acquired it. The next section will discuss this in greater detail.

Theme II

Theme II of Guiding Question 3 *was participants gained additional knowledge they had not intentionally sought through participation in the grou*p. Participants

discussed gaining various types of knowledge that they had not initially sought. As previous sections have discussed most participants stated they joined the group to gain knowledge regarding infant or childhood GERD; however, many reported also gaining emotional knowledge, knowledge regarding general health topics, and learning web talk.

Core Category I. Core Category I of Theme II was *developing emotional intelligence*. Participants described different types of what they considered emotional knowledge that they gained through participation in the group 22 times in interviews and 16 times in postings. Types of emotional knowledge that they reported included altering expectations for their child's infancy and parenthood; altering expectations for how GERD will affect marriage and family; using acquired knowledge to make life-altering decisions; realizing that family will survive GERD; learning to trust their instincts; learning how to ask for help; and realizing the caretaker needs to take care of herself. Table 11 shows the main types participants discussed.

Table 11

Types of Emotional Intelligence Gained through Participation in the Group

Factors	No. Referenced in Interviews	No. Referenced in Postings
Altering expectations for child's infancy and parenthood	8	8
Altering expectations for how GERD will affect marriage and family	6	2
Using acquired knowledge to make life-altering decisions	3	1
Realizing that family will survive GERD	2	0
Learning to trust instincts	2	2
Learning how to ask for help	1	0
Realizing caretaker must take care of herself	0	3
Total	22	16

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Quotations representative of learning about altering expectations for a child's infancy and parenthood during this stage include the following:

> *Interview Participant 10*: Well, you find you don't go out if you know your children are going to puke. You don't have people over because your house is going to smell like puke and nasty poop. You spend a lot of time at the doctors. You rearrange things in your life and in your house to accommodate the fact that your baby is going to be puking and pooping like mad. We had I guess I call them reflux stations on each floor sometimes multiple stations on each floor, so that we always had things within quick reach. We planned around how to get to places so we wouldn't have to eat when we're out. If we did go out, we made sure that places where friendly to our situation. If you knew you were going to have a child [who] was puking, you notify the staff ahead of time and ask for a certain location, if it was a restaurant that was away from other people so that you didn't impact other people as well. You get used to stares and dirty looks.

> *Interview Participant 6*: Yeah. That can be learning about altering expectations. I feel so sorry for any mom whose first baby is a GERD baby. Because they have no baseline for how difficult a baby is anyway. There's no awareness that what you are going through is so much harder than what everyone else is going through. I had four other kids before my GERD baby showed up. I knew something was wrong and there was this

> baby who has really special needs. The emergency mode that we lived in for six months and then 12 months, I knew that there was something wrong. For a new mom who is like is it really going to be like this all the time, how is it this hard? Other moms they go on play dates, other moms they go take their babies to the park or take them places that the baby will actually sleep and this baby just screams all the time. What am I doing wrong that can be that's so hard. To hear other moms say, "Okay I understand what you are going through and there is a reason behind it. This baby has a special need that most babies don't have." That can be very comforting to a new mom who otherwise has so many doubts and so many insecurities and is thinking she is just doing it wrong or something. They are all sleep deprived and everything anyway right.

Participants also discussed using knowledge gained through the group to make life altering decisions like deciding not to have any more children. Following is a quotation representative of this category:

> *Interview Participant 1*: Actually, sadly, through being in this group, and I think maybe it was through [Website Name] I heard it echoed as well, is that when a mom has a child who has reflux, it's very likely, I forget what the percentages are, that some of the moms have said that they had read elsewhere, it's very likely you'll have a subsequent child who has reflux, which ... I could not even fathom having another child who has reflux. It was extremely hard; hard on the child, hard on the mom and the family.

> That information I got, certainly through being part of this group, which is a huge piece of information because it made my decision, at least in my family, to know that obviously our family is done having children because of that information, so ... But all kinds of other stuff, definitely.

> *Interview Participant 22*: That influenced some of our decisions. For example, that baby remained unvaccinated even now two years old has not been vaccinated. All my other kids have certain different degrees of vaccination but that one because of those particulars and how vaccines produce GERD flares, has not been vaccinated. Maybe will later. There was no reason that we were going to do that with such overwhelming anecdotal evidence.

Participants also discussed being able to learn and accept that GERD was challenging, but was something their family would get through. They discussed gaining this emotional knowledge from others who had been in the same situation. A quotation representative of this idea is this:

> *Interview Participant 19*: I don't know that that was a huge part of it, as far as my learning how to deal with the emotional part, other than it gave me better perspective. It's really depressing and lonely to think that you're the only person in that situation, and so, having the perspective, I think, that, "Oh my gosh, there's a ton of other moms going through the same," and there's also a lot of moms going through much worse. I actually at one point, shockingly, through the group I did get a connection to another

> mom with reflux locally. Her baby was older, he was almost two and he had had multiple surgeries, he had had a feeding tube, and so, when you see those work of things, it gives you a better perspective. You're like, "It could be worse." It could be worse and statistically babies do grow out of it. There are all of these other moms who have come through this, and their babies are fine and they are fine. You see all these moms going through the same thing, or have gone through the same thing, and you're like, "Maybe there is light at the end of the tunnel." I think when you're in it, it's so difficult and it seems like when you have this crying baby, day after day, after day, after day, night after night, after night, it seems like, "This is never going to end. Like, this is all my life is right now." It's just helpful to hear from other moms that have been through it, and have found things that worked for them or their babies just grew out of it, and can say, "I've been there and sucks. And it does get better.

Core Category II. Core Category II of Theme II was *gaining knowledge about general health topics*. A few participants, four in interviews and four in postings, also mentioned that they gained knowledge about non-GERD health topics through participation in the group. As Interview Participant 3 stated, "It's an extremely informative database. Even if your kids don't have reflux, there's just all sorts of awesome information about health in general." An additional quotation:

> *Interview Participant 21*: For me, it's been incredibly valuable. It's served every need and then it's even gone beyond. It's surpassed that by giving

me additional health knowledge that I may not have readily sought out, but just received by being a part of the group.

Core Category III. Core Category III of Theme II was *learning web talk.* A few participants also mentioned that they gained knowledge about non-GERD health topics through participation in the group, once in interviews and three times in postings. A quote representative of this category is

> *Interview Participant 3*: There are things like that, even I didn't know when I first started. People would write my DS. I'm like, I don't know what a DS is. It's dear son apparently, but that's like inner webs talk. There's things like that that make it easier to communicate that do happen within this group.

Theme III

Theme III to address Guiding Question 3 was *there are factors of differing importance that affect knowledge-sharing in the group*. Interview participants mentioned different factors affecting knowledge-sharing 150 times in interviews and 98 times in postings. These factors included self-assessing ability to share knowledge; supporting different types of knowledge; ensuring information shared is of good quality and accessible; encouraging external knowledge; group knowledge having limitations; possessing various levels of prior knowledge; topics that most caretakers deal with result in more knowledge sharing; acknowledging and encouraging different talents; sharing knowledge because it is easy to do; positive feedback encouraging knowledge-sharing; high level knowledge being related to having multiple children with GERD; and being personally asked for opinion. Table 12 lists the factors.

Table 12

Factors Affecting Knowledge Sharing

Factors	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
Self-assessing ability to share knowledge	44	16
Supporting different types of knowledge	26	4
Ensuring information shared is of good quality and accessible	26	20
Encouraging external knowledge	23	42
Group knowledge having limitations	15	0
Possessing various levels of prior knowledge	9	1
Topics that most caretakers deal with result in more knowledge sharing	6	9
Acknowledging and encouraging different talents	0	3
Sharing knowledge because it is easy to do	1	0
Positive feedback encouraging knowledge sharing	1	0
High level knowledge being related to having multiple children with GERD	1	2
Being personally asked for opinion	0	1
Total	151	98

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings.

Core Category I. Core Category I of Theme III was *self-assessing one's ability to share knowledge is related to knowledge-sharing*. As Table 12 depicts, participants mentioned some type of self-assessing of their ability to share knowledge 43 times in interviews and 16 times in postings. The types of self-assessing that were mentioned were seeing own knowledge gain; being comfortable about things that they have personally

experienced or feel strongly about, expressing own confusion and lack of knowledge; assessing one's veteran status in group and higher level of knowledge; feeling like they do not know enough to share knowledge; feeling like one can give helpful answers; recognizing lack of knowledge and tagging other group members that possess more knowledge on a topic; sharing knowledge because familiar with group processes; and feel like they still have a lot to learn. Figure 23 elaborates what types of self-assessment they mentioned.

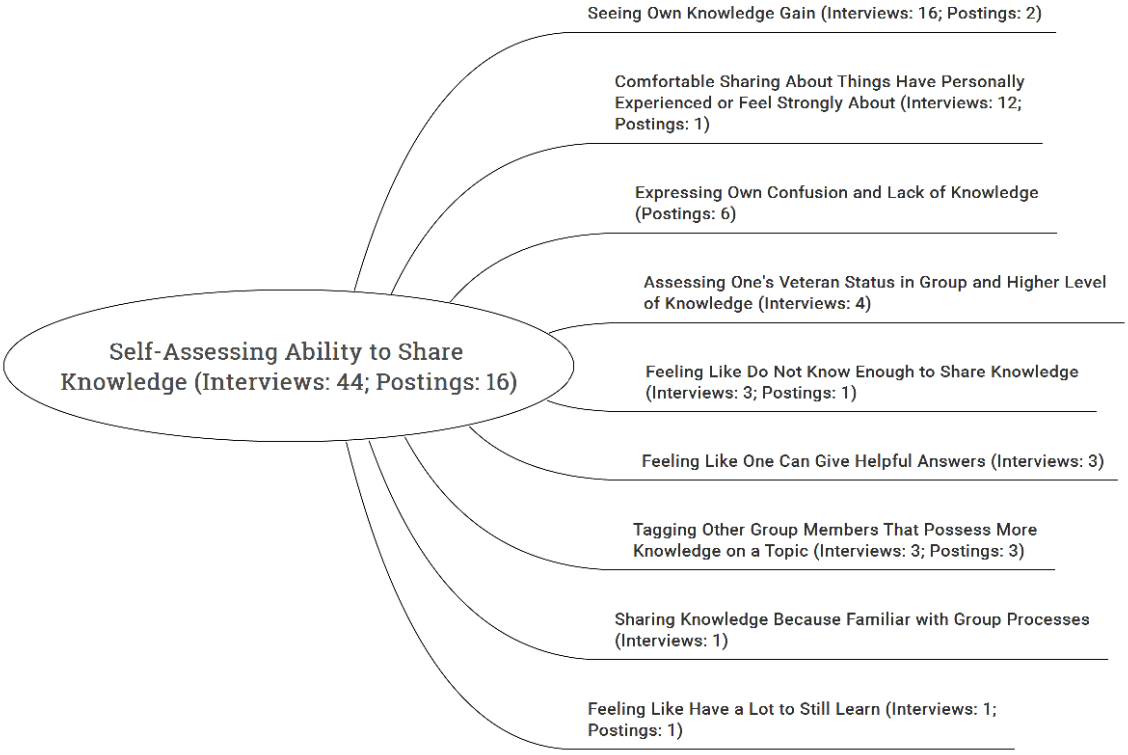

Figure 23. Frequencies of interview responses and postings for self-assessing ability to share knowledge. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

Quotations that were representative of ways participants discussed self-assessing their ability to share knowledge included the following:

Interview Participant 13 (Seeing own knowledge gain): Actually, by the time we went to visit the G.I. it seemed like I was just telling her what the plan should be and she kind of agreed. But it was because I learned all this information through this group from everyone's experiences. So I went to her and said "I think he needs this, this and this". I told her "this is what I have been doing and this is what is not working" and she just agreed. There wasn't much more that she could tell me or give that I didn't already come knowing.

Interview Participant 10 (Comfortable sharing about personal experience): I would say I've shared a lot. I've posted documents in the file section. I've responded to various different post. I do tend to rely on my personal experience and relate what we have done and what worked for me. I advise them that they should seek more information about it.

Interview Participant 20 (Assessing one's veteran status in group): Oh gosh. I try to answer pretty frequently because now I am "one of the veterans" because I've had four kids with reflux. If I see a new mom who is struggling, I try to answer her question because I remember how desperate I felt and how I couldn't receive information. Now I try if I have an experience, I try to respond as quickly as possible. I post, I would say, on average at least once a day, maybe more frequently depending on anyone's needs at the time.

Interview Participant 3 (Feeling like one does not know enough to share knowledge): Some people don't feel secure in their knowledge. I think that you don't want to go out there and ... (I think if you're not sure, you're not going to go out there and tell 1500 people information. I think there's a little bit of hesitancy there.

Core Category II. Core Category II of Theme III was *supporting different types of knowledge*. One factor that several interviewers mentioned regarding knowledge-sharing was that the group accepted and supported different types of knowledge. It was mentioned 26 times in interviews and four times in postings. In this space, both fact-based knowledge, usually acquired through a doctor's visit, and experience-based knowledge were valued and encouraged. In fact, some statements showed a preference for experience-based knowledge over any other type. Quotations that were representative of this category are below:

Interview Participant 11: Just again that people that are in the throes of it need people with experience to help answer questions. It's not something that you can do with your doctor like ask them tell me about all the experiences of parents with infants with reflux or find a book that has interviews or details about specifics about how many kids did well or didn't do well on this treatment. It's information you can't really just find especially when it's someone's experiences. It's kind of a filter when someone has experience and can talk about what is true and is not true and that's what makes it so valuable in the group.

> *Interview Participant 21*: Somewhat yes. I have learned outside the group that the nurses can give you the medical definition and medical information, but you know the mom's in the group that are living with it can give you the other aspect. Like that is what I was prescribed it worked or it worked a little less. Or if we did half the dose it helped more.

The group also supports and encourages both specialized and broad knowledge. For example, some of the members have really grasped and are able to calculate dosing exchanges very easily and are called upon by other group members when a new member or someone needs help with this. A representative quotation regarding this type of specialized knowledge is this:

> *Interview Participant 3*: I have had private message conversations to help moms figure out dosing information because sometimes they get scared of the math. I've been doing it and I'm super comfortable with it now. [Group Member name], the originator of the group, she asks me to update my information and my files. I send her links to my blogs so that she can link them on the group and then on the website so that they're easy and quick. People can find the information easily.

Another member of the group had specialized knowledge regarding elimination diets for breastfeeding mothers and had tested out various food with allergens. Her specialized knowledge regarding this topic is highly valued in the group. A representative quotation demonstrating this sentiment was this:

> *Interview Participant 21*: She did years of facts gathering and studying and information gathering and accidentally consuming things that made her sick. She was able to give these women information that shortcut that. They'd just leapfrog over the crap right to what's working. That is so powerful when you're a mom who's short on time and sleep deprived and stressed and yada yada yada.

Core Category III. Core Category III of Theme III was *ensuring information shared is of good quality and accessible*. Another aspect of knowledge-sharing that participants mentioned was their efforts to share knowledge that was of good quality and accessible in different formats. It was mentioned 26 times in interviews and 33 times in postings. The various actions that participants reported included sharing information backed up by research or personal experience; generating learning artifacts in different formats; urging those receiving information to search for root cause of GERD; wanting to compose well-written messages; and sharing detailed and in-depth information. Figure 24 shows ways participants accomplished this.

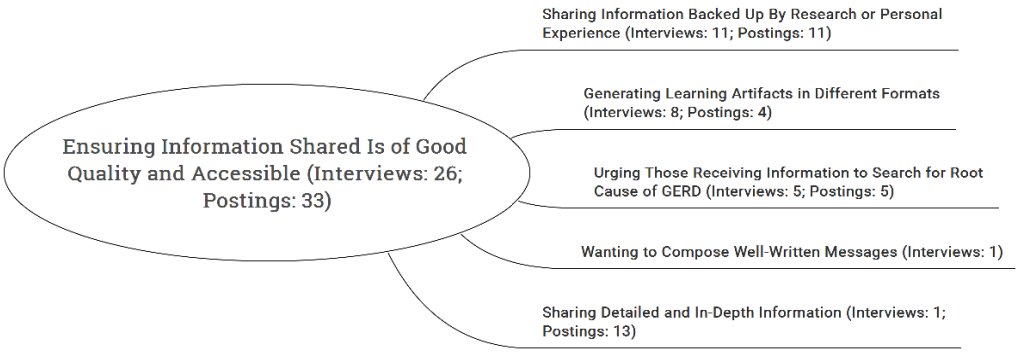

Figure 24. Frequencies of interview responses and postings for ensuring high-quality and accessible information. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Quotations that were representative of the type of research participants felt others in the group completed before posting included the following:

> *Interview Participant 11* (Sharing information backed up by research or personal experience): I would say overall I have been very impressed by how knowledgeable people are with infant reflux and sometimes when people don't know they do ask and I feel that almost all the responses to the questions are reasonable and show sound judgment. Usually people use research and personal experience to back it up so overall I would say very knowledgeable.

> *Interview Participant 19* (Sharing information backed up by research or personal experience): There were quite a few. I thought there were quite a few moms ... I won't say quite a few, I would say there were a handful of regular posters that had been there for a long time. I think I would say, for the most part, their kids were past the reflux. They had been there for a while, their kids were past it, they had done a ton of research, and it had become something that they were very interested in. I don't know if I would call it a hobby, but it was something that they were obviously super interested in, had done a lot of research on their own, and had maintained that research and were updating it. You know what I mean? These were women that had done a lot of research when their kids were babies, and continued to research this even after their kids grew out of it, and had

> continued to stay up to date with what the current research was, even though their kids were past it.

A quotation representative of how participants tried to share knowledge by generating learning artifacts in different formats was the following:

> *Interview Participant 1* (Generating learning artifacts in different formats): My husband and I even made a video about how we compounded our own [Medication Name] and put it on YouTube, so that we could share with other people, because at that time people were going, "How do you do it? How do you mix, how much water, what kind of a bottle do you use, how do you cut open the [Medication Name], blah blah blah." We were able to share that information and just record it simply with my phone, stick it on YouTube for people to be able to share.

A quotation representative of participants urging new members to get to the root cause of GERD is below:

> *Interview Participant 4* (Urging those receiving information to search for root cause of GERD): I've learned to really help people search for the root cause. I did that my own self and it was helpful and I encourage others to do it. I encourage others to really look for that root cause.

Core Category IV. Core Category IV of Theme III was *encouraging external knowledge*. Participants described the group as a space where the use of knowledge external to the group was encouraged. They mentioned identifying related spaces that members could go to for further information 14 times in interviews and 42 times in postings. A quotation representative of this category was this:

> *Interview Participant 3*: For me, this is a funnel. This group funnels you. People can get quick answers, but if you want more in-depth information, we always do the link to a website because it has way more in-depth information than what you can get in the group online.

They also mentioned sharing articles and other information created outside the group within the group. A quote representative of this category was this:

> *Interview Participant 14*: Just to make sure I am not missing anything. All this stuff is pretty new to me. My first daughter didn't have it as bad. I am learning all this stuff. People bring up really good questions. People bring up good topics to talk about or good articles that they have found. Good websites and resources they kind of find.

Another way participants mentioned that external knowledge was encouraged include encouraging caretakers to run things by their medical professionals and sharing what medical professionals outside the group have recommended. A quotation that represents this category was the following:

> *Posting Participant 4*: Get to a ped GI. Research all you can. TELL ped gi what baby needs. Get a rx & don't worry about making your own [Medication Name]?For a good GI in your area, check out this awesome directory that P4 put together, it is sooooo helpful because not all GI docs are created equal :-): http://[website address]

A final way external knowledge was encouraged in the group was when members were referred to outside groups that were focused on a particular topic and have more knowledge about it. As Posting Participant 49 stated, "I recommend a consult here, look

under the work with us tab at [Website Name].” Another quotation representative of this way included this one:

> *Interview Participant 20*: We do refer to if someone consistently complains about a particular issue, there’s other groups that are focused on that that respond better or give you maybe more support than this group in particular provided on that one issue.

Guiding Question 4

Guiding Question 4 asked, according to participants, what patterns of participation exist in this online social network? Participants discussed membership and participation patterns that were existent in the group. In the tradition of Grounded Theory methodology, these comments regarding patterns of participation existing in the group went through several rounds of coding and analysis and were grouped together into core categories and then themes. The themes that emerged from the data within this section were these:

1. *Theme I*: The pattern of participation and membership for most of the group was uneven.
2. *Theme II*: Several factors led to increased participation in the group.
3. *Theme III*: Several factors resulted in decreased participation or members leaving the group.
4. *Theme IV*: A small group of long-term members followed a different participation pattern than the rest of the group.
5. *Theme V*: The patterns of participation of the group led to explosive growth on a global scale.

I explore each of these themes in greater detail in the sections below.

Theme I

Theme I of Guiding Question 4 was *the pattern of participation and membership for most of the group was uneven*. Participants who were interviewed discussed the unevenness of the membership composition and participation in the group. This uneven pattern was mentioned 18 times in interviews. Participants stated that due to the nature of GERD, there were always many new members joining the group who stayed for a short amount of time and left the group once they had the information they needed, or their child's condition improved. They also discussed a smaller group of long-term, more experienced members that stayed in the group and answered most of the questions. Quotations that represented this theme were the following:

> *Interview Participant 2*: I would say it's a majority of newer people. I think there's a minority of, a smaller minority of veterans that are around that still participate.

> *Interview Participant 22*: I'd say ratio of experienced to non-experienced in terms of what I see in the comments, there are, I would say it's a hundred to one people who don't know versus people who do know. A hundred people who don't know to one of us who that does know. That's just based on who's actively commenting.

> *Interview Participant 11*: It's the people that have been there for a while like maybe the admin or people that have the much older kids I think have experiences that tend to respond more to the people that have questions.

The unevenness in membership and participation that individuals noted is further explored in the next two themes that list the factors that led to increased and decreased participation and membership in the group. They further explored how the nature of GERD impacts participation patterns of members of the group.

Theme II

Theme II was *several factors led to increased participation in the group.* Participants mentioned factors that resulted in an increased level of participation 56 times in interviews and 28 times in postings. These factors included being in the most difficult stage of GERD; having multiple children with GERD; GERD manifesting differently in different children; one's child going through flares; GERD reoccurring at an older age; finding and relating to caretakers with similar experiences; being in a supportive environment increases participation; seeing high level of activity in the group; feeling like they are not getting help outside the group; and having children with special needs. Table 13 depicts all the factors mentioned by participants that resulted in increased participation within the group.

Table 13

Factors Leading to Increased Participation in the Group

Factors	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
Being in the most difficult stage of GERD	14	1
Having multiple children with GERD	14	3
GERD manifesting differently in different children	6	3
Child going through GERD flares	5	2
GERD reoccurring at an older age	4	0
Finding and relating to caretakers with similar experiences	4	7
Being in a supportive environment increases participation	3	0
Seeing high level of activity in group	2	0
Feeling like not getting help outside the group	1	1
Having children with multiple special needs	1	11
Total	55	28

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Core Category I. Core Category I of Theme II under Guiding Question 4 was *being in the most difficult stage of GERD*. As Table 13, the factor that seemed to be the most important and best explained both increased and decreased participation is the stage of GERD that both the caretaker or child are in. It was mentioned 14 times in interviews and one time in postings. Participants stated that when either the child is suffering most severely from the symptoms of GERD or when a caretaker is at their most desperate state

of needing information to help their child, their participation is at the highest level. Quotations representative of this category included the following:

> *Interview Participant 11*: I would say that participation has to do with the severity or people's stress about their child's reflux. I know that people that are particularly stressed out with their child's reflux or feel like they are at the end of their rope because they have tried a bunch of things…these are the people that usually post the most. I would say people that are new to the group and in a difficult stage of the GERD such as myself do tend to post more often.

> *Interview Participant 15*: For me, my personal experience which could be the same as everyone else's. I think it depends on your level of desperateness. You know if you are especially in the early stages of reflux or going through teething…when the reflux is at its peak. When the reflux is at its worst. When you feel like there is no hope and you do not know what to do. I think that is when people need someone to reach out to you and I think that is when I use the group more because that is when you constantly have to go on the group and see what you can do or how you can do something. How you can do something that is the best way to do it. I think it depends on the level of how bad the reflux is especially when you have limited information.

> *Interview Participant 24*: I really do think that it just depends on the need of the mom, and like how much do they need? I remember telling you back when you interviewed me the first time, is that I remember the reason why I sought out this group, and I was desperate. Nobody was listening to me, it was comforting to know that other parents were going through what I was going through, but what was more appealing to me is that there was research there. There was research there that was proven to work, and I couldn't understand why nobody was using it. I took it and ran with it, and I'm so glad I did, because it helped my child a lot. I do just think it depends on what mom needs.

Core Category II. Core Category II of Theme II was *having multiple children with GERD*. Another factor that participants discussed as leading to an increase in participation was participants having multiple children with GERD. It was mentioned 14 times in interviews and three times in postings. Caretakers of multiple children with GERD stated they were in need of knowledge despite having gone through the experience previously because each child is different. A quotation representative of this factor was the following:

> *Interview Participant 3*: Then with my second kid, she had GERD, but it was completely different. It manifested completely differently.

Caretakers of multiple children with GERD spoke of going through the experience of caring for a child with GERD and then due to a time gap need to refresh their knowledge of GERD when their next child with GERD is born. A quotation representative of this concept was this one:

> *Interview Participant 1*: I know that as I was going through GERD with my child there was a mom who had just been on the other end and she helped me a lot. I know now she's in this group, and she has a newborn child, she's trying to remember all the stuff from back then ... but she's the one who told me, when I had my child, and she was under 12 months, and now she has a new child, and actually adopted a child who has reflux, coincidentally, and she is back on the website asking for help ... she's like, "Refresh my memory, I can't remember this and that …" and so it's come full circle, so now I'm the one ... I would respond, "Oh yeah, this is what you do."

Core Category III. Core Category III of Theme II was *GERD manifesting differently in different children*. Another factor that participants discussed that led to increased participation is that GERD manifested differently in different children and more severely in some than others. It was mentioned six times in interviews and three times in postings. Hence, if caretakers had some knowledge about GERD it may not directly apply to their child as their child's symptoms and treatment might be different so they would need to acquire more knowledge. A quotation that represented this factor was

> *Interview Participant 19*: As far as my daily life, no. I knew other people kind of tangentially, through my local mom's group on Facebook, that had had children with GERD, but I didn't know anyone else who had had it as severely as we did. I didn't know anyone else that had experienced it for as long as we did. Part of the reason I started seeking out other groups,

> was I kept getting the same suggestions over and over again and they were not working.

Core Category IV. Core Category IV of Theme II was *child going through GERD flare*. Another factor that was mentioned in connection to increased participation was when a caretaker's child was going through a GERD flare. It was mentioned five times in interviews and two times in postings. Participants discussed having a child's GERD well controlled, but than having a flare up due to vaccinations, teething, illness, and so on. This flare-up required caretakers to turn to the group to ask additional questions to try to figure out the best way to handle the flare-up and return to a more controlled condition. A quotation that represented this category was this one:

> *Interview Participant 10*: Well, I think it depends on their own personal situation, obviously. I know that I used to be constantly on there especially if it's a high stress or GERD flare up day, the kids are puking a lot and I was on there at night trying to find information about what could possibly make it better. When they're in that moment, things are just absolutely hell, they're going to be on more.

Although many of the factors listed above were related to increased participation, participants discussed how their inverse leads to a decrease in participation or even leaving the group. The next section will discuss these factors in greater detail.

Theme III

Theme III of Guiding Question 4 was *several factors resulted in decreased participation or members leaving the group*. Participants mentioned factors that resulted in decreased levels of participation or leaving the group, 40 times in interviews and one

time in postings. These factors included their child's GERD being under control and the caretaker having confidence in their knowledge; having their child outgrow GERD; leaving group because participating is a trigger; having insufficient time due to other responsibilities; leaving group because their child's GERD is not severe; and the caretaker not needing as much emotional support. Table 14 depicts all the factors mentioned by participants that resulted in decreased participation or even leaving the group.

Table 14

Factors Resulting in Decreased Participation or Leaving the Group

Factors	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
Child's GERD being under control and caretaker having confidence in their knowledge	18	1
Having child outgrow GERD	8	0
Leaving group because participating is a trigger	6	0
Having insufficient time due to other responsibilities	2	0
Leaving group because child's GERD is not severe	2	0
Not needing as much emotional support	1	0
Total	38	1

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings. GERD = gastro esophageal reflux disease.

Core Category I. Core Category I of Theme III under Guiding Question 4 was *child's GERD symptoms being under control and caretaker having confidence in their knowledge level*. As Table 14 depicts, the factor that participants described which most comprehensively explained a decrease in participation or even leaving the group was

having a child's GERD symptoms being under control and a caretaker having confidence in their level of knowledge. It was mentioned 18 times in interviews and one time in postings. Quotations representative of this core category included the following:

> *Interview Participant 10*: I do, in and of itself ask a lot of fewer questions now than I used to. Because for the most part, we do kind of know where we're at with things. Our reflux is more controlled, we know when it flairs ... When to expect the flairs and how to manage it a little bit more at least for us.
>
> ---
>
> *Interview Participant 13*: Actually, now that my child's symptoms are controlled I am not on there as much. I don't take the time to go on and read other people's stories and help them out, but I know there are a lot of people who do though.
>
> ---
>
> *Interview Participant 9*: I think I am not active because I'm pretty confident in my own experience, the current doctor that I have. Pretty much having a handle on my daughter's GERD.
>
> ---
>
> *Interview Participant 22*: They (members) found a solution and they don't feel like they have to check every day. They're not as desperate, for example.

Core Category II. Core Category II of Theme III was *having child outgrow GERD.* A second factor that participants discussed that led to decreased participation and

even eventual parting with the group is when a caretaker's child had outgrown GERD. It was mentioned eight times in interviews. Some infants reached this point when they began walking, others later into eating solid food, and still others had GERD well into their preschool years; however, once a child reached this point, their caretakers stated they did not need the knowledge or emotional support of the group as much. Quotations where participants discussed not participating as much because their child has outgrown GERD included the following:

> *Interview Participant 6*: Because most people are going to stay when the information is applicable to them. A lot of babies will outgrow their reflux. I know in some other groups that I've been in, once the relevance is gone, then I leave the group.

> *Interview Participant 21*: Some of them, their kids have outgrown it. There are users that aren't checking in every day because they've gone through it, like I said, and they don't need to look back and they leave the group.

Core Category III. Core Category III of Theme III was *leaving group because participating is a trigger*. Still other participants mentioned decreasing their participation level or leaving the group because reading postings and participating triggered feelings of despair and brought back the memories of the trauma they suffered when their infants were dealing with GERD. It was mentioned six times in interviews. Quotations representative of this core category included the following:

Interview Participant 19: Then I left all of them, because my daughter was better. It was actually really stressful for me to see ... you know, coming up on my Facebook feed, posts from that group, from these moms that were really struggling. It reminded me of being in that place, and so I left the group. I was like, "This isn't helpful for me anymore, and it's not helpful for me to see this every day. Once she started doing better, I was able to deal with my own ... and take care of myself better. You know, we talked about that trauma aspect, it seemed almost triggering to see that kind of thing and just ... It was like every time I saw it in my feed, I was just thinking ... I just remembered being in that place and being so frustrated and how seeing that post would have affected me at that time. I was just like, "I don't want to see this. I don't, I don't need this kind of support anymore. These kinds of posts constantly being in my feed are potentially going to upset me when I see them, because they're going to remind me of that." I was just ... you know, I was done.

Interview Participant 17: But I think maybe the people that come through and just move on feel like it's just that…it's a point in their lives that they got help getting through, and they just want to move on. There's no need for it, you know. And maybe it's possibly some people sit back and think, "Well, what could I possibly contribute to help? So, I'll just be on my way." Or, you know, it's just hard to deal with. Maybe there are moms who don't want to relive this, who would rather forget about the first year

of their child's life because of how terrible it was that they don't want to rehash it. It's over, they're moving on.

Interview Participant 16: In some ways I think maybe it's even a desire to, "Oh, we're not in it anymore, that doesn't have to be the first thing I say to people when people ask me how he's doing," and maybe there's a part of me that also wants to not have to talk about it and think about it so much. It was such a sort of painful period and now we're enjoying things, I think some of that passion has abated because I'm wanting to be in the present and live in the joy of it, of just having a child who isn't dealing with it anymore. I think that it's really hard to say.

Theme IV

Theme IV of Guiding Question 4 was *a small group of long-term members followed a different participation pattern than the rest of the group*. Although many group members joined and then left once their child had outgrown GERD or they had enough knowledge to feel comfortable managing their child's GERD, a small group of long-term members stayed in the group and became the highly knowledgeable members and most active in responding. The following core categories will explore this participation pattern further.

Core Category I. Core Category I of Theme IV of Guiding Question 4 was *long-term members had various reasons as to why they stayed in the group past the point where their child outgrew GERD*. Long-term participants that were involved in this deviation from the participation pattern of the majority of members discussed an array of

reasons as to why they stay. These reasons were mentioned 84 times in interviews and 21 times in postings. They included empathizing with newbies; feeling need to give back; participating because they are able to relay experience in a meaningful way; responding rapidly because have breath of experience; serving as institutional memory; wanting to share stories of success; staying because want to ensure members get sound medical advice; remaining because of interaction with other long-term members; liking being a leader; staying in group long-term for continuous education; participating as a way to grieve; child's difficult infancy; and staying in the group to urge members to consult with doctors. Table 15 depicts these different reasons.

Table 15

Reasons Why Long-term Members Stay and Participate Actively in the Group

Reasons	No. Referenced in Interviews	No. Referenced in Postings
Empathizing with newbies	31	4
Feeling need to give back	22	0
Participating to relay experience in a meaningful way	6	2
Responding rapidly because have breath of experience	4	0
Serving as institutional memory	4	0
Wanting to share stories of success	4	5
Wanting to ensure members get sound medical advice	3	0
Wanting interaction with other long-term members	3	0
Liking being a leader	2	0
Long-term continuous education	2	0
Participating as a way to grieve child's difficult infancy	1	5
Urging members to consult with doctors	1	5
Total	84	21

Note. Numbers given in the table refer to the number of instances these methods were mentioned in interviews and postings.

Core Category II. Core Category II of Theme IV was *the long-term members were considered the highly knowledgeable members of the group and responded the most*

frequently. Participants stated that a small group of long-term members were considered the highly knowledgeable members of the group and responded the most quickly and frequently. The following quotations were representative of this category:

> *Interview Participant 15*: I am part of a few reflux groups, but in this one people seem to know a lot whether it is from experience or not. There's a lot of I guess what you would call experts. You know people who know what they are talking about. For sure. I guess I do not know what the reason for that would be, but there is. There's people like myself that are just offering limited experience and then there is other people who can offer lists and lists of things that they have done or could help. They may be on their third child with reflux.

> *Interview Participant 5*: Well I think, I mean some of them I think are probably fairly educated if they've really talked to a lot of different doctors and professionals and are up to date on all the different kinds of medications.

> *Interview Participant 19*: There were quite a few. I thought there were quite a few moms ... I won't say quite a few, I would say there were a handful of regular posters that had been there for a long time. I think I would say, for the most part, their kids were past the reflux. They had been there for a while, their kids were past it, they had done a ton of research, it had become something that they were very interested in. I

> don’t know if I would call it a hobby, but it was something that they were obviously super interested in, had done a lot of research on their own, and had maintained that research and were updating it. You know what I mean? These were women that had done a lot of research when their kids were babies, and continued to research this even after their kids grew out of it, and had continued to stay up to date with what the current research was, even though their kids were past it.

> *Interview Participant 14*: I think it is important. It helps. At least when I first started looking at the group and when I first started reading the posts and stuff, it was important to know that people had been going through it for a while. Even if they are not currently having kids with GERD, but that they are still posting about it and writing their experiences down. That it’s not just new people asking the same questions over and over again.

Theme V

Theme V of Guiding Question 4 was *the patterns of participation of the group led to explosive growth in membership on a global scale*. Due to the nature of GERD as discussed in previous themes in this section, the group has grown explosively with dozens of new members being added daily. It was composed of 822 members on July 11, 2015, increased to 1,232 members on January 26, 2016, 2,200 on September 2, 2016, and has 4,900 members as of January 7, 2018. Quotations that mentioned this growth included these two:

> *Interview Participant 24*: I've noticed it occurring more frequently obviously as the number of members grows. Obviously, like back when I started being an administrator, the group was still very, very small, we're talking maybe 1,000 members, and now we are up like closer to the 4,000-member mark. With more members will come more headache, drama, what have you.

> *Interview Participant 25*: There's so many going through. When I joined the group two years ago, we were at 800 and we're at 3800 now.

This continued growth has led to several developments. These included the need for additional moderators and administrators. Quotations that discussed this development were these:

> *Interview Participant 24*: Yes, when we realized that like again, as the group was going and get so big, when things started to get even out of the control of the three of us, and we needed more hands-on deck, yes, we did, we kind of sought them out.

> *Interview Participant 25*: So, we just felt like we needed more help, but maybe at not quite the level we were at. So, the moderators were kind of a next step down, but we of course still respect their judgment a lot and we actually have a private secret group, so that the moderators and administrators can communicate and discuss what's going on and how things need to be handled and such.

It also led to the creation of a second group for international members with its own set of moderators. Quotations representative of this theme were the ones that follow:

> *Interview Participant 24*: Furthermore, we've gone another step, now we've created like an international version of this group, specifically for moms outside the US, so you know Great Britain, Australia, one of our administrators is from Germany, because we have found that things are a little bit different in that area of the world. The science and the research that we promote still applies, but they have different means of like obtaining things, things that are over the counter here are not there, and vice versa. To kind of like keep those things straight, we have kind of created two divisions. When someone joins, and we see that they're from overseas, we give them the option like, "You're more than welcome to come join us over here." That one is I believe like a private group, it cannot be seen like overall, and we kind of just like, we watch those members and we say, "Hey, do you want to come over here and chat about it?", and that's what they do. We kind of do a lot of like I guess, seeking out I guess. We do a lot of asking, but I think at this point in time, as it grows, will we need to add more moderators? Probably, is there a possibility even for like the admins to grow in their count? Absolutely, I'm sure, but right now we've kind of found a comfortable spot here.

> *Interview Participant 23*: Yes, like the other two people that I'm admins with are admins over there, and then initially I started doing that as well,

> but I told them I can't lie, I'm not fluent on as much of this international stuff as you guys are. What I had done was, I had gotten with one of our main group moderators, and I said to her, "Hey, will you swap me places? Will you be an admin in the international group, and I'll just be a moderator and hang out and try to post, will you trade off with me?", and she said yes. Yes, so there's a lot going on with all of us on info groups, and we do make it a point like that the moderators that we do have in the main group, that they're not all United States based. The three admins are, but there are several moderators, one is from Australia, one is in Canada, one of them is in Germany currently, so we kind of make sure that we have a good, round ... I mean, because it is, reflux is a global thing, it's global, so we try to make sure that we have, you know like all those bases covered, but yes, we are currently going back and forth between two groups.

The role and responsibilities of moderators and administrators are further explored in the next section, how community is characterized.

Guiding Question 5

Guiding Question 5 stated this: *How do participants characterize* community *in this online social media group*? Participants were asked open ended questions about the existence and nature of community within the group. In the tradition of Grounded Theory methodology, the characterizations of community in the group went through several rounds of coding and analysis and were grouped together into core categories and then a

theme. The theme that emerged from the data within this section was that participants characterized the group as being an effective, nurturing, and cohesive community.

As background, upon embarking on this study, I did not know if members would feel that the group was truly a community given its short-life span and lack of in-person contact, but based on participants' voices on the matter, I found that they definitely considered the group a community. As Interview Participant 6 stated:

> *Interview Participant 6*: You could call mama's playgroup a community. Or mama's milk circle or whatever the play day group or the mothers of preschoolers. You could call all of those community. They are not long lasting necessarily they may be short lived, but they are still community and they still build trust [and] they still share a language. They share empathy, similar experiences so yes I definitely think you can call this group a community. I don't know if your research relates to the definition of community. I would definitely say that it fits those things or the dynamics of community over time or what, but I definitely say that you can call it a community.

The characterization of community in the group is explored further in the following section.

The only Theme under Guiding Question 5 was *participants characterized the group as being an effective, nurturing, and cohesive community*. Participants described the sense of community in the group in the following manner:

> *Interview Participant 18*: I definitely feel like there's a sense of community, and I feel like it's expressed because even if a lot of people

> don’t have information, they go on there and say, “I don’t have an answer for you, but I’m sorry. I know how it feels. I understand,” and that means a lot when people in your everyday life and real life, they don’t understand.

Participants discussed various characteristics that they attributed to the cohesion and nurturing nature of the group 279 times in interviews and 182 times in postings. These characteristics included having effective leaders; respecting each other; supporting each other emotionally; sharing lived experience of struggle; reciprocally trusting each other; expressing gratitude to each other; being a collaborative community; sharing a common language; receiving validation from the group and feeling empowered; being like-minded; individual members taking on roles voluntarily; being a nurturing environment; forming friendships outside the group; being a stable community with longevity; group members bringing levity to a difficult situation. Table 16 below lists the various characteristics that participants described the group as having along with how many instances of these appeared in interviews and postings.

Table 16

Characteristics that Participants Attributed to the Cohesive and Nurturing Nature of the Group

Characteristic	No. Instances Referenced in Interviews	No. Instances Referenced in Postings
Being led by effective leaders	75	35
Respecting each other	63	15
Supporting each other emotionally	32	67
Sharing lived experience of struggle	34	13
Reciprocally trusting each other	27	13
Expressing gratitude to each other	1	21
Being a collaborative community	11	2
Sharing common language	11	3
Receiving validation from the group; feeling empowered	10	6
Being like-minded	7	0
Individual members taking on roles voluntarily	0	5
Being a nurturing environment	4	0
Forming friendships outside the group	3	0
Being a stable community with longevity	1	0
Group members bringing levity to a difficult situation	0	2
Total	279	182

Note. Numbers given in the table refer to the number of instances these characteristics were mentioned in interviews and postings.

Core Category I. Core Category I was *being led by effective leaders*. As shown in Table 16, the most frequently-mentioned characteristic related to the theme of community, was being led by effective leaders, mentioned 75 times in interviews and 35 times in postings. Effective leaders were defined by participants as performing duties that supported the group. These duties are listed in Figure 20 and include screening future members, establishing rules for acceptable behavior, enforcing group rules, encouraging use of other learning spaces, encouraging knowledge sharing, delineating topics that are

beyond the scope of the group's knowledge, and admitting and guiding new members. It was also discussed in guiding question four, patterns of participation, where participants noted the existence of a solid body of group leaders that were important to the functioning of the group. Participants mentioned the administrators and moderators as well as long-term members as being the leaders of the group. Participants indicated the leadership was very knowledgeable and helpful to the sustaining of an effective community. In the tradition of Grounded Theory upon hearing these individuals mentioned several times, I sought out the individuals in the group that took on these roles and interviewed them. These participants described a complex and devoted group of leaders that have kept the group alive. They discussed their motivation for being a leader, their makeup and recruitment, their duties, processes for functioning, and time commitment. A quotation from a group leader that speaks to their motivation was this:

> *Interview Participant 24*: Because I really, really wanted to help people, not suffer like we had and go through what we have and try to educate people as fast as we can and in an efficient manner.

The next quotation speaks to how leaders were chosen in the group:

> *Interview Participant 25*: I was in constant contact with the other two administrators. We were chatting on a daily basis for several months, and since I often try to help write up pieces for the website or write down explanations of different formulas or calculations or recipes, I was automatically made an administrator when an opening came up.

The following quotation is representative duties and effectiveness of group leaders:

Interview Participant 25: Well, the administrators are really the people, the person who started it of course in the very beginning, Admin1, and then Admin2 came on next and she's really good at handling drama, especially if people are being short or unappreciative or just rude. She's very good at handling that. And then I think the thing that got me in, the thing is that I was the quickest with math. And then because the three of us actually speak every single day from first thing in the morning until before we go to bed. When I wake up at six in the morning, these are the people I speak to before I even speak to my husband or my children. So, we were in constant contact. And then we decided, because the group was growing at such a rapid rate, we definitely needed more help, but we didn't want to really give over administrative, because we have such a perfect balance between the three of us, we weren't ready to upset that so we got moderators instead. We tend to happen to fall on different shifts because we live in different time zones, so that's one thing. Usually, unless one of us is tagging the other ... like for me, if I see that one of the mods is on it, then I don't bother going to the post unless they request me because I feel like they have it under control.

The next quotation speaks to group processes and rules that group leaders enforce:

Interview Participant 24: Well, I think part of it is the organization system that one of the other admins got up. I think that has a lot to do with it, is that she requested that, "Hey, before anybody starts commenting, posting, what have you, read this and then introduce yourself to us, and we'll go

> forward." When someone takes the time to do that and follow, like I guess simple rules or instructions, drama tends to not happen. I find drama happening more frequently with the members that don't bother to do any of that, and then just kind of like jump in and just start talking willy-nilly. I think it has a lot to do with that organization factor that we have going on.

The subsequent quotation demonstrates the responsibility of group leaders to deal with conflict and ensure cohesiveness.

> *Interview Participant 23*: Well, we definitely, like I try to keep some sort of organization to the group, definitely helping members. If we have insights or thoughts in a particular area, we certainly like to comment. There are definitely times when conversations need to be dialed down or closed or deleted altogether, because they're just off-topic and there are certainly times where it's come up that members have had to be removed, so that's involved as well.

In the next quotation, the participant highlights another duty of group leaders which is to keep threads on topic:

> *Interview Participant 24*: Basically like I said, it was kind of off the original topic, but she still wanted some assistance, and I want to make sure that that happens, but we don't want it to overtake someone else's help, someone else's post, if that makes any sense, because we just don't want like the whole conversation to shift to that area, as opposed to what the original poster was asking for. Yes, like just try to stay on the topic

that was originally presented, because she asked a specific question, and looking for a specific answer, and it kind of gets like off topic with that. I mean yes, it's all relative, but it's not exactly pertinent to the original topic that the original poster was asking for help with so we had to step in and re-focus.

The next quotation is regarding the group leader's responsibility of dealing with any "drama" or differing opinions in the group and keeping it safe for other members:

Interview Participant 25: Unfortunately, yes, we have, lots. I have done it plenty of times. Oftentimes, like we'll let it go on, because I feel like there's always room for good discussion, but once it sounds like it's starting to take some sort of demeaning tone, then yes, I will step in and I will either close it down and make the topics available to like admins and moderators only, or shut it down completely, depending upon I guess how bad it is, but yes, it has happened.

In the following quotation, the participant speaks to the screening process for new members that group leaders constantly engage in given the group's growth pattern:

Interview Participant 23: Basically, we really like it that the people that are requesting to join do indeed have children, that we see children somewhere. You know, more often than not, it's most likely a female requesting to join, and the female will have said photos of her and brand new baby on her page. That's okay for us, that's good enough for us. A lot of times, people would want to add their spouses, and they told us that they're doing that, they were like, "Hey, I want to add my husband, will

> you please admit him?", and we'll do that without looking at anything. Yeah, we do kind of take a peek before we start adding members, mostly because we get a lot of like fake Facebook accounts. I don't even know what to call them, but like it's someone that, their Facebook profile was just created two days ago, and suddenly they're a member of 3,000 groups, that stands out as something not accurate to us, so we kind of stray away from those ones, because they seem to be like not authentic, if I may. We also send them questions that only people in the situation would understand to screen them.

The next two quotations were from group leaders discussing the type of time commitment being a group leader entails:

> *Interview Participant 24*: I would have to say generally like I would say per week, at least, I would say at least 15 to 20 on a weekly basis. Because some days I'm not on it at all, and other days, like if I'm off, it'll be an all-day thing, like I'll be carrying the phone with me in between doing chores and what have you. I would say that's a good estimate, 15 to 20 a week.

> *Interview Participant 25*: I'm on there ... the only time I'm not on there is when I am working 40 hours a week and driving of course. So, I'm on there a lot. So easily probably 20, 30 plus hours a week, depending on what my kids give me the ability to do.

Another key factor in maintaining a cohesive community that participants discussed was the respect that members had for each other. I discuss this further in the next section.

Core Category II. Core Category II was *being respectful of each other*. Participants noted that part of the reason the group is effective is because members show respect for each other. It was discussed 58 times in interviews and 15 times in postings. These included being supportive and non-judgmental; rarely seeing snippy members or drama; respecting others despite conflicting opinions; not forcing their advice on others; not criticizing other group members; not criticizing other group members; and not posting inappropriate or off-topic comments. Figure 25 shows some of the ways in which members showed respect for each other along with how many instances of these appeared in interviews and postings.

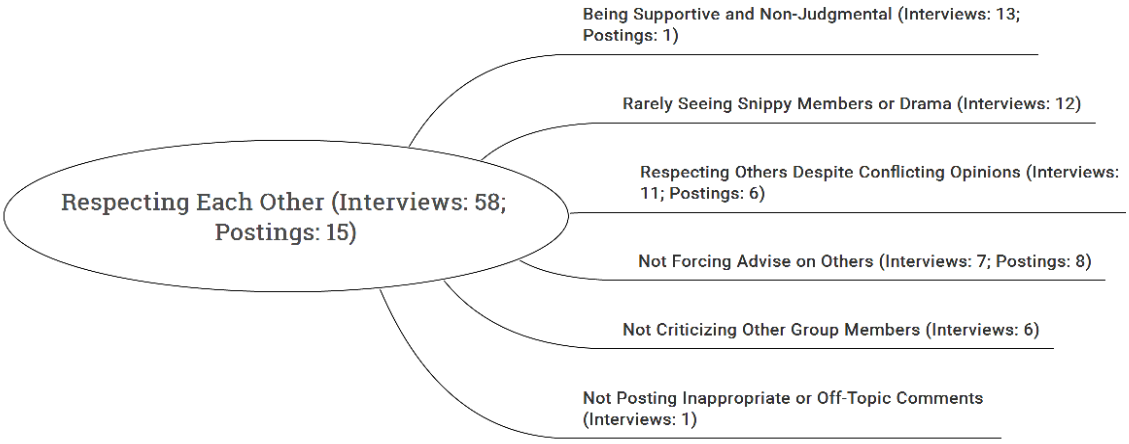

Figure 25. Frequencies of interview responses and postings for being respectful to each other. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

The following quotation from a participant describes the type of respect shown in the group:

> *Interview Participant 7*: I feel like it's pretty open and accepting. There really doesn't seem to be a whole lot of negativity if any when people come and ask questions and make comments as opposed to sort of I think

> what weakens some of the other groups I'm in is that you really just have some people on there that don't know what they're talking about or they're just rude and unhelpful and have a real need to sort of be mean.

This next quotation from a participant speaks to the lack of drama in the group:

> *Interview Participant 5*: Oh yeah and definitely in this group, like I said I'm not on it that much but there doesn't seem to be a lot of drama that goes on between people. It seems to be pretty supportive between people, like there's not a lot of judging and people can be offering a lot of great advice.

The next three quotations from participants describe the respect members show for each other despite having differing opinions:

> *Interview Participant 10*: Well, one of the things that I think is just like an unwritten rule in all groups is we're all adults and we shouldn't need to have to call mommy to police us. There's a basic understanding that everybody has the right to their own opinion. People are free to express their opinions but they need to do with respect.

> *Interview Participant 15*: I think it is other people respecting each other's point of views and experiences. People share their own experiences without being overbearing. That is what I have experienced.

The next quotation is from a participant who describes how members show respect, even when they disagree on the effectivity of a certain method for treating GERD:

> *Interview Participant 11*: If some people don't agree with a particular method, they just don't say anything. Some people believe in cranial therapy which is using chiropractic practices to help with reflux. It is not something that I think I would pursue, but you know if people don't agree with the advice they just take it or leave it and don't really respond. The only time anyone might respond in opposition is if they feel like it is unsafe, but usually people respond with "oh, I am working with my doctor and this is safe for my kid". Then the issue is dropped and the conflict is resolved and usually avoided because people respect differences.

Despite most participants describing how members of the group were respectful of each other's opinions, there was one participant that described feeling pressured to breastfeed her baby instead of giving formula. When she asked about which formula she should use, other members stated she should breastfeed instead. She described the experience in this quotation:

> *Interview Participant 8*: Like for me when I was going to change my baby to formula and some moms came on and told me that breastfeeding was better for my baby and I should try again. But by that time my milk supply had died down and I just couldn't get any milk and I was really sensitive to it. Most of the moms were saying do breastfeeding, but then finally I realized that no. That was one of the best decisions I made was to put him on formula because he wanted to breastfeed every five minutes. With a house to run and an elder child to take care of I couldn't do that. I had to drop the elder one at school or take him to swimming class, but at that

> point I would read the postings and call my husband at work and cry because I felt I should have continued breastfeeding because everyone was telling me to do that. So there are some negative aspects of that, but compared to the positive aspects the negative is very low.

Another participant described seeing that event happen, but from her perspective. She stated this:

> *Interview Participant 17*: Again, I will stress though that I remember one time ... I told you I try to stick to things that I know. One time there was a mom that was breastfeeding, and she made the decision to switch to a formula and she was picking a formula that I had used. So, I gave her my two cents about the formula. That's what she was asking about. I do remember however her getting bombarded about, "Oh my god, why would you choose not to breastfeed? Why would you do that?" That's not what she was asking. She was asking about the formula, not about the decision she's already made. That's the only time I noticed anything kind of ... I don't know, but maybe I was reading too much into it because I don't get it, because I don't breastfeed. So I try to stay away from those, because I really don't know about it. Maybe I should have said something, but I don't know about it.

Although having strong leaders and being respectful of each other was important, according to participants, an additional and very powerful unifying factor was also the fact that they were sharing a lived experience of struggle. In the next section, I discuss this aspect of community in more detail.

Core Category III. Core Category III was *sharing lived experience of struggle*. Participants credited a shared lived experience of struggle with fostering a sense of community as mentioned 34 times in interviews and 13 times in postings. Given that members do not meet in person or interact in any other way other than posting in a virtual space and that most follow a short-term participation pattern, participants credited sharing their struggle as a strong unifying force. Quotations that were representative of this category included the following:

> *Interview Participant 3*: Strong sense of community formed because we've all struggled and struggle makes people closer together than any other thing.

> *Interview Participant 7*: I've seen many times a sort of a tone that I support you, you've gone through this too. Just sharing these experiences I think brings together other moms who are going through the same thing and makes them feel like they're not alone in it. That to me would be a sense of community.

The next quotation from a participant describes finding members in the group with whom she could identify and build community:

> *Interview Participant 10*: The people in the group have children who are similar to mine in many ways. One of them actually has a child who had almost the exact same diagnosis as my children which is great because then we can talk to each other and completely understand each other and we can help each other. Even if they don't have a suggestion, they listen

and they tell you how much they do understand and they can relate to what you're saying as opposed to somebody who has never experienced anything like that and has a baby who maybe spits up once to twice a day. Their thought is well it's just spit up, that it can't be that bad. Yet most of them have never seen a child like mine that will vomit. We're talking like my kids would vomit constantly. It wasn't just feed them and then they vomit once. It was constant. It's not a teaspoon or two like you would say for spit up. We're talking entire bottles' worth of amounts is what they were doing. It's not these tiny amounts that other people are talking about when it's a normal baby who goes to the doctor for spit up. There was extreme pain, refusal to eat. No sleeping, my children did not nap at all until over 18 months. They would go from whenever they woke up in the morning until whenever they would fall asleep in the evening and there would be no naps, whatsoever. It was just screaming or puking all day. Other people really didn't have anything to say other than they too were in that same boat and they were hopeful for us to all find a solution.

The next quotation speaks to the idea that sharing a struggle builds cohesion:

Interview Participant 11: I would say that it is a pretty cohesive group. People have this shared experience and shared stress that has taken over their life in some shape or form and just having that experience or having gone through it people are bonding together to kind of help each other get through it. So it is a very helpful, empathetic, caring group with a lot of

knowledgeable and experienced people who are just trying to help each other get through this difficult experience of having an infant with reflux. Another key characteristic of the group that led to a sense of community was the emotional support that participants described as existing in the group. This emotional support are described in the next section.

Core Category IV. Core Category IV was *supporting each other emotionally*. A characteristic that was brought up 32 times in interviews and 67 times in postings was that the group was emotionally supportive. The same core category has also appeared in other themes as a key aspect of the group. The types of emotional support participants mentioned were providing a safe space to share fears, frustrations, failures, and desperation; members showing empathy for each other; sharing stories of success and giving hope; feeling like you are not alone; and providing support without expecting anything in return. Figure 26 shows the types of emotional support participants stated they received from the group along with how many instances of these appeared in interviews and postings.

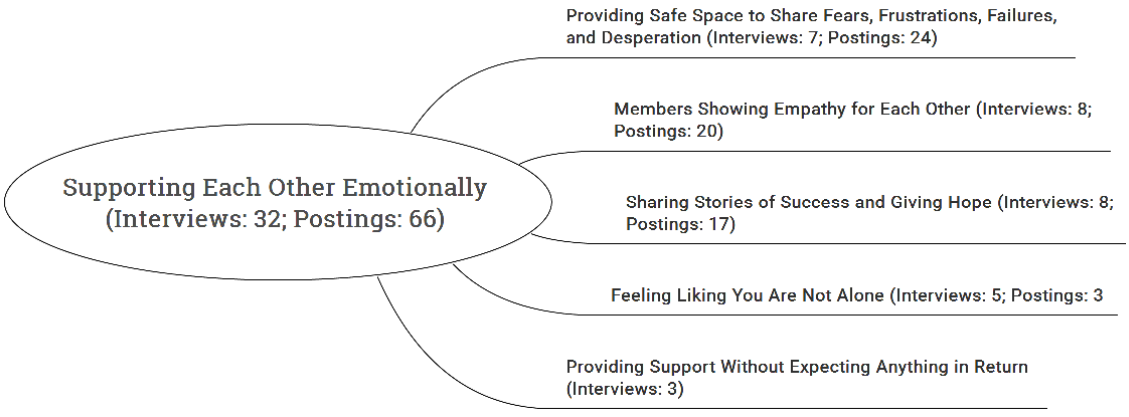

Figure 26. Frequencies of interview responses and postings for types of emotional support received.

The following quotation describes how this participant felt she was emotionally supported by the group:

> *Interview Participant 9*: They share stories about how they've been through things, and how things have gotten better. They share jokes. They offer various different positive experiences and words to give people hope. They let them know that it's going to be o.k., I've never heard these words on there and they're some of my most hated words. It's basically letting somebody know that this too shall pass. Overall, they're just they're there for you when you need them. They listen which is for me one of the biggest things. Because when you've got the people who you feel in your life are supposed to be able to help you and assist you and there's nobody there. Then you find a group of people who can understand and it's 2:00 in the morning. You're in tears, going, "What the hell am I supposed to do?" There's somebody there.

This next quotation underscores the idea that participants felt supported and not alone and how important it is that members in the group share stories of success:

> *Interview Participant 15*: It's a support network. It is definitely that. It makes you feel like you are not alone. Sometimes people post things and it really helps. It helps to the point where it is not going to last forever even though you know you miss out on the joy of infancy because all they do is cry. It is not enjoyable and when people some people have posted things in the past. It's nice because it helps you realize that this stage will pass.

Other participants, like described in the following quotation, use the group as a safe space to vent and relate to others in the same challenging situation:

> *Interview Participant 17*: Yeah. It's kind of like emotional support. I would say because there are times when I and other people just vented. We haven't really asked anything, but just vented and just kind of explained what we were going through and our situation. Some people say "oh yeah, I am going through that too" and can relate to how frustrating it is. So it's kind of like an outlet for the difficulty of having a baby with reflux and being able to just share those experiences which you usually can't mention to other people.

The next quotation from a participant speaks to the sense of hope that participants get from hearing stories of success and knowing people lived through the experience and got through it.

> *Interview Participant 4*: I think, like for the new people, I think that just the fact that the veterans are there and have lived through it. We're alive to tell the story, you know? Our kids are fine. We can help. I think that's ... hope. I would hope that it gives hope and is helpful in the community. I would hope so.

Along with receiving emotional support, participants described being able to trust each other. Given that GERD is often complex and challenging, participants felt that being able to trust others and the information they shared was invaluable. The trust that participants described is explored in the next section.

Core Category V. Core Category V was *reciprocally trusting each other*. Another response that participants mentioned 27 times in interviews and 13 times in postings in terms of fostering community, was the sense of trust that existed in the group. They described the following ways this trust was shown including: sharing very personal information; trusting the medical advice from the group members over their doctor's advice; trusting members of the group despite never meeting in person; sharing their Facebook identity with the group; and by trusting the quality of knowledge shared in the group. Figure 27 shows the ways that members in the group showed trust for each other along with how many instances of these appeared in interviews and postings.

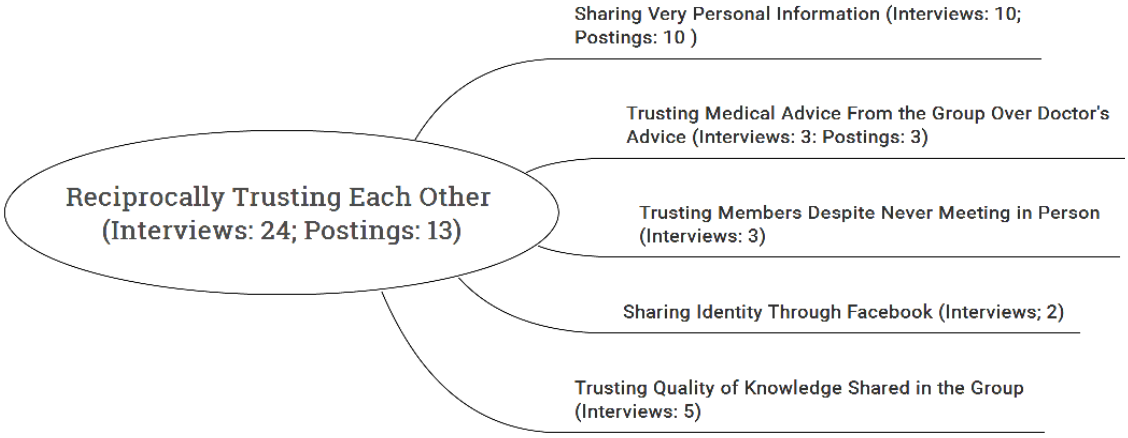

Figure 27. Frequencies of interview responses and postings for trust among group members. Numbers given in the figure refer to the number of instances these behaviors were mentioned in interviews and postings.

The following quotation describes the evidence of trust that is evidenced just by joining the group:

> *Interview Participant 5*: You know, I would think there is a level of trust because it, well in just thinking about the reflux group, because if you're going to take the initiative to join a group like that then you're obviously

> dealing with an issue like that, you're not just some random person joining the group. I think there's less chance of there being somebody on there who doesn't have a buy-in to the group. I mean, I don't know if I'm explaining myself correctly, I think that people just automatically have a level of trust because they're joining a very specific group for a very specific reason. Like people looking for support, so I think there is that level of trust.

The next two quotations speak to the level of trust the participants felt in other members that they felt comfortable sharing very personal information:

> *Interview Participant 19*: Sometimes they're asking is this poop normal? Which is one of the things that you would never ever before you deal with this expect to be having a conversation about and seeing pictures of dirty diapers. It's interesting. You become comfortable then with the people who you're interacting with. Sometimes people will tell you just about everything going on in their life from marital disputes to going shopping.

> *Interview Participant 1*: Sometimes people will post pictures of their children, whereas I know a lot of people are not very willing to post pictures of their children otherwise. The group which is of course on the Internet, but it's a smaller group. It's a closed group so putting photos I guess makes it more of a personal group. I know I have, in the beginning when my child was trialing yogurt for the first time, which is a huge deal

back then, and everything passed and so I was ecstatic so I shared a picture of my child.

The next quotation speaks to the level of trust exhibited by participants and members of the group who have taken the group's advice and trusted it over their doctor's advice after doing their own research:

Interview Participant 6: Sometimes you'll hear comments like that but the pediatrician says that I can't do that. I'm very worried about using this dosage the [Former Name for Group] suggested dosing my baby. Because the pediatrician has got my baby on half that and only one time a day and you are saying double it and it should be three times a day. Then over time researching more and maybe deciding that might be a better fit. I would say that there is an element of trust in that other moms have gone through it, when maybe in real life that mom doesn't know anyone who's been through it.

Posting Participant 22: So I'm back trying [Medication Name] after everything else failed. My baby is nearly 6 months and weighs 8.1 kg and the doctor prescribed 0.5mls *3 daily from a solution of 150mg/10mls. I did the reasearch [*sic*] and found this is the minimum dose for his weight at 3mg/kg per day. For a baby who has pretty bad reflux, I doubt this is going to work. So I'm going to dose him myself. I just wanted to double check with you all that I'm getting the dose right. I thought I'd try him at 6mg/kg per day which I think is a middle dosage. And to give it twice a

> day. Am I right in getting this dose as 1.6mls *2 daily for an overall amount of 3.2mls? Or am I way off? Im [*sic*] worried about overdosing as I'm going against his peds advice <unsure emoticon>.

Summary of Findings

The purpose of this study, which employed a modified Straussian Grounded Theory design, was to explore the learning experiences of members of an online social media group hosted by a social media site, Facebook. To fulfill this purpose, I tried to answer the following guiding questions:

1. According to participants, what learning strategies do participants use to gain knowledge in this online social media group?
2. According to participants, what factors influence activity in this online social media group?
3. According to participants, what types of knowledge exist in this online social media group?
4. According to participants, what patterns of participation exist in this online social media group?
5. How do participants characterize "community" in this online social media group?

In this chapter, I presented the findings from the study organized by guiding question, theme, and the supporting core categories for each theme. They are summarized in-text and on Table 17 for ease of reading.

Table 17

Study Findings by Guiding Question, Theme, and Core Category

Guiding Question	Theme	Core Categories
According to participants, what learning strategies do participants use to gain knowledge in this online social media group?	*Theme I*: Participants engaged in distinct information seeking behaviors in non-linear patterns.	• Evaluating information acquired within the group. • Initiating information seeking. • Requesting information. • Being guided through information seeking process by highly knowledgeable member usually a group leader. • Lurking or learning vicariously.
	Theme II: Participants followed a clear process of knowledge acquisition or steps to go from newbie to an experienced member.	
	Theme III: Participants learned by applying acquired knowledge to the care of their GERD child and then reporting back, asking questions, and applying again.	
According to participants, what factors influence activity in this online social media group?	*Theme I*: There were factors that were important to participants prior to joining the group that led them to join.	• GERD being a complex medical and emotional issue. • Existing characteristics of the group or learning space. • Seeking emotional support. • Feeling high level of desperation. • Seeking practical knowledge based on experience
	Theme II: There were factors that were important to participants that led to their continued membership in the group.	• Knowledge found in the group is validated, deep, and easy to understand. • Caring for an infant/child with GERD being a challenging experience. • Strong leadership being present 24/7. • Wanting to find solutions fast 24/7. • Group and learning space having limitations.
	Theme III: An overarching factor that was important to group membership and participation was a disconnect between caretakers and medical professionals.	• Doctors not being knowledgeable about infant and childhood GERD

Table 17 (continued)

Study Findings by Guiding Question, Theme, and Core Category

Guiding Question	Theme	Core Categories
According to participants, what types of knowledge exist in this online social media group?	*Theme I*: The type of knowledge that was most acquired in the group was knowledge about practical, day to day living with GERD.	• Learning how types of GERD medications and dosages work in infants and children. • Learning how to get to the root cause of GERD. • Learning best positions for sleep and best positioning devices for GERD infants. • Learning how to compound medication.
	Theme II: Participants gained additional knowledge they had not intentionally sought through participation in the group.	• Developing emotional intelligence. • Gaining knowledge about general health topics. • Learning web talk.
	Theme III: There are factors of differing importance that affect knowledge sharing in the group.	• Self-assessing one's ability to share knowledge is related to knowledge sharing. • Supporting Different Types of Knowledge. • Ensuring information shared is of good quality and accessible. • Encouraging external knowledge.
According to participants, what patterns of participation exist in this online social media group?	*Theme I*: The pattern of participation and membership for most of the group was uneven.	
	Theme II: Several factors led to increased participation in the group.	• Being in the most difficult stage of GERD. • Having multiple children with GERD. • GERD manifesting differently in different children. • Child going through GERD flare.
	Theme III: Several factors resulted in decreased participation or members leaving the group.	• Child's GERD symptoms being under control and caretaker having confidence in their knowledge level. • Having child outgrow GERD. • Leaving group because participating is a trigger.
	Theme IV: A small group of long-term members followed a different participation pattern than the rest of the group.	• Long-term members have various reasons as to why they stay in the group past the point where their child outgrows GERD. • The long-term members are considered the highly knowledgeable members of the group and respond the most frequently.
	Theme V: The patterns of participation of the group led to explosive growth on a global scale.	

Learning Strategies

Findings that were presented regarding learning strategies include the engaging in information-seeking behaviors such as initiating information-seeking, requesting information, being guided through information-seeking by a highly knowledgeable member, lurking or learning vicariously, evaluating information, and reconciling information.

A second finding was that there was a clear process made up of stages of knowledge and skills acquisition or a process to go from a newbie to a highly knowledgeable member. This process included the stages of *questioning*, *asking*, *receiving*, *reconciling*, *applying*, and *sharing knowledge*. Table 5 showed how these each step was identified and made up of several minor codes in participant interviews and postings. For *questioning* this includes the codes of the caretaker questioning what is normal for their child; the caretaker being discontent with their child's health care; caretaker doing their own research. For *asking* this included the minor codes of the caretaker desperately sharing their situation and asking for help from group members; members asking detailed questions of caretaker; and the caretaker answering members' follow-up questions in the thread. For *receiving*, this included the minor codes of members helping the caretaker identify related conditions; members encouraging the caretaker to do their own research; highly knowledgeable members suggesting sources or actions for caretaker to take; and members personally messaging newbies. For *reconciling*, this included the caretaker evaluating information; the caretaker looking for duplicating responses; the caretaker assessing the applicability of the information in their own life; and the caretaker asking follow-up questions of the members. Minor codes for

applying included the caretaker applying the group's advice, seeing results, and reporting back to the group; and the caretaker having doctors acknowledge their knowledge. The last step or *sharing knowledge* included minor codes of the caretaker assessing their own knowledge-sharing ability; the caretaker having other parents seek their advice; and the caretaker sharing knowledge and becoming a new highly knowledgeable member. These steps are of course not always followed sequentially and have no time limit.

A third finding was that participants learned by applying their knowledge. These applications included using acquired knowledge to advocate for their child, applying their knowledge care for subsequent children diagnosed with GERD, applying their knowledge by compounding their own medication for their child, generating new learning artifacts for the group, using their knowledge to change their diet when breastfeeding, using their knowledge to discern misconceptions their pediatricians or specialists had, using their knowledge to inform medical practice, using their acquired knowledge to explore natural treatment or design a new treatment, and using their acquired knowledge to control the direction of their learning both inside and outside of the group.

Factors Influencing Activity in the Group/Space

The first finding is that there were factors that were important to participants prior to joining the group that led them to seek out the group and join. These included GERD's being a complex medical and emotional issue, existing characteristics of the group or learning space, seeking emotional support, feeling high level of desperation, seeking practical knowledge based on experience, existing characteristics of the individual learner, and the child's GERD being severe.

A second finding was that there were factors that were important to participants that led to their continued membership in the group. These factors included the validated, deep, and easy to understand knowledge found in the group; caring for an infant/child with GERD being a difficult experience; strong leadership being present 24/7; participant wanting to find solutions fast 24/7; group and learning space having limitations; family support for participation; and having time for participation.

A third finding was an overarching factor that was important to group membership and participation—a disconnect between caretakers and medical professionals. Dimensions of this disconnect included doctors not being knowledgeable about infant and childhood GERD, caretakers and doctors having a combative relationship, doctors being ineffective, and having knowledgeable and helpful medical professionals.

Types of Knowledge that Existed in the Online Social Media Group

The first finding was that the type of knowledge that was most acquired in the group was knowledge about practical day to day living with GERD. Participants identified 47 different knowledge topics that they acquired that were of this type. The top 10 included learning how types of GERD medications and dosages work in infants and children; learning how to get to the root cause of GERD; learning best positions for sleep and best positioning devices; learning how to compound medication; identifying the best formula type for infants with GERD; learning about the secondary effects of GERD; learning how to do the elimination diet if breastfeeding; analyzing the associations between GERD flares and vaccines, teething, and ear infections; learning how to identify symptoms of GERD in infants and children; finding natural treatments for GERD

symptoms; discovering methods for thickening milk; and learning about stools and to what conditions different types are connected.

A second finding regarding types of knowledge was that participants gained additional knowledge they had not intentionally sought through participation in the group. Most participants stated they joined the group to gain knowledge regarding infant or childhood GERD; however, many reported also gaining emotional knowledge, knowledge regarding general health topics, and learning web talk.

A third finding regarding types of knowledge was that factors of differing importance affect knowledge-sharing in the group. These factors included self-assessing ability to share knowledge; supporting different types of knowledge; ensuring information shared is of good quality and accessible; encouraging external knowledge; group knowledge having limitations; possessing various levels of prior knowledge; topics that most caretakers deal with result in more knowledge sharing; acknowledging and encouraging different talents; sharing knowledge because it is easy to do; positive feedback encouraging knowledge-sharing; high level knowledge being related to having multiple children with GERD; and being personally asked for opinion.

Patterns of Participation Existing in the Online Social Media Group

The first finding was that patterns of participation and membership for most of the group was uneven with many new members staying for a short amount of time and a smaller group of long-term, more experienced members staying in the group.

A second finding was that several factors resulted in increased participation. These factors included being in the most difficult stage of GERD; having multiple children with GERD; GERD manifesting differently in different children; one's child

going through flares; GERD reoccurring at an older age; finding and relating to caretakers with similar experiences; being in a supportive environment increases participation; seeing high level of activity in the group; feeling like they are not getting help outside the group; and having children with special needs.

A third finding was that several factors resulted in decreased participation or even members leaving the group. These factors included their child's GERD being under control and the caretaker having confidence in their knowledge; having their child outgrow GERD; leaving group because participating is a trigger; having insufficient time due to other responsibilities; leaving group because their child's GERD is not severe; and the caretaker not needing as much emotional support.

A fourth finding was that a small group of long-term members followed a different participation pattern than the rest of the group. Long-term members had various reasons as to why they stayed in the group past the point where their child outgrew GERD. Long-term members were considered highly knowledgeable members of the group and responded the most quickly and frequently. A fifth finding was the pattern of participation of the group led to explosive growth in membership on a global scale.

How Participants Characterized *Community* in the Online Social Media Group

Participants characterized the group as being an effective, nurturing, and cohesive community. Participants discussed various characteristics that they attributed to the cohesion and nurturing nature of the group. These characteristics included having effective leaders; respecting each other; sharing lived experience of struggle; supporting each other emotionally; reciprocally trusting each other; expressing gratitude to each other; being a collaborative community; sharing a common language; receiving

validation from the group and feeling empowered; being like-minded; individual members taking on roles voluntarily; being a nurturing environment; forming friendships outside the group; being a stable community with longevity; and group members bringing levity to a difficult situation.

Although the table lists the core categories that emerged, there were many other categories that were subsumed by the core categories. These were shared on the tables within each section of this results chapter. In addition, as described earlier, data were coded using gerunds, many in vivo, to connote a sense of action or a process. To stay as true to the data as possible, gerunds were kept *as-is* in the results. In addition, the artificial separation of data into themes in this chapter created an occasional repetition as each theme was discussed; however, in Chapter 5, all themes and their core categories were reintegrated together to cohesively share a story relating to the central core concept.

CHAPTER 5

DISCUSSION

In this study, I focused on a Facebook or online social media group and by extension the informal learning space it created. I selected this group to explore because I had used it to learn about GERD and how to care for my own child with GERD. As my first-person account in the introduction described, caring for an infant or child with GERD was a very challenging and almost traumatic experience for my family; however, the group, and the space it allowed me to inhabit for a time, made a significant difference in the quality of life for my daughter, my husband, and me. Having gained so much knowledge from the group, I wanted to better understand how learning occurred within the group and the space it created. I wanted to explore "how learning communities, create, share, and remix content and peer-to-peer knowledge constructions" (Jones & Alony, 2011, p. 102). In addition, given the exponential growth of the group globally, I knew I was not the only one who had used it as a learning space. I wanted to understand from other members what made the group such a successful informal learning space for us. Thus, I chose and adapted a methodology, Grounded Theory, which would allow for the findings to be grounded in the voices of the participants. Whereas much of the previous chapter described details about the data gathered in this chapter I will theoretically reintegrate the findings to tell the central story as shared by participants of this study.

Central Substantive Theory: The Story of Learning to Survive

When this study began, all I knew was my experience with GERD. It was my account of my life caring for an infant with GERD and being a member of an informal

online social media group that helped me survive a very difficult time. It provided the experience to situate the study and my motivation for conducting it. At that point, I believed my daughter's experience to be a severe case of GERD and my difficulty getting help uncommon; however, after speaking to 25 different members in extensive interviews and reading and analyzing hundreds of the postings on the group's wall as part of this study, I know now that my experience was not unique. I also know now, according to participants, what factors about the space, about their situation, about the community, were important and led to their participation in this space. I feel like I can now tell the central story of the participants of the study in a way that does their experiences justice.

Figure 28 introduces the components of this substantive theory and the story based on it whereas the next section unfolds each part of the story. The components of this story being experiencing a severe disconnect, seeking knowledge to survive, seeking a supportive learning space, learning by participating, and becoming part of a community within a learning space.

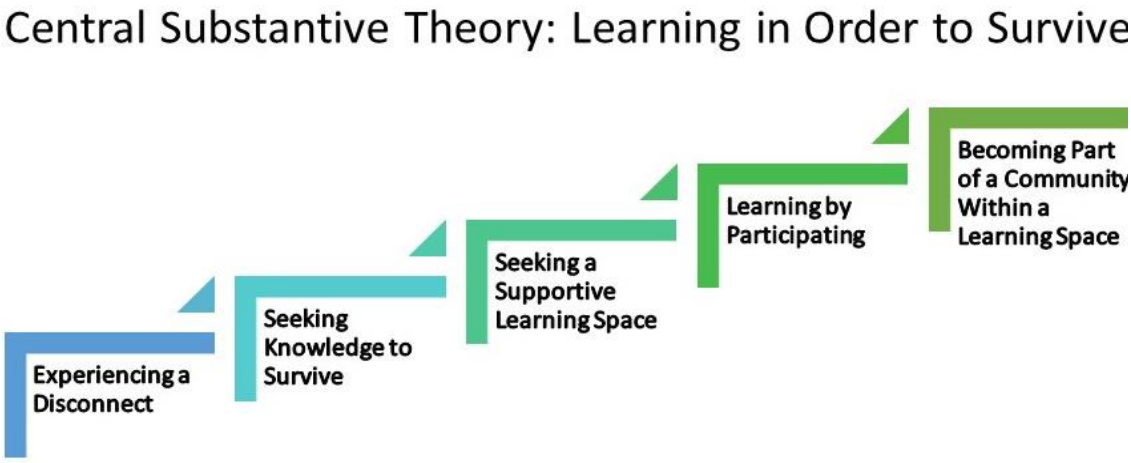

Figure 28. Key components of Vargas-Wright Central Substantive Theory. Reprinted from Vargas-Wright, J., *The story of learning to survive*. Manuscript in preparation, 2018.

Experiencing a Disconnect

To begin to tell the central story, I will revisit a salient theme in the findings, the concept of a disconnect. There were several factors participants mentioned for joining and remaining in the group, but by far the most significant was the disconnect, in their words, that most of the participants felt. They felt disconnected from the medical professionals caring for their children, who often diagnosed GERD as colic or as normal behavior that caused no harm. They felt disconnected from doctors who thought they were not feeding their children or exaggerating their child's pain. They felt disconnected from fact-based knowledge that doctors and specialists provided in short visits, but that did not help when implemented in real life or helped for a time and then stopped working. Participants felt disconnected from other friends or acquaintances who could not relate to having an infant who cried most of the day, who would not eat, who had trouble sleeping, who was not gaining weight properly, and who could not lay flat, and so on. They felt disconnected from family members and even their other children who could not understand why this infant constantly needed attention, costly medication, and sleeping devices. They felt disconnected from the outside world when they could not take their child out to dinner because they did not want others to be bothered by the crying or throwing up. They felt disconnected from their child when they felt so utterly unable to help their infant feel better.

A participant posted her disconnect experience on the wall of the online social media group during the week that postings were analyzed. It was not solicited by me or anyone in the group, but is a valuable window into the motivations, background, and actions of the participants of this study and the concept of a disconnect. I share it below

in its entirety to demonstrate the tremendous significance of this disconnect and the actions it propelled participants to take. The posting itself was coded line by line and became part of the themes and core categories which were analyzed during the second phase of the study and shared in the previous chapter.

> *Posting Participant 96*: Hi everyone. I hope this is allowed. Just wanted to share our real and raw reflux journey in hopes of shedding light to others that it can get better. This is something I wrote today, and I hope others can relate. I also want to thank the many members of this group that helped us get to this point.
>
> The Screams of Silent Reflux
>
> The screams of my baby were something I had never experienced before and over time they eventually became the screams of me, the screams inside my head as I held my wailing baby, the screams exploding from me as my husband held our baby and watched in horror as I clung to the dining room table leg for dear life. As if clinging to that table leg was going to save me from this horror I was living and stop me from being engulfed into the kitchen floor.
>
> As a first-time mother, a mother who had watched her baby refuse to eat and cry herself to sleep, I was broken but fighting. Fighting to keep my sanity so I could keep fighting to help my precious baby.
>
> As soon as baby [Baby's Name] was born she spent the nights at the hospital crying. The days she slept so we were told she simply has her days and nights mixed up.... fine. Once we arrived home she would feed

every hour day and night and pooped constantly, explosive and acidic poops. We were told this is normal... okay. By two and a half weeks old she changed. It was like a switch flipped in my beautiful child and the normal newborn behavior excelled to the point where she screamed and simply screamed some more. Nothing made her sleep. My husband and I would take turns rocking and swaying in the bathroom; with the shower running, for hours at a time. After 4 hours she would finally sleep on my chest while I laid on the couch. Peaceful experience? Laying snuggled with your new baby on your chest? No. To keep her asleep required constant shushing and jiggling while she grimaced in pain in her sleep.

Each checkup with family doctor went fine. Feeding issues were brought up and dismissed with colic, babies cry, and first time parents.

4 weeks old we brought (her) to (the) emergency room after a 6-hour screaming marathon. Wracked with anxiety and shaking from lack of sleep and nutrition I walked my baby in to the emergency room where a doctor watched her attempt to eat. She screamed, she clenched her fists, she arched her back and the doctor said reflux. We said but she doesn't spit up. She said silent. How could something be more of an oxymoron? Silent reflux equals screaming. I started searching and found information and learned about medications and dosages.

We tried medication that worked for a day and then made her scream more, so we stopped. We switched to liquid [Medication Name]. It worked some. I had a baby who I could convince to eat instead of fully

refusing all bottles. And by convince to eat I mean bouncing while I held her vertical in my arms while vibrating my lips to distract her from the pain she was surely suffering. By the end I was dripping in sweat, but this was progress. [Medication Name] is a very weight sensitive drug so we continued to increase. We increased beyond doctor dosages to find relief for our child. Eventually [Medication Name] stopped working.

We scrambled every waking moment to feed our child. Meticulously tallied up every half an ounce she ingested from either bottle, sippy cup or syringe, desperately trying to get enough in her for her to continue to gain weight and meet her milestones. She got to the point where she only drank while sleeping. My husband, who slept on the floor by her crib to comfort her through her constant night wakings, would feed her 4-5 times a night so she would consume 18 ounces. The doctors told us, good, as long as she is eating. We looked at them through puffy eyes growing bags in pure dismay. Clearly a baby who only drinks while sleeping isn't good. Clearly a baby who arches and screams at the sight of a bottle while awake isn't good. Clearly a baby who constantly kicks and stirs all night isn't good. A baby who simply gets laid in their bouncer to eat, because they will no longer eat in their loving parent's arms, and immediately cries isn't good. Our baby isn't good. We are not good. We needed help and began to research more and to further defy beyond simply controlling the [Medication Name] dosage and demanded answers. We

demanded a specialist, and then pestered that specialist until a swallow study was done, until our baby was prescribed proper medication.

Proper medication. We receive the prescription and feel relieved. Finally our baby will have relief. We will get to experience parenthood the way others do. Proper medication is then underdosed. Full bottle refusal, no food for 48 hours, more emergency room visits, more breakdowns and tears from us all.

Again, based on what we had learned in the group, we took measures into our own hands. Increased the dose then told the doctor and she agreed. Increased again, told the doctor and again agreed until we were triple the original dosage and 3 weeks in and finally our sweet baby was eating! I cried tears of relief. She sucked back so many bottles before and after every nap! We had a child [who] could eat for the first time in her life. We could feed her and then not have to think about feeding her again for another few hours. The constant bouncing and shushing and vibrating could stop. Until the insomnia hit. This drug caused zero sleep. It was like her neurons were firing and a shot of electricity would jolt her awake again. Defeated once again. Tears once again. Deep breathing once again to be strong for your child. To endure for your child. To find answers for your child.

We changed medications and went through the whole bottle refusal, no eating all over again. On day 13 she increased her feeds a little

and gradually continued to do so. Sleep also improved, no more shots of electricity jolting her awake. We cautiously breathed a sigh of relief.

Reflux. Sounds simple enough. Classic heartburn right? Every baby has it to some degree. Every adult eats a spicy meal from time to time and suffers. No big deal right? Until you, as a mother, watch your baby scream when they are hungry but can't eat. Until you hold them as they cry themselves to sleep because you couldn't feed them before bed....again. Until you cradle them in the wrap you wear day in and day out because it's the only place they feel comfortable enough to sleep. Until you sit up with them lying on your chest every day for 7 months because it's the only way they find relief. Until you see the pain in your husband's eyes as he holds your child and watches you break because you can't handle being on the end of another bottle refused or bounce on a yoga ball in a dark room for one more second. Until you experience all of this you will not understand the true implications of a child with silent reflux. Reflux is not colic. Reflux is not every baby cries. Reflux is not they will eat when they are hungry. Reflux is not first time parents exaggerating. Reflux is loud. Reflux is screaming by all involved. Reflux is tears and reflux is breaking and then reflux is looking into your daughter's eyes and finding the strength to put yourself back together and to pursue on to find answers from this group and others and get through another day.

Seeking Knowledge to Survive

Much like the poster and myself, thousands of group members engaged in a desperate search for practical knowledge about a complex, under-researched, and often misunderstood medical condition, infant and childhood GERD. Their search led them to join the group on Facebook, a social media site. The diagnosis, symptoms, and how these affected the lives of the parents and children involved were often unexpected and overwhelming. They included dealing with the emotions of the situation as well as the practical day-to-day caretaking involved in caring for an infant or child with GERD. It required an altering of expectations for what raising an infant would be like as the GERD overshadowed everything (Landgren & Hallstrom, 2011). It evidenced a lack of knowledge for being able to do straightforward things like feeding to more complex things like addressing developmental delays and advocating to medical specialists all while dealing with little sleep and feelings of isolation.

Seeking a Supportive Learning Space

Upon feeling a strained and sometimes combative relationship with medical professionals and others in close physical proximity, participants sought informal online learning spaces through the Internet that offered validated, experience-based knowledge they knew they lacked. Although most of the participants came to the group in desperation due to lack of some support from their doctors, some had supportive doctors, but were still seeking emotional support and emotional knowledge based on experience. The group had few initial membership requirements and thus allowed participants to join after completing a short screening. Participants found comfort in finding others going through the same struggle and realizing they were not alone. Often the similarities were

uncanny—the arching of the back, the lack of sleep, the inability to be comfortable in a car seat—things that no one else understood or experienced. Participants found a range of participation and knowledge levels among the other members; however, there was evidence of a core group of long-term members who among them represented many years of personal experience and knowledge seeking.

Learning by Participating

After finding the online social media group, participants began learning how to participate. They learned that the group had some expectations regarding sharing details of their own situation before asking questions, but not regarding level of participation. Some participants lurked for a while before posting or engaging in other ways. Others felt their information needs were urgent and began posting and absorbing the learning artifacts available in the space immediately. They often found themselves led by a highly knowledgeable member of the group or a group leader who guided them through the knowledge acquisition process including asking follow-up questions, questioning assumptions, and encouraging them to do their own research and share back with the group to help others. Participants began learning how to evaluate and reconcile information given by the group with their own past experiences and what their medical professionals were saying. They learned how to apply the information in "real life" settings. Other members in the group helped the participants learn how to advocate for their children and shared stories of success to encourage participants to seek knowledge and get to the root cause of their child's medical issues. Members also modelled supportive, empathetic, non-judgmental, and respectful behaviors. Participants felt a sense of community and camaraderie in the group as everyone was living the same

struggle, though they were at different stages. Group leaders modelled the encouraging of external and different types of knowledge by tagging members with special expertise or unique insight or by uploading journal articles or news stories or U.S. Food and Drug Administration (FDA) studies. They modelled behavioral expectations of the group by being present in each thread and intervening when drama came to the forefront or when questions were beyond the scope of the group.

Becoming Part of a Community within a Learning Space

Affective transformations began occurring in the participants. They began feeling more confident in their own knowledge and began self-assessing their ability to share their own limited knowledge based on experiences or validated through research. They began to reframe their situation, raising a child with GERD, in a new way as something they could handle and survive. They became aware of their own needs and learned to seek help for their own depression, anxiety, and post-traumatic stress disorder related to the experience of raising a child with GERD. They began questioning their doctors and the medical research community in general as to why infant/childhood GERD was not a top research agenda for anyone given that so many people were going through the same difficult experience. They began producing and sharing artifacts and external knowledge. Some participants self-assessed their knowledge gain and became less active as their child's condition improved. Some participants left because their child's condition was controlled, and they wanted to get distance from the ugliness of the experience.

Some participants left and came back when their next child was diagnosed with GERD or when their child had a flare-up or a return of GERD at a later age; however, a smaller group continued in the group without interruption and joined the long-time highly

knowledgeable members who had welcomed them. Perhaps because their child's GERD was more severe, their desperation greater, or the group's help more beneficial, they felt a need to give back (in their words). They began guiding new members through the knowledge acquisition process, including encouraging questioning what the group was saying, finding external corroboration, and getting to the root cause of a child's symptoms.

They also began sharing their emotions and changing expectations of what life with a child with GERD was like. They spoke of marital strife, frustrations with their children, failures when trying treatments or due to human error, and other personal information. They became part of the community of the group, no longer just taking but co-creating and giving back. They now empathized with the new members who reminded them of the stage they had been in when they joined the group. They spent time answering questions, sharing experiences, sharing external sources despite not needing help themselves anymore. They did not leave because they were now part of a community to which they felt tied and wanted to make sure that other caretakers and their children did not suffer as they did.

Re-conceptualizing Informal Learning Spaces

The central story shared in the previous section and based on this study's findings, highlights four major components of the online community space that were explored. These were a disconnect, various learning processes, types of knowledge, and a community and learning space. In this section I will further explore these components and how they came together to form a successful online informal learning community space.

Chapter 2 of this study introduced two key frameworks for examining successful informal social learning spaces. These were communities of practice (Wenger, 1998, 2000) and affinity spaces (Gee, 2004). Key aspects of COPs and affinity spaces are depicted in Figure 29.

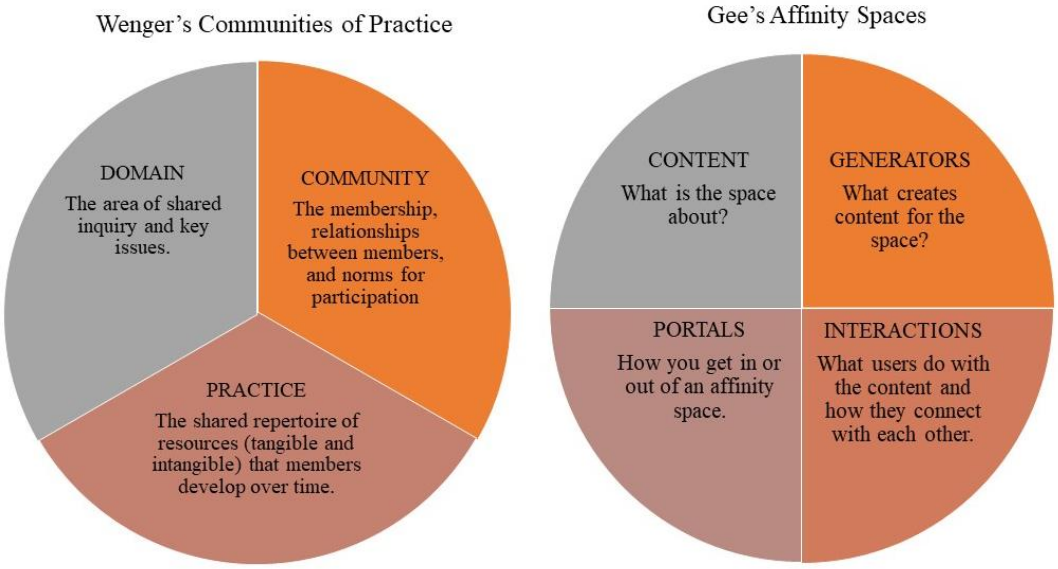

Figure 29. Key components of Wenger's communities of practice framework and Gee's affinity spaces framework. Adapted from Wenger et al. (2002). *Cultivating communities of practice: A guide to managing knowledge*. Cambridge, MA: Harvard Business School Press and Gee, J.P. (2004). *Situated language and learning: A critique of traditional schooling*. London: Routledge.

Whereas Wenger considered primary components of a COP to be a domain, community, and practice, Gee (2004) asserted that content, generators, portals, and interactions were primary components of affinity spaces such as informal learning settings. Wenger's focus was the community or group of individuals that interact on a continuous, long-term basis in a social learning setting. Meanwhile, Gee advocated for the examination of the affinity space or place where people interact based on shared

activities, interests, and goals. In fact, Gee's framework arose in reaction to the limitations he felt that were inherent in the communities of practice framework.

Although this study's findings pointed to aspects of both Wenger's and Gee's conceptualizations (see Table 19), they also led to a new conceptualization. Whereas, Wenger's framework focused on community and inter-relationships and Gee's framework focused on the characteristics of the space, this study's findings support the idea that both the community as well as the space are crucial for the success of a social learning setting especially an online one. In addition, findings from this study showed that the learning processes and types of knowledge that are encouraged and available are equally important. Last, but not least, I found that a disconnect, whether emotional, communicative, or cognitive, between the learner and his or her available resources around a topic or information need drove information-seeking and participation in the online social learning space explored in this study. Figure 30 illustrates the key components I propose in this new framework: *a disconnect*, *characteristics of the community and space*, *encouraged and available types of knowledge*, and *encouraged learning processes*.

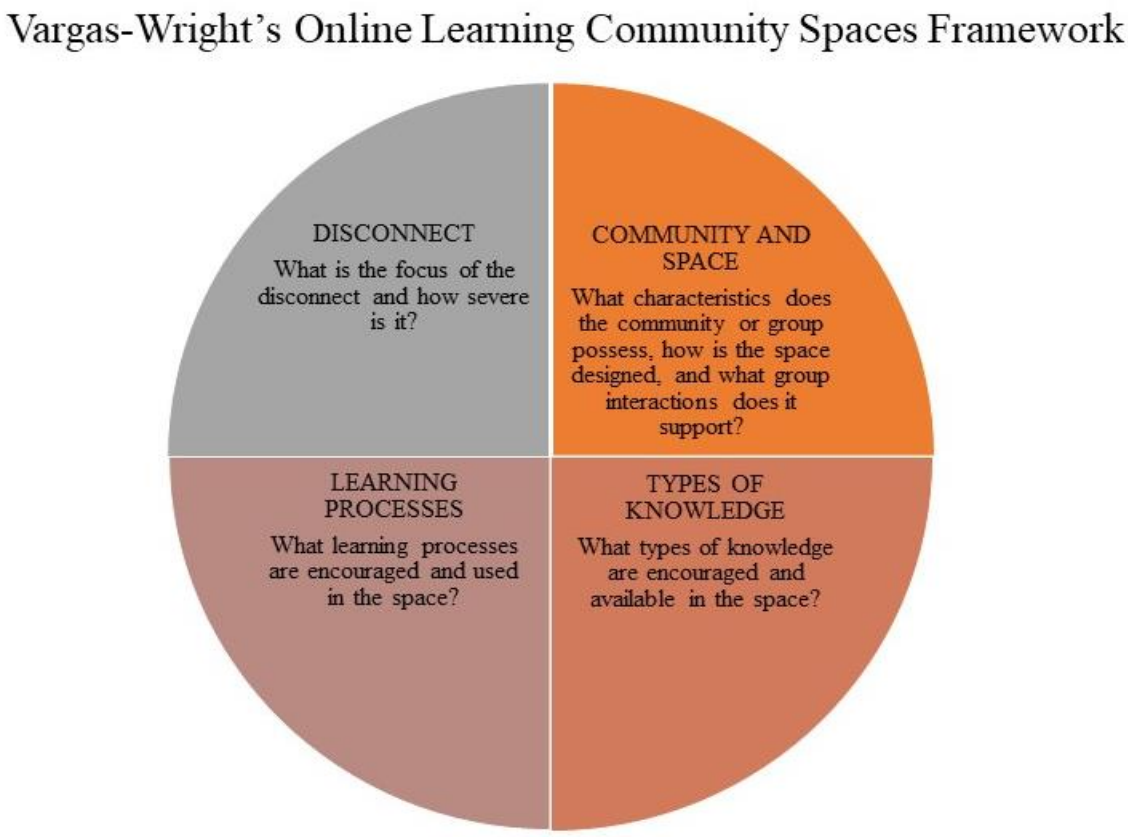

Figure 30. Key components of Vargas-Wright's online learning community spaces framework. Reprinted from Vargas-Wright, J. (2018). *The story of learning to survive*. Manuscript in preparation.

In this new framework community and space are equally important, as are the learning processes employed in the space, the types of knowledge that are encouraged and available, and the disconnect which motivates the creation and participation in the space. Table 18 summarizes the similarities and differences among all three frameworks.

Table 18

Comparison of Lave and Wenger's, Gee's, and Vargas-Wright's Conceptions of Key Components of Informal Social Learning Settings

Frameworks	Lave and Wenger's *Communities of Practice*	Gee's *Affinity Spaces*	Vargas-Wright's *Online Community Spaces*
Subject matter	Domain	Content	Focus of disconnect (i.e., GERD)
Relationships	Community	Interactions	Characteristics of the community and space
Activities	Practice	Generators, Portals	Learning processes
Other			Type of knowledge

Note. GERD = gastro esophageal reflux disease.

Figure 31 depicts how I arrived at these components based on the concepts put forth by the themes and core categories that emerged from the voices of participants of the group and which were presented in the previous chapter. For the component of *disconnect*, the concepts are others in learner's physical environment are not knowledgeable or helpful or are dismissive about the topic leading to a disconnect; topic or focus of disconnect is complex; the information need, or problem is personally challenging, and learners are emotionally connected to it; and the learner is at his or her most desperate stage of information-seeking. For the component of *community and space*, the concepts are that highly knowledgeable members are present in the space and guide new members; various levels of participation like lurking is allowed and encouraged; effective leadership, as defined in the previous chapter, is present 24/7; entry, exit, and re-entry are allowed; strong sense of community exists, and the

community is perceived as effective, nurturing, trusting, supportive, and cohesive. For the component of *learning processes*, the concepts are engaging in information-seeking behaviors in non-linear patters is allowed; a clear process for knowledge and skills acquisition exists; learning by applying knowledge is the norm; knowledge-sharing is an integral part of interaction and participation in the community; problem-based learning is highly valued. For the component of *type of knowledge*, the concepts are space provides validated, deep, and easy to understand knowledge based on lived experience 24/7; different types and levels of knowledge are honored and shared (i.e., emotional or intensive knowledge); external knowledge is encouraged. Although the community space depicted in the study and framework are important, so are the information-seeking behaviors and learning processes participants utilized. These behaviors are explored further in the following section.

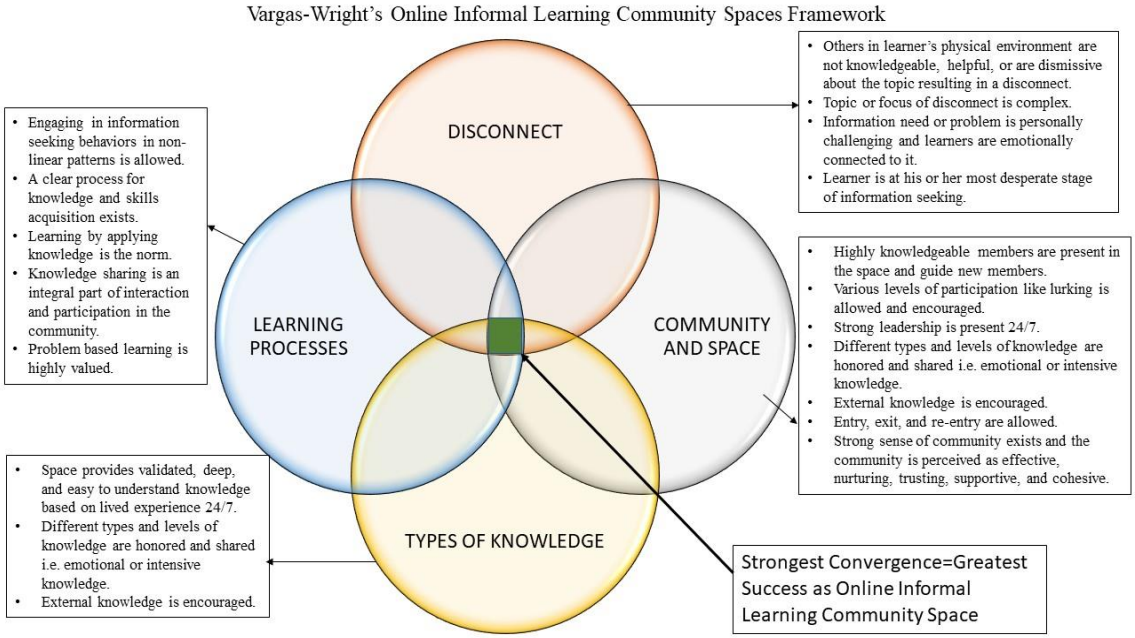

Figure 31. Study findings supporting Vargas-Wright's online informal learning community spaces framework. Reprinted from Vargas-Wright, J. (2018). *The story of learning to survive*. Manuscript in preparation.

While in this section, I have put forward a new framework for exploring informal learning in social media spaces, it is important to note that some of the components of this new framework were already being considered by other researchers like Gee. Moving beyond affinity spaces in his recent work, *Teaching, learning, literacy in our high-risk, high-tech world* (2017), Gee puts forward a new paradigm for learning in a high-tech, high risk, global environment. In this new paradigm, he urges educators to use technologies for collaboration, collective intelligence, and real problem solving. All three of these uses echoed findings in this study. The participants in this study described collaboration, valuing and contributing to collective knowledge, and working together to solve a real-life problem they were all experiencing.

In addition, Gee (2017) states that there are three features that are very important for encouraging deep and long-term learning. These are that the learner must emotionally care about the outcome of their learning action; that something or someone must help the learner know what to pay attention to in a learning experience; and that the learning experience must be rooted in experiences. Gee's significant features echo aspects of the new framework that is being proposed in this study and support overall findings of this study. First, the substantive theory of this study was that participants learned to survive. They sought and gained knowledge due to the challenging life experience they were living. As in Gee's feature, participants in this study emotionally cared about the outcome of their learning. The disconnect that drove their participation, as detailed earlier in this chapter was emotionally charged. Second, Gee's new work underscores the importance of having something or someone that helps guide leaners or allows them to engage in guided knowledge construction. Findings from the present study showed that there were

highly knowledgeable members in the group that serve as guides for new members and help them know what to pay attention to and how to seek, gain, and share knowledge in the learning space. Third, Gee contentds that learning experiences must be rooted in life experiences. The entire learning experience for participants in the social media group explored in this study was rooted in life experiences and was a highly-situated learning process.

Information-Seeking Behavior

Much has been written about information-seeking processes and researchers have come up with models for better understanding of the information-seeking processes that individuals engage in. One of the most cited is that of Carol Kuhlthau (1991) or the Information Search Process (ISP). This six-stage model was developed based on series of five studies exploring the experiences of participants' information-seeking. Some were case studies, whereas others were quantitative and served to statistically validate the model of the ISP. The six-stage model incorporates three dimensions of information-seeking behavior which are the *affective* (feelings), *cognitive* (thoughts), and the *physical* (action; Kuhlthau, 1991).

Figure 32 shows that during the initiation stage feelings were uncertainty, thoughts were vague, and actions were seeking. During the *selection* stage, feelings were optimism, thoughts were still vague, and actions were relevant information-seeking as well as exploring. During the *exploration* stage, feelings were confusion, frustration, and doubt. Thoughts were vague, and actions were information-seeking and exploring. During the *formulation* stage of the model, feelings were clarity, thoughts were focused, and actions were information-seeking and exploring. During the *collection* stage, feelings

were senses of direction and confidence, thoughts were increased focus, and *actions* were documenting and information-seeking of pertinent information. During the presentation stage, feelings were satisfaction or disappointment, thoughts were increased interest, and actions were seeking pertinent information. During the last stage of *assessment,* feelings were sense of accomplishment and thoughts were increased self-awareness.

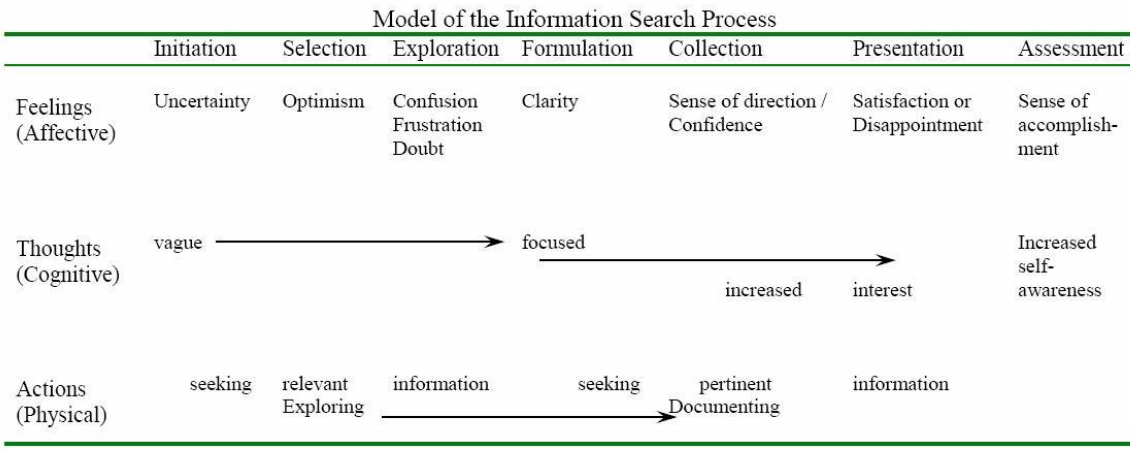

Figure 32. Kuhlthau's Information Search Process model. Adapted from Kuhlthau, C. (1991). *Model of the Information Search Process*. Retrieved from http://wp.comminfo.rutgers.edu/ckuhlthau/information-search-process

However, one of the significant limitations of Kuhlthau's model is that "all of the studies were conducted in field situations with actual library users who were responding to an imposed rather than a personally initiated information need" (Kuhlthau, 1991, p. 362). I believe that a new model is needed to understand information-seeking behavior when it is initiated by the information-seeker to solve a real-life problem they are experiencing and invested in versus an imposed need. In addition, Kuhlthau's model was created in the 1990s and much has changed in technology and the use of new spaces to find information such as the social media group that this study focused on. As Beheshti, Cole, Abuhimed, and Laoureux (2015) stated,

> A panel of experts, meeting recently to discuss the information behavior and needs of the new generation of users, concluded that a research agenda is urgently required to investigate the "characteristics and preferences of this tech savvy group that surprisingly lacks basic skills in information evaluation and retrieval". (p. 943)

The present study's findings about the information-seeking behavior of individuals within an online social media group may help to contribute to the limited body of research on this topic.

Based on the findings of the present study, the model of information-seeking that participants engaged in was different from that of Kulthau's (1991) ISP model. Figure 33 shows the information-seeking model that best describes the information-seeking behaviors of participants in this study, including their feelings, thoughts, and actions at each of the six stages.

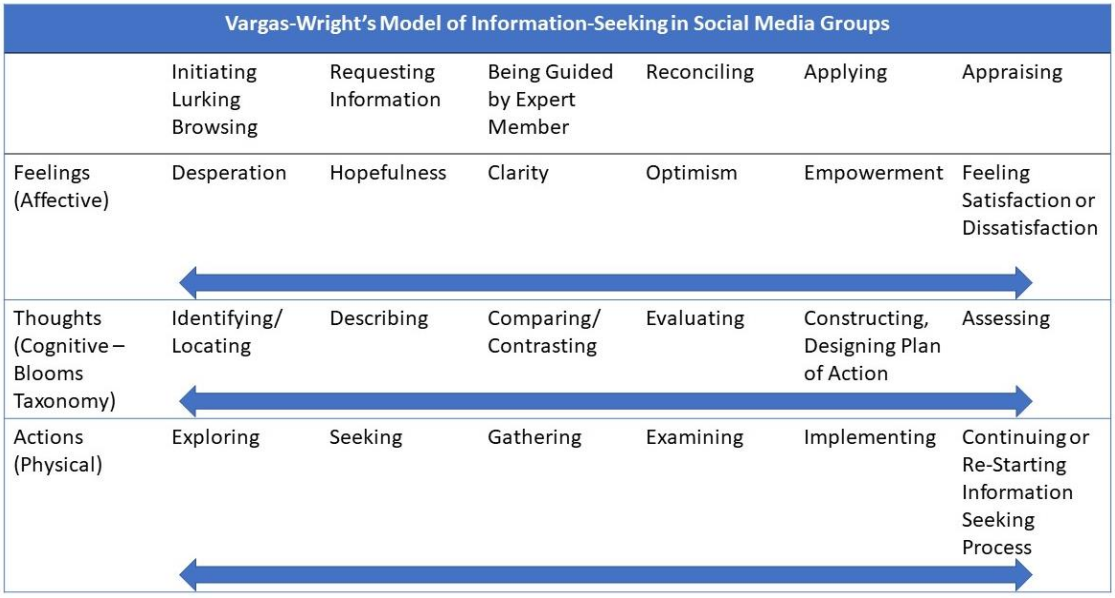

Figure 33. Vargas-Wright's Model of Information-Seeking in Social Media Groups. Reprinted from Vargas-Wright, J. (2018). *The story of learning to survive.* Manuscript in preparation.

It is depicted in a similar fashion to Kuhlthau's (1991) model to facilitate comparison. The identified stages were *initiating, lurking, and browsing*; *requesting information*; *being guided by a highly knowledgeable member*; *reconciling*; *applying*; and *appraising*. The stages are in gerund form to remain consistent with the sense of action that was conveyed by using gerunds throughout the study. For the first stage of *initiating, lurking, and browsing*, feelings were desperation, thoughts were identifying/locating, and actions were exploring. For the stage of *requesting information*, feelings were hopefulness, thoughts were describing, and actions were focused information-seeking. For the third stage or *being guided by a highly knowledgeable member*, the feelings were clarity, thoughts were comparing/contrasting, and actions were gathering/sorting. For the *reconciling* stage, feelings were optimism, thoughts were evaluating, and actions were examining. For the *applying* stage, feelings were empowerment, thoughts were constructing and designing plan of action, and actions were implementing. For the *appraising* stage, feelings were satisfaction or dissatisfaction, thoughts were assessing, actions were continuing or re-starting information-seeking process.

One of the findings of this study, reflected in the model, was that each stage of the information-seeking process was not always engaged in sequentially. In fact, many participants engaged in multiple behaviors simultaneously while delving into deeper levels of their knowledge acquisition. For example, one participant would apply information while requesting information or would be reconciling the information they had already gathered while initiating a new search on a related topic. Therefore, the model is best illustrated by Figure 34, which intentionally depicts the information-

seeking process as a continuous cycle, with the individual at the center deciding which stages in which he or she will engage and when.

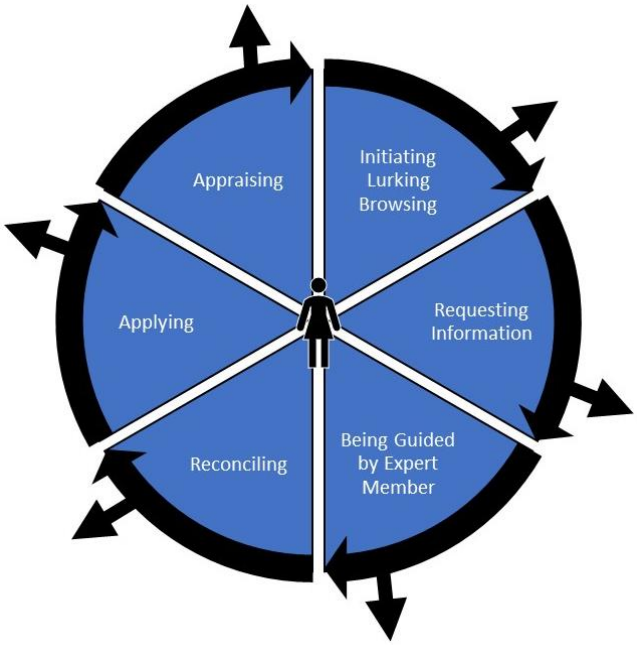

Figure 34. Vargas-Wright's Information-Seeking in Online Social Media Groups Directional Model. Reprinted from Vargas-Wright, J. (2018). *The story of learning to survive*. Manuscript in preparation.

The individual's role as both the learner and the one who directs his or her information-seeking and knowledge acquisition process speaks to the flexibility and non-linear information-seeking afforded by new informal learning spaces, such as social media. In addition, although the model is depicted as a cycle, there are exit/entry points at each stage. As interviews and postings analyzed in this study showed, in social media spaces and other newer informal learning spaces, individuals can exit at any point and re-enter at any point in the cycle.

As the figure shows, the learners are in control of their learning paths and can engage in different behaviors whenever they need to. Whereas this study examined

information-seeking, the focus of the group that was explored was health related and thus a discussion of online health information-seeking follows in the next section.

Online Health Information-Seeking

As this study and other research (Czaja, Manfredi, & Price, 2003; Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Suziedelyte, 2012; Xiao, Sharman, Rao, & Upadhyaya, 2014) has demonstrated, individuals are seeking health information on the Internet in greater numbers than ever before. This type of information-seeking behavior is not only driven by the availability of Internet resources, but also the increasing costs of obtaining health care. In addition, health consumers want customized health information from people who are experiencing their same conditions. If they do not get that information from their medical providers, they seek it online. As Fox (2011) stated,

> The internet has changed people's relationships with information. Our data consistently shows that doctors, nurses, and other health professionals continue to be the first choice for most people with health concerns, but online resources, including advice from peers, are a significant source of health information in the U.S. (p. 2)

Prevalence of Health Information-Seeking via Online Social Media Sites

Of the 46% of adults who use social media sites, 15% (7% of all adults) have gotten health information from social media groups (Fox, 2011). Nine percent of social network users (4% of all adults) have started or joined health-related social media groups (Fox, 2011), and this increase is propelled by the accessibility of social media, as well as by the desire of people who are dealing with chronic conditions to connect with others living the same experience. The Pew Research Center report also found that caretakers

use social network sites to obtain information and support at a higher pace than non-caregivers (Fox, 2011). The Pew Center findings coincide with those in this study which show that caretakers of children with a chronic condition, GERD, sought experience-based knowledge and emotional support or a connection with others in the same struggle.

Learner Characteristics

Another factor that previous researchers have found to affect health information-seeking behavior, and which was also salient in this study's findings was the socioeconomic and psychological learner characteristic pattern. Czaja et al. (2003) found that a female with higher income, married, and younger was more likely to search for health information online. Iverson, Howard, and Penney (2008) also found that women make up a higher proportion of individuals who use the Internet to seek health information. In this study I also found that most of the group members except for one member were female. In addition, as Figure 5 showed, 92% percent of interview participants had a degree higher than a high school diploma. In fact, 60% of those interviewed had a Master's degree or a Doctoral degree. The ability to obtain a graduate degree may speak to the participant's higher than average SES. Although it was not formally investigated, many participants also described psychological conditions that led to their participation, including anxiety, depression, and post-traumatic stress syndrome.

Self-efficacy of Information-Seeking

Another key finding of this study that echoes other study's findings as relates to online health information-seeking is the importance of a person's perceived ability to find information or their self-efficacy of information-seeking (Xiao et al., 2014). Participants in interviews and postings expressed their lack of knowledge explicitly and believed they

could get their questions answered by the group members. Figures 8 and 9 speak to why participants may have perceived that their questions would be answered in a reasonable time by the group. The figures showed that 98% of the questions posted received responses at least three times and up to 53 times. They also show that 83% of them received a response within an hour or two of posting no matter what time they were posted. Figure 10 showed that responses came at all hours of the day and night and many on weekends. Figure 12 showed that 91% of original postings received relevant information in the first response that was posted.

Trust

Participants of this study also displayed what is known as *channel belief* (Griffin, Dunwoody, & Neuwirth, 1999; Oetzel, De Vargas, Ginossar, & Sanchez, 2007), or the perception that the channel they were using to obtain information was trustworthy and useful. Many of the core categories that emerged in this study spoke to the perception that the participants had that the group's community was trustworthy, respectful, and knowledgeable. The level of trust in the group was exceptionally high for not having ever met in person or sharing much about their personal background.

Disconnect between Doctors and Patients

Although many studies (Fox, 2011; Xiao et al., 2014) cite surveys showing that individuals still trust health care providers more than any other source for health information, they also show that poor relationships between doctors and patients drives individuals to seek health information using other online channels. Patient use of web-acquired health information continues to grow (Wald, Dube, & Anthony, 2007). In addition, studies (AlGhamadi & Moussa, 2012; Suziedelyte, 2012; Wald et al., 2007) that

have been done on the effects of individuals use of the Internet to research health care topics show that despite concerns regarding negative effects on patients' relationships with doctors, "online information gathering has the potential to foster greater patient engagement in health maintenance and care" (Iverson et al., 2008, p. 699). It also has the potential for an improved relationship between physician and patients if a more collaborative model is used (Sommerhalder, Abraham, Zufferey, Barth, & Abel, 2009; Wald et al., 2007), which includes better communication, access to health information, shared decision-making, and better use of appointment time. Wald et al. (2007) also found that online support group can help patients to handle their condition better and have more confidence in their health choices. Researchers have asserted that an informed health consumer or well-informed patient can be better for the patient-physician relationship than an un-informed one (Dedding, Van Doorn, Winkler, & Reis, 2011; Wald et al., 2007).

Social Learning

Sharing Lived Experience

One of the key factors that affected membership in the group explored in this study was the ability to find other human beings who were going through the same experience. In fact, it is a core category in several of the themes of the study. Participants often mentioned the strength of the collective knowledge of thousands of parents with children in different stages of GERD. They were significantly affected by the stories of success and frustration that other caretaker in the group shared and showed evidences of trust and willingness to learn from other members in the group. As Oh, Lauckner, Boehmer, Fewins-bliss, and Li (2013) state when examining support individuals gained

from Facebook groups, “effectiveness of social support are maximized when the type of support one receives matches the type of support one needs” (p. 2077). Participants in this sturdy were able to benefit from the social support received because it was the one they needed, and this was only possible because other members were living the same experience.

Need for New Understanding of Social Learning in Online Social Media Spaces

Although in Chapter 2 of this study I discussed social learning theories as posited by Bandura (1977, 1986, 1997, 2006), those theories were not created by examining social learning within online social media. Although many of Bandura’s conclusions, such as the importance of modelling and self-efficacy hold true in these spaces as well, these spaces present new considerations and versions of social learning that I think are just beginning to be explored. For example, the idea that learning spaces can welcome and encourage different levels of knowledge and participation without losing efficacy is a new dimension to social learning. In addition, the fact that strangers can enter online spaces and develop trust (Greenfield & Campbell, 2006; Lewicki & Bunker, 1996; Madhok, 1995; Tseng & Kuo, 2010), and evidences of collaboration such as artifacts without ever meeting in-person or even being in the same time zone is a new aspect of social learning.

Guided Knowledge Construction

An additional aspect of social learning that this study’s findings brought out was the importance of guided discovery and guided knowledge construction (Douglas & Chiu, 2012; King, 2000; Leutner, 1993). Although the community space allowed for different paths to knowledge construction, it also provided a type of safety net. There

were highly knowledgeable members and leaders who engaged with new learners continually and provided guidance as they constructed knowledge. New members were not just expected to figure out norms and procedures on their own. In fact, the group rules called for new members to introduce themselves by answering over 20 different questions about their situation and knowledge seeking. Thus, the group was guiding new members as to how to initiate their information-seeking within the space. Later on, experienced members would ask new members follow-up questions and ask them to report back to the group to acquire additional knowledge. Group members in the present study were being guided in their discovery of information. As King (2000) stated, "use of different types of guiding questions might promote the building of qualitatively different knowledge structures" (p. 341).

Importance of Practical and Experience-based Knowledge

Another study result that warrants discussion is the importance of practical and experience-based knowledge. Participant statements in interviews and postings showed the value participants placed on experience-based knowledge that was shared in the group. Several participants stated that they found this type of knowledge to be more valuable than the fact-based knowledge doctors provided. This finding coincides with that of other studies (Panahi, Watson, & Partridge, 2012, 2016) that state that this type of knowledge is often the most valuable and biggest asset for individuals and organizations. Researchers have found that efforts to promote sharing of this type of knowledge is enabled by interactions that social media sites can accommodate (Majchrzak, Faraj, Kane, & Azad, 2013; Panahi et al., 2012, 2016). "Social web paradigm can be helpful for tacit knowledge-sharing through interactive and collaborative technologies where a

community of specialized practitioners can share, critique, and validate their collective experiential knowledge" (Panahi et al., 2012, p. 1095). Features of social media sites that these researchers have found to be helpful to the sharing of experiential or tacit knowledge include the ability to have social interaction, experience sharing, observation, informal relationships, and mutual trust. All these factors were present in the social media community space this study explored and several were core categories or themes (i.e., experienced-based knowledge-sharing, informal relationships, high level of trust).

Whereas the above tries to share the substantive theory that came out of this study's findings through a story and new frameworks and models, the following sections attempt to situate the findings by reviewing the literature shared in earlier chapters of this dissertation and assessing how this study's findings supported or rejected these previous works.

Knowledge-sharing

Previous research on what motivated members of online communities to share knowledge (Lin et al., 2009) concluded that factors such as trust, self-efficacy, expectations, (Hsu et al., 2007) and social capital (Chiu et al., 2006; Hall & Graham, 2004) were important. Findings in this study support the idea that trust within the community, self-efficacy for information-seeking and knowledge-sharing, and lack of group participation expectations were important factors that influenced knowledge-sharing in the online social media group that was explored. In addition, findings from this study echo other research findings that show that sense of community (Brickson, 2000; Triandis, 1995; Tseng & Kuo, 2010; Wagner, 1995), interpersonal trust (Greenfield & Campbell, 2006; Lewicki & Bunker, 1996; Madhok, 1995; Tseng & Kuo, 2010), self-

efficacy and social awareness (Gist & Mitchell, 1992), and community identity (Neufeld et al., 2013; Wenger et al., 2002) must be present to promote knowledge-sharing. As discussed in Chapter 4, participants felt that the sense of community and high level of trust within the group allowed for knowledge-sharing and sharing of personal information and feelings. Participants in this study also expressed self-assessing their ability to share knowledge and being aware that other members in the group possess more knowledge or lacked knowledge that they had and could share with them. Last, participants in this study described feeling part of a community that had at times its own language, focus, and mission, of working together to share knowledge to care for children with GERD.

Review of Informal Learning Literature

Forms of Informal Learning

In revisiting the literature that was discussed in Chapter 1, I considered Schugurensky's (2000) taxonomy or three forms of informal learning, self-directed, incidental, and socialization. I concluded that based on participant's statements, aspects of all three forms of informal learning appeared to be evident in the online social media group that was explored in this study. Participants in this study described engaging in self-directed learning activities within the group. They sought out the group and asked questions of their own accord. They posted questions in their own words on the group's wall as they wanted to or needed information. Participants in this study also described engaging in incidental learning or learning things that they had not intentionally sought out such as web talk or gaining emotional knowledge to help them deal with changing expectations of their role as a caretaker of an infant with GERD. Participants also discussed engaging in socialization or a process where they internalized skills and values

from their participation in the group that they may have not even realized. An example of this would be learning how to question medical professionals and advocate for better medical care. Participants learned these skills by reading about other members doing the same and by realizing how important it was.

Characteristics of Informal Learning

Chapter 1 also described primary characteristics that exist in informal learning situations no matter their type. Findings in this study demonstrated that these characteristics existed in the online social media learning space the study explored. The first is that informal learning is shaped by the learner (Marsick & Volpe, 1999). Participants described being able to shape their own learning within the group. There were no expectations for participation or time limits imposed on the participants or limitations on what knowledge they could seek and acquire or share.

The second characteristic described in chapter 1 was that informal learning was not location-specific (Vygotsky, 1962). Participants in this study described learning within the online social media group space and outside of it as they applied the knowledge they gained at home or in doctor's offices advocating for their children.

The third characteristic was that informal learning was unstructured, experiential, and participants self-select (Carliner, 2013; Marsick & Volpe, 1999). Participants in this study self-selected joining the group that was explored. The type of learning they engaged in the group was unstructured and could be started and stopped whenever they wanted.

A fourth characteristic was that informal learning was indeterminate and was a process of becoming (Hager, 2006). Participants described not knowing when their

participation and membership in the group would end and that their learning and participation in the group was a contextual process that was highly dependent on the needs of their child or life situation at the time.

Informal Learning in the Workplace and Online Social Media

Chapter 1 also shared findings from other studies (Dale & Bell, 1999; Garrick, 1998; Marsick & Watkins, 1990) regarding informal learning albeit in the work place. These studies found that informal learning in the workplace occurred through observation, social interaction, and problems solving. Although in this study, informal learning occurred in an online social media space, it also occurred through observation of other group members, interactions among members, and trying to problem solve how to care for their infants with GERD.

Dimensions of Learning in Online Social Media

As described in the first chapter of this study, Heo and Lee (2013), identified three dimensions of learning that occurred in social media. These dimensions were a learning or acquisition process, creating meaning and reflecting, and learning as a practice-based community. The participants interviewed for this study along with postings from the group's wall evidenced all three of these dimensions in the online social media group that was explored. As reported in interviews, some participants described engaging in a learning or lurking process where they gained information from other members in a passive role. There were other interview participants who described engaging in a meaning creation and reflection process and were more active in their knowledge acquisition by asking questions and personally messaging members. This type of informal learning, creating meaning and reflecting, was also visible in the postings and

interactions that appeared on the social media group's wall. Last, there were other interview and posting participants that seemed to engage in the third dimension that Heo and Lee (2013) described which included creating and increasing their knowledge by interacting with other members through knowledge-sharing and knowledge reconciling and negotiating.

Importance of Connectedness and Sense of Community

Davis (2010) in her study focused on the importance of connectedness or sense of community and learning in an OCOP as was mentioned in Chapter 1. She found a statistically significant correlation between the two. She also found that lurking behavior was considered LPP and was a key component of OCOPs. In much the same way, participants in this study cited the sense of community and connectedness in the group as one of its strengths and a factor in why they remained in the group. Findings in this study also point to the existence of lurking or peripheral participation as shown in Figure 6 and interview participants discussed how prevalent lurking was in the group.

Solitary versus Interactive Learning

Smock (2012) found that users in OCOP engaged in two types of learning strategies, solitary and interactive. He also concluded that less knowledgeable members used solitary learning until they progressed to more interactive types of learning activities. Participants in the present study, both in interviews and postings, also exhibited both types of learning strategies. Some participants described engaging in solitary activities like reading the postings or the group files, but not posting questions or responding to anyone else's postings. Some participants described engaging in interactive learning activities such as posting questions or responding to someone else's. Unlike,

Smock, I did not find that newer members engaged in more solitary activities until they felt more knowledgeable and then engaged in interactive learning strategies. In fact, in this study, newer, less knowledgeable members engaged in interactive strategies right away as they felt a desperate need to connect to others going through the same experience to ask for advice and to learn from other member's experiences.

Community of Practice or Affinity Space

One of the questions I had coming in to the study was what type of informal learning space this was—community of practice or affinity space. As discussed earlier in this chapter, I felt like neither framework adequately described the space that was explored. Thus, the creation of a new framework; however, I think that there are features of both frameworks that the findings of this study evidenced. Table 19 compares features of both frameworks and the features of the space that was explored in this study.

Table 19

Features of Communities of Practice Framework, Affinity Spaces Framework, and of the Space Explored in This Study

Features	Features of Communities of Practice (Wenger, 1998)	Affinity Spaces (Gee, 2004)	Features of the space explored in the study
Sustained mutual relationships	☑		☑
Shared ways of engaging in doing things together	☑		☑
Rapid flow of information and innovation	☑		☑
Absence of introductory preambles	☑		☑
Very quick setup of a problem to be discussed	☑		☑
Substantial overlap in participants' description of who belongs	☑		
Knowing what others know, what they can do, and how they can contribute to an enterprise	☑		
Mutually defining identities	☑		
The ability to assess the appropriateness of actions and products	☑		
Specific tools, representations, and other artifacts	☑		☑
Local lore, shared stories, inside jokes, knowing laughter	☑		☑
Jargon and shortcuts to communication as well as the ease of producing new ones	☑		☑
Certain styles recognized as displaying membership	☑		
A shared discourse reflecting a certain perspective of the world	☑		☑
A common endeavor that is not based on age, race, class, gender, or disability.		☑	☑
Newbies and masters and everyone else share common space		☑	☑
Individuals who participate in the "portal" or shared space are able to generate new signs and relationships for the original generator or common endeavor.		☑	☑
Content organization is transformed by interactional organization		☑	
Both intensive and extensive knowledge is encouraged		☑	☑
Both individual and distributed knowledge are encouraged		☑	☑
Dispersed knowledge is encouraged		☑	☑
Tacit knowledge is encouraged and honored		☑	☑ ("external knowledge") ☑ ("experienced-based knowledge")
There are many different forms and routes to participation		☑	☑
There are lots of different routes to status		☑	☑
Leadership is porous, and leaders are resources		☑	☑

Limitations of the Study

A limitation of the study included its focus on a group of people in a space interacting around a particular topic in one moment in time. Generalizability is not possible; however, the study does add to the small body of research (Davis, 2010; Dolan, 2013; Mak, 2013; Smock, 2012) on informal learning in online social media spaces. It also adds to the limited body of research focused on online health information-seeking in social media spaces (Xiao et al., 2014).

A second limitation of this study is that I was not able to interview members who had left the group, as their information was wiped out of the social media group. Hence, I could not recruit them for participation. Their experiences with the group and what caused them to leave are missing from the study. The closest I came was to find members who were less active or who were thinking that they would be leaving in the next short while. These interviews led me to findings such as participation being linked to stages of GERD, with some participants leaving the group or participating less once the GERD was under control.

Another limitation, as noted in the beginning of this dissertation, was my role as a participant observer. I was a member of the group before the study and am still a member. I acknowledge that this led me to make certain assumptions; however, as discussed in the methods section, I used triangulation, member-checking, analytical memos, and other processes to check my assumptions and focus on the messages shared by participants.

Implications for Practice and Policy

Design of Informal Learning Spaces

Although not much research has been done on informal learning in online social media spaces, I believe the findings of this study hold great insight for those trying to design either online social media spaces or just online informal learning spaces. Although it is often believed that being online leads to more isolation and independence, in this study I found the opposite. Participants highlighted the sense of belonging in a community as a factor in their continued membership, participation, and knowledge-sharing in the group. Thus, the design of these spaces needs to consider the needs of social learning and the need for guided discovery. New members need to be guided as they learn group processes and negotiate knowledge acquisition and sharing. In addition, group leaders and their visible presence allow participants to feel like the group is focused and is a safe space to share personal information and seek knowledge.

New Models for Understanding Information-Seeking

Information-seeking behaviors and models (Kuhlthau, 1991) that depict them need to evolve to match the advances in information access, creation, and distribution and the diversity of online spaces where information-seeking may occur like Facebook (Oh et al., 2013). In addition, information-seeking in social media sites presents an additional layer of culture and behaviors peculiar to social media sites (Cookingham & Ryan, 2015; Dunaev & Stevens, 2016; Kim, Sin, & Tsai, 2014) that must be taken into consideration when examining information-seeking behaviors.

Medical Providers' Use of Health-related Social Media Groups

One common thread throughout this study's findings was the sense that participants had that their medical providers were not listening to them or were not knowledgeable about infant GERD and the day-to-day care of infants with GERD. Many felt that their doctors would be better informed if they joined groups like the one this study explored to learn what needs caretakers had and how to best help them. Medical providers would also be able to explore ways to communicate with patients better to improve or close the distance between them and patients. Iverson et al. (2008) discussed the historical role of the doctor as a health authority and screener of medical information and how that role is no longer possible given time constraints and the desire of patients to investigate on their own and be proactive. He suggested that doctors be encouraging of patient questions and health information searching as they can increase patient compliance and lead to better health outcomes.

Recommendations for Future Research

This study added to the body of work on information-seeking in online spaces, but more needs to be done to examine information-seeking in social media and specifically in Facebook. Although some researchers such as Hanan Asghar (2015) have developed scales to evaluate information-seeking in Facebook in general, there is still much research to be conducted on information-seeking within Facebook groups.

Although this study provided insight into information-seeking behavior for health information in social media sites, more studies need to be conducted on the same. As Xiao et al. (2014) stated, "despite the availability of extensive health related information on the Internet and despite the information's impact on public health, there has been

limited attention toward users' online search behaviors in IS literature" (p. 418). The researchers were just discussing health searching on the Internet and the research gap that exists in that field, but it is even more acute when focusing specifically on online health searching in social media sites. In addition, more research needs to be done on the effects of seeking emotional support for a health issue online through Facebook or other social media groups (Oh et al., 2013).

In addition, although this study focused on a group centered on infant/childhood GERD, I believe the Vargas-Wright Online Learning Community Spaces Framework (Vargas-Wright, 2018) and the Vargas-Wright Information-Seeking in Online Social Media Groups Model (Vargas-Wright, 2018) that resulted from the study's findings would hold true with groups centered on other topics. In fact, as a member of three distinct social media informal learning spaces centered on doctoral studies, injured veterans, and diabetes support, I can see the disconnect driving each group along with the other factors mentioned in the Vargas-Wright Online Community Spaces Framework namely types of knowledge that is encouraged and available, community and group characteristics, and utilized learning processes.

Conclusion

This adapted Grounded Theory study explored the learning experiences of members of an online informal learning community space. The emergence of the central core concept of a disconnect and a storyline and substantive theory of learning to survive was theoretically saturated to understand its association to learning in informal online social media groups. The core concept and its supporting themes and categories were validated through existing literature as discussed in this chapter; however, the real

significance of this study lies in its contributions to a better understanding of online informal learning spaces in social media and what components are part of thriving ones like the one explored in this study. A new framework for exploring online informal leaning spaces in social media was developed and proposed. Its key components being a motivating disconnect; learning processes; community and space characteristics; and types of knowledge that are encouraged and available (Vargas-Wright, 2018). This study also contributed to a better understanding of online information-seeking behaviors and online health information-seeking behaviors by introducing a new model of information-seeking within online social media groups (Vargas-Wright, 2018). This model includes the stages of initiating, lurking, and browsing; requesting information; being guided by a highly knowledgeable member; reconciling; applying; and appraising. In addition, this study contributes to the belief that social media spaces are a viable avenue for the transferring of experience-based knowledge and new dimensions of social learning.

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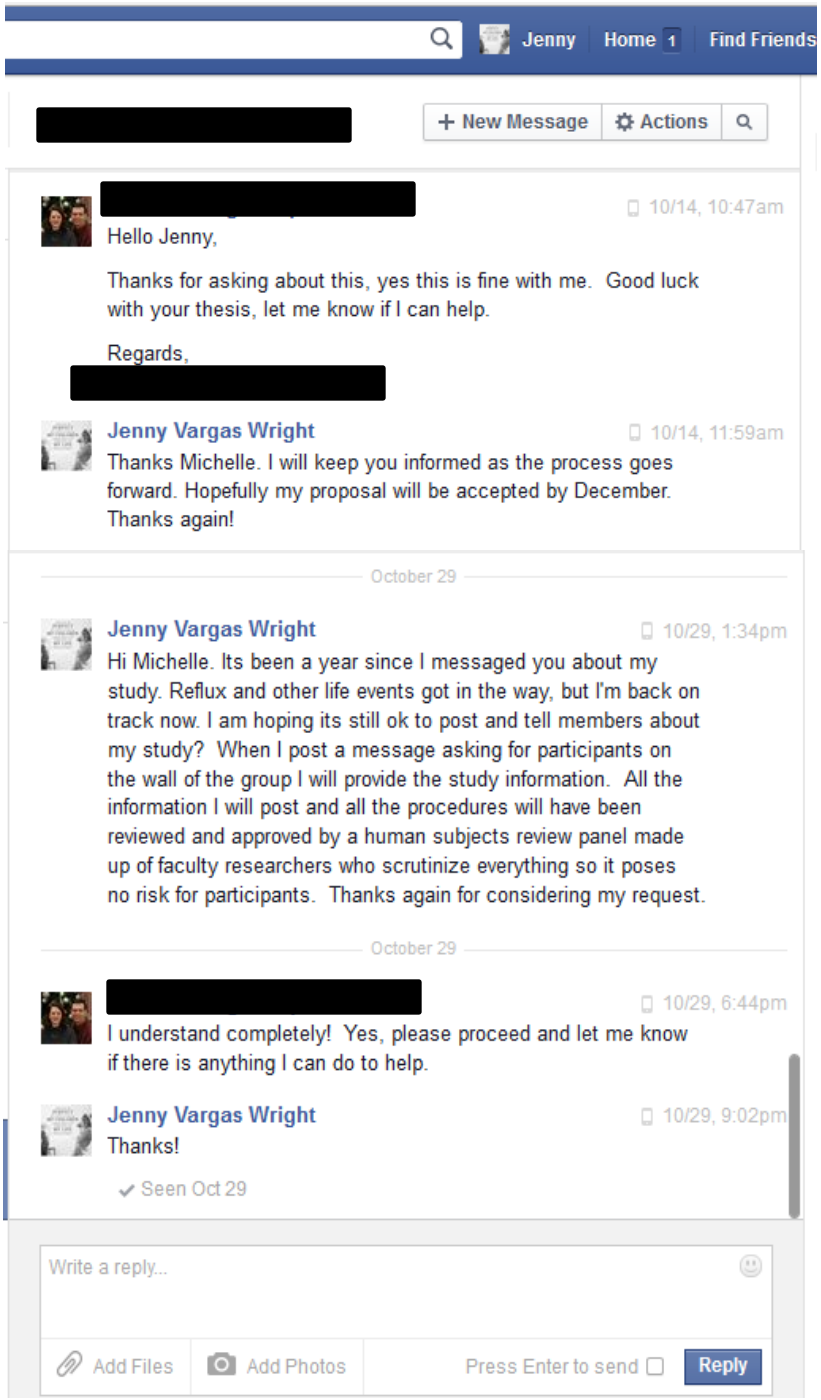
APPENDIX A

PERMISSION FROM THE ADMINISTRATOR OF THE SOCIAL MEDIA GROUP TO RECRUIT PARTICIPANTS FOR BOTH PHASES OF THE STUDY


Jenny
Home 1
Find Friends
[redacted]
+ New Message
Actions
[redacted]
10/14, 10:47am
Hello Jenny,
Thanks for asking about this, yes this is fine with me. Good luck with your thesis, let me know if I can help.
Regards,
[redacted]
Jenny Vargas Wright
10/14, 11:59am
Thanks Michelle. I will keep you informed as the process goes forward. Hopefully my proposal will be accepted by December. Thanks again!
October 29
Jenny Vargas Wright
10/29, 1:34pm
Hi Michelle. Its been a year since I messaged you about my study. Reflux and other life events got in the way, but I'm back on track now. I am hoping its still ok to post and tell members about my study? When I post a message asking for participants on the wall of the group I will provide the study information. All the information I will post and all the procedures will have been reviewed and approved by a human subjects review panel made up of faculty researchers who scrutinize everything so it poses no risk for participants. Thanks again for considering my request.
October 29
[redacted]
10/29, 6:44pm
I understand completely! Yes, please proceed and let me know if there is anything I can do to help.
Jenny Vargas Wright
10/29, 9:02pm
Thanks!
Seen Oct 29
Write a reply...
Add Files
Add Photos
Press Enter to send
Reply

APPENDIX B

ARIZONA STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD EXEMPT APPROVAL

EXEMPTION GRANTED

Wilhelmina Savenye
Division of Educational Leadership and Innovation - Tempe
480/965-4963
Willi.Savenye@asu.edu

Dear Wilhelmina Savenye:

On 3/11/2015 the ASU IRB reviewed the following protocol:

Type of Review:	Modification
Title:	Parents Learning Together: An Exploratory Look at Informal Learning in Facebook
Investigator:	Wilhelmina Savenye
IRB ID:	STUDY00002060
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• Recruitment Message for Second Phase Transcript • Analysis of Postings2.pdf, Category: Recruitment • Materials; • Interview Protocol_JVW2.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Protocol Template Social Behavioral Jenny Vargas • Wright2.docx, Category: IRB Protocol; • IRB training Certificate Jenny Vargas Wright, Category: Other (to reflect anything not captured above); • CITI Completion Report - Savenye_040311.pdf, Category: Other (to reflect anything not captured above); • Recruitment Message and Consent Form for First • Phase Interviews.pdf, Category: Consent Form; • Recruitment Message and Consent Form for First • Phase Interviews.pdf, Category: Recruitment Materials;
	• Permission from the social network administrators.pdf, Category: Off-site authorizations (school permission, other IRB approvals, Tribal permission etc);

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 3/11/2015.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,
IRB Administrator

APPENDIX C

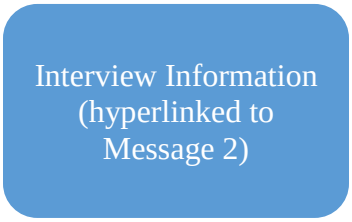
RECRUITMENT MESSAGE FOR INTERVIEW PARTICIPANTS

Recruitment Message for Interviews

Message 1: Sent via Facebook messaging to targeted participants

Hello. I am sending this message with the permission of this group's administrator, XXXX. I am Jenny Vargas Wright, a fellow member of this group and parent of a toddler who has suffered from reflux since she was an infant. I joined this group almost a year ago and have really enjoyed being a member.

In addition to being a parent, I am also a doctoral student in the Educational Technology program at Arizona State University conducting this study under the supervision of Dr. Wilhelmina Savenye, Arizona State University professor. One of my research interests is how technology can facilitate informal learning and how informal spaces such as this network can be valuable sources of information. At present, I am conducting a study on how knowledge is shared and community formed within this social media group. My study will be composed of two different phases. The first phase will involve interviewing members of this social network to better understand how they participate in this social network. If you are willing to participate in this first phase and be interviewed you will receive a $20 Amazon gift card. Please click on the following link for more information including what is required of you and to set up an interview time.



Message 2: Informed Consent for Interviews (hyperlinked from Message 1)

This message is an approved request for participation in research that has been approved by the Arizona State University Institutional Review Board (IRB).

This consent form will give you the information you will need to understand why this research study is being done and why you are being invited to participate. It will also describe what you will need to do to participate as well as any known risks, inconveniences or discomforts that you may have while participating. You are encouraged to ask questions at any time. If you decide to participate, you will be asked to provide your consent below.

- **Purpose and Background**

You are invited to participate in a study whose purpose is to explore informal learning experiences in social networks like this one. It will further advance understanding of how people become part of naturally occurring online communities around something they are passionate about like infant reflux. It will help improve educational practice by offering insights into how people share information and learn together.

- **Procedures**

You must be 18 and older to participate in the study. If selected to interview, you will be contacted to set up the interview at a time that is convenient for you. The interview will last about 45-60 minutes and be conducted via telephone or Skype. During the interview, you will be asked about your participation in this social network. The interviews will be audio-recorded with your permission to allow for transcription so that all the information is captured accurately. The researcher may take notes as well. Audio files will be stored on a dedicated drive and be destroyed upon completion of the study.

- **Risks, Benefits, Extent of Confidentiality**

During the interview, you will be free to decline to answer any question or stop your participation at any time. There will be no direct benefit to you from participating in this study. However, the information you provide may help researchers, educators, and others to better understand how adults learn informally and how social networks can serve to promote learning. Reasonable efforts will be made to keep the personal information in your research record private and confidential. Once you agree to the interview you will be assigned a number and any identifiable information will be removed from any records. Your name will not be used in any written reports or publications that result from this research.

- **Compensation**

You will receive a $20 Amazon.com gift card to show appreciation for your time spent participating in the interview.

- **Questions**

If you have any questions, concerns, or complaints contact the research team made up of Dr. Wilhelmina Savenye (willi.savenye@asu.edu) and Jenny Vargas Wright (vjenny@asu.edu or 602-570-2658).

This research has been reviewed and approved by the Social Behavioral IRB. You may talk to them at (480) 965-6788 or by email at research.integrity@asu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

- Participation

If you would like to participate please click on the link below to submit your contact information to set up the interview.

"By clicking the Continue Button I acknowledge that I am at least 18 years old and that I voluntarily agree to participate in this study"

Continue (hyperlinked to contact information page)

Contact Information Form (hyperlinked from Message 2)

1. Name you want to use for the interview (can be made up)?
2. How would you like to be contacted to set up the interview? (By phone—branches to space for phone number, email – branches to space for email, Facebook – branches to space for Facebook ID?)

APPENDIX D

INITIAL INTERVIEW QUESTIONS

Initial Interview Protocol

I appreciate your willingness to speak with me about your participation in this social network regarding infant reflux. The questions I will ask include open-ended questions. You will also have an opportunity to add additional thoughts you might have about this topic at the end of the interview. It is expected that this interview will take about 45-60 minutes to complete. Your participation is voluntary, and you may end the interview at any time. You may also choose not to answer specific questions. Your responses to this survey will be confidential and will be reported in aggregate without any identifying information.

1. May I record this interview?
2. What is your gender?
    a. Male
    b. Female
3. What is your highest level of education?
    a. Some high school or less
    b. High school diploma
    c. Associate's degree
    d. Bachelor's degree
    e. Master's degree or equivalent
    f. Doctorate, law or medical degree or equivalent
4. On average how many times per day to you log on to this social network and read postings?
    a. More than once a day
        i. Approximately how many minutes per day on average do you spend on this social network?
    b. Once a day
        i. Approximately how many minutes per day on average do you spend on this social network?
    c. A few times per week
    d. A few times per month
5. How often do you post an original message or comment on the social network's wall?
    a. One or more times a day
    b. A few times per week
    c. A few times per month
    d. Never
6. How long have you been a member of this social network?
    a. 1 month or less
    b. 3 months to 1 year
    c. 1 year or more
7. What was your motivation for joining this social network?
8. What motivates you to participate in this social network and to remain a member?
9. What types of participation do you think this social network encourages?
10. What do you think influences how much members participate in this social network?
11. How would you describe your knowledge about infant reflux before joining this social network?
12. What knowledge regarding infant reflux have you gained by being a member of this social network?
13. Potential Probes:
    a. What have you learned about medications for infant reflux?
    b. What have you learned about available medical testing for infant reflux?
    c. What have you learned about the life span of infant reflux?
    d. What have you learned about available therapeutic or homeopathic treatments for infant reflux?
14. What activities have you engaged in within this social network to learn about infant reflux?
15. Potential Probes:

a. How have you asked questions?
b. How have you shared information or opinions?
c. How have you collaborated with other members?

16. How have you applied any of the knowledge you have gained in this social network to your handling of your child's reflux needs?
17. How do the members of this social network share their knowledge about infant reflux?
    a. Potential Probes
       a. How do they use the social network wall for knowledge-sharing?
    b. How do they use the file tool for knowledge-sharing?
    c. How do they use the chat and personal messaging system for knowledge-sharing?
18. What kinds of knowledge do members of this social network share?
19. How would you describe your experience posting an original message on the social network's wall?
    a. Potential Probes:
    b. What was your goal in doing so?
    c. What response did you receive from other members?
    d. What motivated you to post an original message?
20. How would you describe your experience posting a comment in response to someone else's original message?
    a. Potential Probes:
    b. What was your goal in doing so?
    c. What response did you receive from other members?
    d. What motivated you to post a comment?
21. How do you feel about asking questions of the members of this social network?
22. How do you feel about the expertise and knowledge that members of this social network possess?
23. What types of knowledge are valued or encouraged in this social network?
    a. Potential Probes:
    b. Is tacit (knowledge built up in practice) or explicit (factual) knowledge valued?
    c. Is intensive knowledge (specialized) and extensive knowledge (knowledge about many aspects) encouraged?
    d. Is individual knowledge (knowledge that exists in individual's heads) and distributed knowledge (knowledge that exists in others, materials, tools or artifacts) encouraged?
    e. Is dispersed knowledge (knowledge not on site itself, but in other sites/spaces) encouraged?
24. What kinds of information do members of this social network trust other members with?
25. How would you describe your capabilities for sharing knowledge with members of the social network?
26. How do you think that members of this social network feel about being part of this social network?
27. How do you experience a sense of community in this social network?)
28. How does the sense of community in this social network affect your participation in this social network?
29. What types of connections exist between members of this social network?
30. How do members of this social network support each other?
31. What information like a shared vocabulary, do you feel that members of this social network use that those outside the network may not be familiar with or understand?
32. Would you like to add any information that you feel is pertinent to my understanding of your participation or the environment that exists within this social network?

APPENDIX E

RECRUITMENT MESSAGE FOR POSTING

Recruitment Message for Transcript Analysis of Postings

Hello. I have been given permission by this group's administrator, XXXX, to post this message. I am Jenny Vargas Wright, a fellow member of this group and parent of a toddler who has suffered from reflux since she was an infant. I joined this group over a year ago and have really enjoyed being a member.

In addition to being a parent, I am also a doctoral student in the Educational Technology program at Arizona State University under the supervision of Dr. Wilhelmina Savenye, Arizona State University professor. One of my research interests is how technology can facilitate informal learning and how informal spaces such as this network can be valuable sources of information. At present, I am conducting a study on how knowledge is shared, and community formed within this social media group. For this phase of the study, I will be analyzing messages and comments made on the wall of this group for trends and themes like sense of community or interpersonal trust. Before analyzing the messages and comments, I will remove any identifiable information including Facebook usernames that appear with each comment. All files associated with the study will be saved on a dedicated drive which will be destroyed upon completion of the study. Once my analysis is completed I will write up my results in aggregate form and without any identifiable information. If any quotes are shared, pseudonyms will be used such as "member 2Aj32". I will be looking at comments during the week of February 21-28, 2014. If you would rather not have me analyze your messages or comments posted during February 21-28, 2014 please click on the link below or send me a personal message through Facebook or by email at vjenny@asu.edu.

Opting Out of Transcript Analysis (takes participants to a short form to submit Facebook username)