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Electronic Support Group Communication Behaviors Among Parents of Children with Eosinophilic Esophagitis

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Abstract

The purpose of this study was to explore content and organizational themes within an electronic support group for parents of children with eosinophilic esophagitis. This group experiences a high degree of potential stress and geographic dispersal and thus provided a distinct population with high support needs. A thematic analysis of the text from a public group hosted by a social networking site was performed. Inductive coding was used to identify content themes. The following four domains were identified within the text: good doctors, bad doctors, medical advice, and practical advice. The bad doctor theme elicited particularly high response rates and was most emotionally charged. It was also most often seen in conjunction with the medical advice theme. In addition, no internal conflict was observed. The results suggest that parents are in conflict with doctors largely due to poor communication strategies on the part of the clinician. This conflict can co-opt medical advice in order to gain some control in the doctor-caregiver relationship. However, evidence within the text suggests that good doctors can enhance the clinical interaction and its lasting effects via a patient centered communicative approach that frames the interaction on the caregiver and child experience. This study suggests that this interaction is crucial for characterizing the healthcare experience for parents and that doctors can improve the experience of caregivers and patients by orienting the communication event around the parent and patient.

This paper will explore the use of electronic support groups (ESGs) among parents of children with eosinophilic esophagitis (EoE). More specifically, it will address caregiver communication and conflict with healthcare providers as well as disease experience. As the internet has become increasingly embedded in the fabric of society, it has not only converted communication to a new medium but has transformed the communication event, facilitating new interactions in significant ways. One such site of this transformation has been ESGs. In the medical context, ESGs represent a new space for health conversation between patients or caregivers. They also have the potential to reflect shifting power dynamics between providers and patients. As the dialogue moves out of the privacy of exam rooms, hospitals, and pharmacy windows, patients can join together in public collectives. This reflects the larger move in healthcare away from paternalistic communication to a more patient centered and patient empowered approach.

One novel population for consideration in this context is parents of children with EoE. Due to the nature of the disease, this group faces a high degree of uncertainty from and simultaneous dependence on medical providers. ESGs provide a space to address these tensions in a unique way. The special conditions of electronic support groups that appear to attract populations distinct from other support group users are especially relevant to this collective of caregivers. First the geographic dispersal of patients given its relative rarity makes ESGs a much more accessible option for peer support in this group of caregivers. Also, the limited concrete answers available for treatment makes this group potentially more vulnerable. Hence this population of users provides a particularly useful example of the intersections of medical ambiguity, uncertainty, doctor-patient relationships, clinical communication, technology, and the power dynamics in medical contexts.

This paper will begin with background for the study consisting of a literature review and a justification. A description of the methods used to collect data for this study will follow. The results of the data collection will then be elaborated. This will lead to a discussion of the results and their implications for clinical practices and future research.

Literature Review

Eosinophilic esophagitis is a specific medical condition that has just been relatively recently identified, diagnosed, and treated. The stresses that families face in caring for a child with this condition can be quite significant. Some of these frustrations can stem from dealing with ineffective and inappropriate clinical communication with providers. As a way to cope and access support, many parents have turned to electronic support groups. These online groups provide an alternative to traditional support groups and can serve users in different ways. While such groups can help families in a variety of ways, online support can also have a distinct impact on the doctor-patient-caregiver relationship as power and roles are negotiated.

Eosinophilic Esophagitis

Eosinophilic esophagitis (EoE) is an allergic illness that is increasingly diagnosed in both adult and pediatric populations (Gonsalves, 2008). Characterized by a variety of symptoms including vomiting, pain in the throat, food impactions, and dysphagia(difficulty of pain swallowing), it is an illness that significantly impacts quality of life for patients. Knowledge about EoE is increasing, yet it is still incomplete (Putnam, 2008). This is a condition with a high degree of ambiguity as gaps in the knowledge of the condition continue to emerge. For instance, doctors continue to debate on criteria for its diagnosis. Patients may present without symptoms while biopsies indicate support for EoE. Thus the importance of symptomology is brought into question (Putnam, 2008). In addition, as Chehade (2008) notes, the pathogenesis of EoE is

poorly understood and work by Chehade and Sampson (2008) suggests that epidemiological and etiological understandings are minimal. This indicates a general gap in knowledge of the causes, processes, and distinctions of EoE.

Clinical understandings of the disease are also highly contested and ambiguous. Symptom presentation and duration can be immensely variable (Chehade & Sampson, 2008). As noted above, patients can present with a range of indications of the disease or none at all. Once the disease has been identified, there are several potential outcomes even with treatment. These include spontaneous and permanent resolution, temporary remission, fixed stable state, and continuous progression (Straumann, 2008). Thus, a patient who is diagnosed is not necessarily on their way to recovery with clinical support.

Treatments that could lead to these outcomes are also not concrete. Liacouras (2008) notes that there are multiple treatment options for EoE and that no one therapy is indicated as uniquely effective. Therefore treatment options are typically evaluated on an individual patient basis, and there is a high degree of variation in treatment guidelines within a relatively similar patient population. Additionally, many treatments include complex dietary and nutritional specifications leading to major nutritional concerns within the population (Spergel & Shuker, 2008). As a result, patients often must adhere to a complex and changeable treatment plan that involves many lifestyle adjustments.

As Klinnert (2009) notes, these factors can have profound effects on the patient and the patients' family. Coping with both symptoms and treatments can be especially difficult for children diagnosed with EoE and their families. While the symptoms and restrictions impact children, parents can also experience psychosocial difficulties in caring for their needs. These populations often experience a high degree of stress (Klinnert, 2009). Therefore this disease is

characterized by a high degree of uncertainty and strain that makes doctor-patient interaction especially crucial as patients and caregivers attempt to cope with and manage an EoE diagnosis.

Clinical Communication

In theory, clinical communication represents a space in which some of the concerns around diagnosis, treatment, and general coping can be identified, discussed, and potentially addressed. Families of children with chronic illness are especially in need of effective clinical communication due to the coping concerns of the diagnosis. Therefore, as Albrecht et. al (2009) argue from an observational study of communication between health providers and cancer patients, clinical communication needs to become a significant focus within healthcare. Researchers have argued that quality clinical communication can help patients better receive bad news, manage the emotional impact of illness, comprehend and remember important information, communicate between multiple providers, maintain hope in the face of uncertainty, build trust in providers, and engage in health promoting behaviors (Epstein & Street, 2007). In fact, the communication behaviors of both doctors and patients can be better predictors of adherence to care plans, satisfaction with care, and higher accrual in follow-up than the traditionally considered factors such as age and race (Albrecht, 2009).

Researchers have found that positive medical outcomes are correlated with quality clinical communication. One form of communication advocated by health researchers is patient centered communication (PCC). Patient centered communication emphasizes the needs and the context of the patient experience and is characterized by improved communication and resultant improved outcomes (Epstein & Street, 2007). For example, a doctor engaging in PCC might look to parent descriptions of a child's behavior as connected to experiencing pain. Even though there may be no other clinical support that pain is occurring, the doctor can honor the report of the

parent and look into the possibility of pain and what it might mean. Another example would be a doctor recognizing that a mother was anxious about the child's condition and offering referral support to the mother while addressing the health needs of the child. Wanzer, Boothe-Butterfield, and Gruber (2010) discuss extensively the notion of PCC from research on clinical behaviors in a large Children's Hospital. In this model, the needs and abilities of the patient are emphasized as opposed to the traditional baseline communication behaviors of providers. The patient's and caregiver's understanding become the measure of successful communication as opposed to information provided by clinicians. This has become an area of increasing importance in clinical settings as healthcare providers are made more aware of the positive clinical consequences of engaging in such behavior (Krumholz & Herrin, 2000). One such very direct reward of PCC is decreased fear of litigation (Engler et. al 1981; Levinson, 1994). In addition, physicians have also become very aware of the positive interpersonal consequences of engaging in PCC including general patient satisfaction and comfort with care (Albrecht et al., 2009). This is particularly important in pediatric populations. Albrecht et al. (2009) suggest that early clinical experiences will inform future psychosocial functioning for child patients. Thus clinical communication should continue to be emphasized as a site of study with the PCC model highlighted as a frame related to increases in adherence, satisfaction, and functioning especially in the context of pediatric clinical experiences. However, positive outcomes can only occur if patients take advantage of it.

Online Health Information/Support Seeking

Despite the major importance of clinical communication, a relatively new alternative space in which to engage in health communications has arisen for patients: the internet. Online health information seeking behaviors have become increasingly relevant to health outcomes and

systems of care as their use. This is especially true in situations in which there exists a high degree of ambiguity, such as when there is limited ability to diagnose and uncertainty in prognosis and treatment. A study by Pew Research Center indicated that approximately 80% of internet users search for health information online (Fox 2006). Given the sheer magnitude of internet use, this represents an immense group of the population that goes beyond traditional sources such as healthcare providers for health information to inform decisions about health behaviors.

These forums allow users to simultaneously contribute to and consume massive volumes of information. Ancker (2009) posits that this makes health information online an increasingly collaborative production. Kivits (2009) expands this from her interview research on health information seeking behaviors online. Based on her findings she argues that with higher internet access, users have become more active not only in the pursuit but also the creation of information texts online. This supports the claim that the internet effectively allows users/patients to pool their resources/information (Radin, 2006). Prior to the internet, this collective space of contribution and consumption would not have been possible.

People participate in the online health communication in a variety of manners. Ancker (2009) suggests four major types of peer-peer communication that occur online: informational, emotional support, instrumental support, and peer modeling. Online, information is streamlined for the user as it is presented in more "lay language" than the traditional clinical language that patients may encounter with their doctors (Ancker & Kaufman, 2007). In addition, patients may share different types of information than what one may encounter in the clinical setting. Information goes beyond diagnosis and treatment and may extend to general coping measures or "tricks" for handling the condition (Civan & Pratt, 2007). Emotional support can also occur in

online communications. This is typically demonstrated as one user discloses and describes feelings with another user responding in turn by providing feedback and support (Frost & Massagli,2008). Instrumental support is characterized by offering resources such as childcare, financial assistance, transportation, etc (Civian & Pratt, 2007). Lastly, peer modeling occurs as norms for management and coping are communicated and established (Dedobbeleer, Morissette, & Rojas-Viger 2005). For example, a user might describe their own ability to stay compliant with medication regimens or eat a healthy diet. This does not provide direct information or advice but might give other users motivation for engaging in their own positive behaviors. It is also worth noting that these four functions or uses are not practically discrete. They can interact and blend in a single communication to provide multi-functional support. Therefore the peer-peer internet communication can serve a variety of functions that extend past what might typically be discussed by a doctor.

All of these functions are present and can be accomplished within electronic support groups (ESGs). Early in their use Galegher (1998) characterized ESGs as virtual text communication available for individuals to discuss problems with people in similar situations. Barker (2008) studied these spaces extensively and described them as online message boards in which users can post information, request support, and share stories. Users then wait for responses to the posts by other users. This is distinct from simple hobby groups which focus on elective experiences and the objects of their interests. This allows for a highly collaborative space in which patients, as the name suggests, can support one another in many different ways.

Some researchers have argued that this is not very different from the more traditional group face-to-face format. Winzelburg (1998) compared electronic and face-to-face formats in his study of eating disorder support groups. From observation of the group, he concluded that

assistance strategies are very similar between the two types of groups. This would indicate that those who seek support in ESGs and face-to-face groups may have similar expectations of how to access that support.

However, according to other studies the very nature of the ESG has distinct consequences when compared to outcomes for social support formats. Mickelson (1997) has studied ESG use among parents of children with special needs. She compared the experiences of online support seekers with experiences of parents who engaged with more traditional support groups. Her data suggests a marked difference between the two populations. To begin, the findings indicate far more father participation in the online groups. Because participants in the ESG do not have to be physically present, this could create more accessibility for those who would perceive stigma in support group involvement. In online spaces, one may feel less vulnerable to judgment due to the geographic separation and anonymity of many participants. This is further supported by Mickelson's (1997) other findings. She described the ESG users as reporting feeling that their child's condition was more publically visible than tradition support group participants. The population of online users also reported sensing less social support from parents and friends. In addition, those who publically posted information tended to report being more stressed. Thus users in ESGs tend to be more vulnerable in their coping and in their general sense of the experience of having a child with a chronic condition. Online spaces then may be perceived as safer places in which users can express concerns without fear of judgment. This suggests that ESG participants are more vulnerable due to decreased perceptions of support, increased perception of stigma, and increased stress. However, they may offer more resources as individuals pool together their social capital. Therefore, the high risk group might be investing in higher resource formats for support.

Wright and Bell's (2003) analysis of ESGs suggests that by very nature of the medium the interaction will be different from a face-to-face group. They suggest that ESGs become weak tie networks that change the nature of the supportive communication. Gustafason et al. (1999) further argue that this is an advantageous change. This is supported by their research on HIV-positive patients' use of an online computer networking system that facilitated support between users. Research on breast cancer support groups has indicated similar findings. Lieberman et. al's (2003) work on ESGs for women with breast cancer suggests that with participation, patients tended to indicate positive increase in indicators for quality of life. However, their findings also imply that some personality types are not well suited for participation in an ESG such as those who did not previously self-identify as having a high need for social support. This would suggest that certain characteristics of the ESG are appealing to certain populations. Therefore, the ESG should be considered as distinct of the face-to-face group and further explored as a tool for patients and/or caregivers.

Consequence in Doctor-Patient Caregiver Relationship

Online spaces can have a profound effect on the doctor-patient-caregiver relationship and be a reflection of this dynamic in significant ways. Online communication is a tool by which patients can empower themselves, decreasing dependence on their providers for information. This echoes and reinforces a paradigm shift that is occurring in healthcare in which the patient becomes a consumer of care in a more economic framing of healthcare provision. Radin (2006) performed a case study of an online breast cancer support group in which she identified such a consumer model at work. Radin suggests that, in this new context, those who seek information online are rewarded with more extensive access to knowledge and other peers than would exist

in the clinical space. Those who actively pursue knowledge about their conditions build their capital as informed investors in their health and the services of medical providers.

Not only are there more contributors in this online space than in classic clinical realms but the geographic dispersal lends itself to increased disclosure within groups for informational and psychosocial benefits (Putnam, 2000). Barker (2008) observed an online fibromyalgia support group and suggests that in these spaces, patients support each other by confirming the nature of their situation and by becoming experts in their own conditions. Users are able to share and consequently constitute the reality of their suffering while lending support. Again, this builds capital as a collective. Lastly, accessibility is increased immensely as media and health are collapsed into a remotely accessible location (Kivits, 2009). This means that users can more easily work to empower themselves as the ESG diminishes such barriers as formal clinical encounters, distance, and time diminished.

Patients/consumers are also empowered as they search for information online. Users must become critical of the information presented online precisely because of its accessible and collaborative nature. In this manner, patients/consumers become reflexive and critical users of health information found within ESGs (Kivits, 2009). Thus users gain new skills that are applicable in a variety of healthcare contexts but especially in the doctor-patient relationship where they may be able to challenge information presented by clinicians.

Use of the internet for information and support has implications for the negotiation of the relationship between patient/caregivers and the doctor. Tustin (2010) studied cancer patients and their health seeking behaviors in relation to attitudes toward care providers. He found that dissatisfied patients were more likely to rate the internet as their primary source of information about their health. If a patient views his or her relationship with a clinician as unsatisfactory

there are alternatives, and the internet is one such option. However, patients' use of ESGs can be both a response and in anticipation of a clinical encounter. As Tustin (2010) describes, patients can experience a poor interaction with a clinician and consequently seek information from an alternative source. On the other hand, Kivits (2009) noted in her study of general health information seeking online that patients can also empower themselves with information before they interact with a doctor by "leveling the playing field" in a sense through increased understanding of the condition. Patients can also collaboratively work through clinical encounters as they provide peer-peer support to seek care from certain providers and reject it from others (Kivits, 2009). The mere act of engaging in health information seeking brings health outside the traditional provider space to a more communal area of expression mediated by other users, empowering the patient to have control over the interaction (Broom, 2005).

Electronic support groups have then become spaces for patients/caregivers to share information, support one another and model behaviors as well as safe spaces to indirectly challenge healthcare providers and confront their assessments. In ESGs, an event between doctors and the patient/the patient's family becomes public. When a user reports back to the ESG for evaluation and support, they open the once private dialogue between themselves and the care provider up to scrutiny of the other users. Thus the interaction contrasts with the traditional private interaction of the clinical encounter to one that is open, public, and more democratically assessed outside of the institutional doctor-patient relationship (Barker, 2008). This challenges the traditional flow of information from the doctor to the patient by rechanneling it through the ESG and consequently through the lens of others (Broom, 2005; Nettleton et al., 2005). The skepticism or assertions of a doctor can then be immediately challenged. This can take the form of expression of empathy that legitimizes the "true" shared experience and the difficulty of the

disease (Barker, 2008). Experiential expertise of the patient or caregiver is contrasted with the specialty medical expertise of providers. As the user discloses an experience others will often validate the patient with stories of similar events, claims to the reality of the sufferer, and other moves to strengthen the poster's position within the doctor-patient relationship.

Online health communication can then be conceptualized as part of an ongoing trend in healthcare that moves away from traditional paternalistic models of care to more egalitarian collaboration. Brown, et al. (2004) extensively describes this in the notion of the embodied health movement. As patients gather in these collective spaces they consciously or not are engaging in such an action. Patients and their advocates begin to give language to the experience of suffering with the illness/disease and maintain their credibility in their assertion because they live the experiences. As a result, the narrative of suffering and hardship can challenge the existing medical practices and scientific knowledge. ESGs provide a space for patients to advocate for themselves in the expression of the narrative to one another (Radin, 2006). Consequently, more people can participate in meaningful ways constituting the gathering of social capital within the population (Radin, 2006). Power in numbers is achieved through representation and new concepts of legitimacy via lived experience.

Patients are empowered in the increasingly market based healthcare systems, patients can, at times, choose to take their bodies and their business elsewhere. Communication within these settings then begins to mirror the "customer service" orientation of other business models (Radin 2006). It no longer suffices for patients to simply be cured, healed, or treated. There is an expectation of an experience within those activities (Ballard & Elston, 2005). This again signals a departure of medicine from physician centered and controlled to a more equitable system of expression of power. Clarke (2003) suggests that in this era of biomedicalization, healthcare is

viewed as multisite and multidimensional. Patients can become key actors who influence the institution that provides them care as they receive necessary services. This new model then becomes not top-down or bottom-up but instead an inside out transformation that is based on informational reorganization.

Yet not all patients are empowered in this shift. Radin (2006) argues that consumer oriented healthcare serves those that seek information and disadvantages those that rely exclusively on their doctor. The patients that invest the time and effort to go online are rewarded while those that either choose not to or do not have the skills/resources to seek online information are left behind. Consequently, agency is active in both the role of the patient to seek and the role of the provider to adapt communication styles.

Justification

Although one might argue that doctors and other providers no longer exercise the significant power they have had in the past, patients are also not in complete control. Patients/advocates can express concern with the system and challenge it but at the end of the day continue to rely on physicians. Therefore there remains a hesitant dependence on the part of the patients and caregivers characterized by a rejection of the doctors' invalidation of the embodied experience yet a continued reliance on healthcare providers for treatment. There is little question that providers and consumers must interact but the concern is how this interaction informs the action of caregivers in the context of the disease experience.

Additional concerns result when there exists a high degree of ambiguity and uncertainty. Under these conditions populations of patients or caregivers are especially vulnerable. This can make ESGs very appealing as ways to cope with the stress of clinical interactions and

perceptions of lack of support. The online space allows those that rely on healthcare to express their needs while not engaging directly in conflict with providers.

Caregivers of children with EoE can experience elevated levels of anxiety and uncertainty. The diagnosis and treatment processes can greatly impact the child as well as the family. High emotional, physical, financial, and time investments must be managed. Patients and their families may be far apart because the condition is not very commonly diagnosed. In addition, caring for a child with any chronic illness but especially one with an illness that is not very well understood can be very frustrating. ESGs can be one outlet for coping. While any family caring for a child with chronic illness requires support, the needs of this population make its study in this context particularly salient.

An understanding of the lack of needs met in clinical settings addressed in these groups could potentially inform clinical initiatives to create more patient centered communication. Such moves would benefit patients as well as doctors by granting patients a sense of control and satisfaction while doctors could improve essential outcomes. Therefore the ESG should be regarded not only as an alternative but a reflection of the needs of certain populations and their encounters with the healthcare system. This study examines the central themes and patterns within ESGs for parents of children with EoE and will discuss potential implications for clinicians and parents.

Data and Methods

Study Site

Data was gathered from an electronic support group hosted on a social networking site. Participation is public and all content can be accessed without becoming a member or the group or becoming visible to members. Users can communicate by posting on a main page. Group

members can also chat with one another in private exchanges. This function was not utilized for the purposes of this study. Instead exchanges made in public postings are emphasized. The group currently has 781 members and can be accessed through the American Partnership for Eosinophilic Disorders (APFED) resources page. The APFED site is in the top 30 results when "eosinophilic esophagitis" is entered into the Google search engine. It is also the largest advocacy group for eosinophilic disorders in the country.

Observation

Due to the public nature of the group page, it was not essential for the researcher to disclose their intention to observe the group. As Eysenbach & Till (2001) note, if subscription is required to an online group, the postings should be considered protected and therefore to a certain extent private. However, this is not the case in the context of the group that was observed for the purposes of this study. While this does constitute "lurking", it is acceptable because the content of the page can be considered public. Moreover, due to the electronic nature of the group and the large membership it was not possible to obtain informed consent from participants. It is also possible that disclosure of researcher presence could influence communication in the group. Therefore, it was ideal to observe the group unannounced to other participants.

Six months of previous posting were utilized. The time frame was chosen based on periods of high activity, more specifically, the months prior to and following the APFED gathering and the winter holidays. This retrospective data collection will hopefully address Barker's (2008) concern about obtaining "natural" data while at the same time respecting the assumed privacy of the posting space.

Data Collection

As stated previously, data was collected from the main posting page within the group. The running text of these interactions, including initial postings and responses, was copied exactly from the site into a word document. For the purposes of this study, any images or video was not collected to protect the privacy of participants. The text collected was recoded into independent subject ID numbers so as to track patterns in the interaction while protecting the identity of the participants. There were 50 active, posting members in the text for the six months that the data was collected. These users posted 186 messages.

Participation

The group at the time of the study had 781 members. There is a moderator that hosts the group and has administrative power of the site. All communication is conducted in English. Parent communication about their children's condition constitutes approximately 95% of communication. However, there are exchanges concerning adult EoE patients. It is described as "A place for those diagnosed with or effected by EE (eosinophilic esophagitis)." It is listed under the category of "Common Interest-Health and Wellness".

Data Analysis

After the exchange was re-coded, analysis began. The text was assessed using thematic analysis. This was modeled heavily on Strauss & Corbin's (1990) notion of inductive coding. This essentially posits that for effective thematic analysis the data should be grouped based on observable patterns within that set. The data itself should informs the categories as opposed to a more deductive approach involving imposition of external categories upon the data. This is described as "open coding" or the process of "breaking down, examining, comparing, conceptualizing, and categorizing data" in that order (61). This involved several original readings of the text and subsequent coding based on impressions of the content and interactional patterns

of the exchange. The exchanges (either single posting or string of posts) were coded into groups based on frequency and intensity within the text of the exchange. Therefore the subject matter and the type of exchange (request for information, emotional support, etc.) is noted.

Axial coding, further elaborated by Strauss & Corbin (1990), was performed after open coding was completed. This involved a reassembly of the categories established in order to begin to identify relationships between the concepts outlined. This allows for consideration of the context and conditions in which certain themes are apparent. This is based on the Paradigm Model detailed by the authors. This is described as linking subcategories to a higher concept in an order of relationships. The simplified model is depicted below (99):

(A) Causal conditions → (B) Phenomena → (C) Context → (D) Intervening Conditions→ (E) Action/Interaction Strategies → (F) Consequences

Therefore the categories were reexamined in their larger context of the text and other expressed concepts apparent in the interaction. Process was then identified through analysis of contingencies and changing action within the text. This allowed for the potential identification of larger "master themes" or macro concepts that seem to run through the entirety of the online interaction. Full analysis of the online text lends itself especially well to this analysis strategy as interactions can be repeatedly analyzed in their original form before formal categories are established.

In this study, the text was reviewed extensively before categories were formed. After multiple readings, the researcher identified content themes within the text. Sub-themes identified in the larger, more general content themes were identified. After the content had been coded into the themes identified, the type of exchange was identified. Finally, the content themes were

grouped and assessed by frequency, duration (number of responses), and intensity or emotional tone.

This analysis aimed to answer the following research questions:

RQ1: What are the primary themes in content within the interaction of members of the ESG?

    a. How do the content themes address the disease experience and social support?

    b. How do the content themes address the disease experience and interaction with the healthcare system and medical providers?

RQ2: What patterns of interaction are observable in the group?

    a. How are these patterns distinct from other support group formats?

    b. How is power managed in group communication?

Results

After performing a textual analysis, four primary themes were identified within the content of the text. These included good doctors, bad doctors, medical advice, and practical support. These themes were not seen as completely distinct but overlapped in significant ways. Frequency of themes, number or responses and position as original posting or response was noted. These domains are described below and summarized in Table1. Long, extensive quotes were not used in order to protect the privacy of users.

Content Themes

Good Doctors

The "good doctor" theme was characterized by descriptions of positive clinical experiences and beneficial interactions with medical professionals. Doctors were largely described in this theme area as supportive, however there was less elaboration than in other domains. In addition, good clinical experience was the least common theme both in responses

and in original positing. There were no postings that originated with a discussion of good

doctors. Instead, it always overlapped with the bad doctor theme. Thus postings were often made

by users that characterized themselves as parents of newly diagnosed children who needed

information about where to seek care or in response to postings that expressed frustration about

current care.

As a result the good doctor was an alternative to the highly emotionally charged poor

care. The quality care was in contrast to its pair theme in the lack of emotional expression. The

most expressive language that was used was "great" and "wonderful"; and these were used only

once each. However, users did describe their own action in pursuing good doctors. One reported

that they traveled several hundred miles to see a certain doctor. Another posted that their family

"fired [the other hospital] to go to him [(the other doctor)]". The doctors' own actions were also

described by users. A parent praised a team of specialists, writing, "they [(the doctors)] say and

do". Another noted, "they [(the doctors)] work […] regarding ALL your needs".

This worked to frame the doctor's communication as patient centered. They worked to

establish personal ties with the patients. Doctors in this group also recognized the multiplicity of

families' needs beyond simply providing physical care. Finally, these doctors also demonstrated

follow-through and a high level of communication with families regarding care. The good

doctors were then connected to good experiences and positive results. The postings were short,

with a maximum length of two lines, and were minimally descriptive. No specific encounters

were elaborated.

Bad Doctors

The "bad doctor" theme was in many ways the opposite of the good doctor theme. It

concerned negative clinical experiences and health professionals in this domain were

characterized as incompetent, insensitive, and unresponsive. While this was the second least common theme overall, it was most popular for responses. Thus original postings received relatively numerous comments and were elaborated extensively. While the bad doctor theme accounted for all the good doctor postings, the most common overlapping theme with the poor clinical experience discussions was medical advice.

In the bad doctor postings, strong language was very common and postings were emotionally charged. The relationship was at times described with the word "hate". In another posting, one user described filing a complaint against a team of physicians. Another family went beyond the complaint against the relationship and stated that the doctors themselves kept their child from having the correct diagnosis. A user later posted that all she learned from her appointment was to get a new doctor. Exclamation points were common and postings continued for as long as ten lines.

Users also explicitly described their emotional states. For example, one user posted that her experience with a clinician was "unbelievably frustrating". Other users also very clearly described the negative experiences with clinicians. One stated "ours was a disaster". Another recalled that "no one [(the doctors)] would listen to us". Finally, another admitted "I don't trust so much [what the doctors said]". Therefore the doctor was implicated in the bad experience and in bad results.

This characterized the clinicians as poor communicators in several different ways. First, they were generally hard to communicate with. The context of the posting made this claim suggested that there was no personal connection or concern on the part of the doctor for the family. In addition, doctors in this category did not appear to honor the experiences and the feelings of parents. One caregiver noted that the doctors would not listen to her concern about

her child and the result was the child self-denying food for an extended period of time. This was connected to another aspect of the encounter that was described under the bad doctor theme: lack of trust. Part of this is that doctors did not appear to be explaining why certain advice or treatment was given. For example, one parent exclaimed, "[I] can't imagine why [the doctors] would want to try that!" This also speaks to the general quality of relationship building that clinicians were engaging in.

Users that posted in this category appeared to be both new parents and veterans of the site. However, parents were highly aligned regardless of their status. Therefore "othering" was very common. Users positioned themselves against doctors. This was evident as users posted comments concerning that it was not appropriate what "they" (doctors) were doing and it was not fair to "us" (parents). There was never an instance of users challenging other parents' posts about doctors treating parents/patients poorly.

Medical Advice

Medical advice was distinct from other types of advice in the text (practical) in that it concerned clinical treatment and interpretation of medical tests. It generally concerned potential treatment options for children and interpretation of test results. This was the second most common theme in general and elicited the second most responses. It also overlapped the most with the bad doctor theme.

Users that posted medical advice were clearly veterans to the caregiver role. Postings were framed as presenting knowledge for advocacy for the patients. This was done most in response to queries of new caregivers. One caregiver responded to another's question about a particular treatment with "[the drug] is pretty safe but can have a few side effects". She elaborated that she would worry about a few particular side effects with a high dose. Never did

this parent identify herself as a medical care provider. Another user interpreted a poster's test results, claiming that the child in question probably had acid reflux instead of EoE. Again, this caregiver did not identify as a medical provider.

Users did not ever challenge one another's medical advice postings but did challenge information that was attributed to doctors. In response to one user listing the advice from a recent doctor's appointment, a parent indicated that there was no way that the treatment would work and they needed to find an alternative. Many other postings followed this pattern.

The advice was not as passionate or emotional as the bad doctor posting but was very concrete and absolute. The language used was highly medical and discussed extensively test results, prognosis, symptoms, and co-morbid conditions. Often, this followed another user's posting that served as solicitation of a second opinion. One user would disclose symptoms, testing, current treatment, and the previous doctor's recommendations. This was then interpreted by other users. This mirrored a medical encounter in which a description of the issue is given by a caregiver followed by a prognosis and treatment given by a provider.

Practical Support

Practical support concerns advice and empathy given through the role of the parent and caregiver. This centered around everything from recipes, to supplies, to coping. It was the most common general theme but elicited the second least responses. There were also only two instances of overlap: once with bad doctors and once with medical advice. Thus it was often the original post and was isolated to that original post and its concern.

Again, these postings situated the caregiver in a traditional care role. Empathy was commonly expressed in simple messages of "we're here for you" or "just know that you're not alone". However, there was minimal intensity associated with these postings. The most

passionate posting involved getting support on "fighting" for homecare but the majority of concerns were less emotionally charged. The first or second response often appeared sufficient for the original positing and were not highly elaborated.

Table 1. Content Themes

Theme	Original Posts	Responses	Overlap common	Tone	Characterization of user	Examples
Good Doctor	4	15	Overlaps only with the bad doctor theme	Not passionate, reactionary or question about good doctors	New user looking for medical support; frustrated user looking for different care	"doctors keep working with you on a personal level"; "would recommend […] to anyone"; "great GI department"; "would you recommend […]?"; "[…] is wonderful"
Bad Doctor	7	54	Most commonly overlaps with medical advice but also overlaps at least once with other categories	Angry, highly emotionally charged	Frustrated parent; knowledgeable enough to challenge doctor	"can't imagine why [the doctors] would want to try that"; "hated them! (doctors)"; "now filing a complaint (against doctors)"; "it took him stopping eating completely for drs. to take it seriously"; summary: lesson 1-don't listen to doctors, lesson 2-get new doctor; "our doctor is really hard to talk to"
Medical Advice	11	49	Most commonly overlaps with bad doctor theme but overlaps once with practical support theme as well	Passionate but absolute, concrete	Patient advocate; highly expert in medical knowledge and experience	"if his numbers are high, then there is no way you can start adding foods back in"; "she's obviously eating something that's triggering all of this"; "my understanding is the patch test is the best way to figure out allergens for people with E.E."
Practical Support	19	38	Very little overlap; only overlaps once with bad doctor theme and medical advice once each	Empathy	Traditional caregiver role	"This would be a great way to get more awareness for EE"; "Glad to see a FB page for this"; "any good recipes out there?"; "trying to fight for homecare for my son, has anyone else has this problem?"

Patterns of Interaction

There were 50 total users who posted content in the time period studied. Four users were male and 46 were female. These users generated 36 original postings and 150 total responses to the original posts. Therefore the average number of posts per user was nearly four. However, there was a range of levels of activity from one post to 12. The distribution of total number of responses showed that there were two groups: high frequency users and low frequency users. There were very few members that posted around four to five times. There were, in fact, many single time posters.

The average number of responses to a post was approximately four. The longest string from a single original post consisted of 23 responses and one initial posting. Considering, that the average number of posts per user was only around four, it is worth noting that this response string involved just three users (see Figure1). Yet, this was a common trend throughout the text. The most number of users contributing on one thread from a posting was nine, with the second most involving five users (see Figure 2). The large majority of threads involved just two to three users. Therefore while the group hosted many users, communication appeared to be isolated to smaller dyads or triads.

Figure 1. Number of Responses per Posting

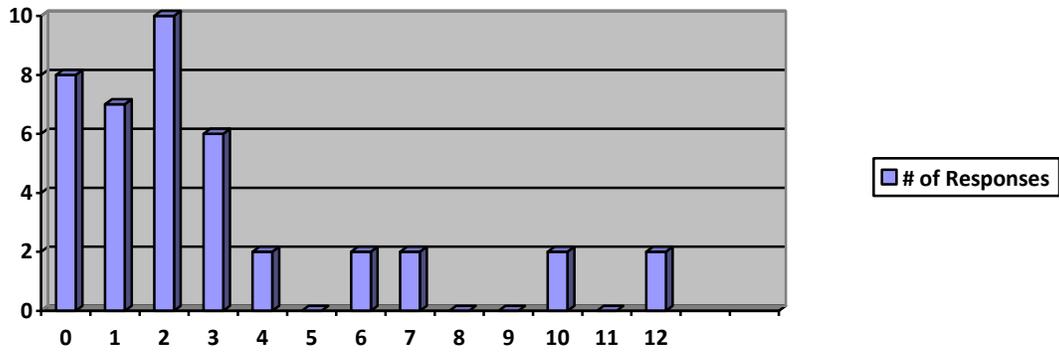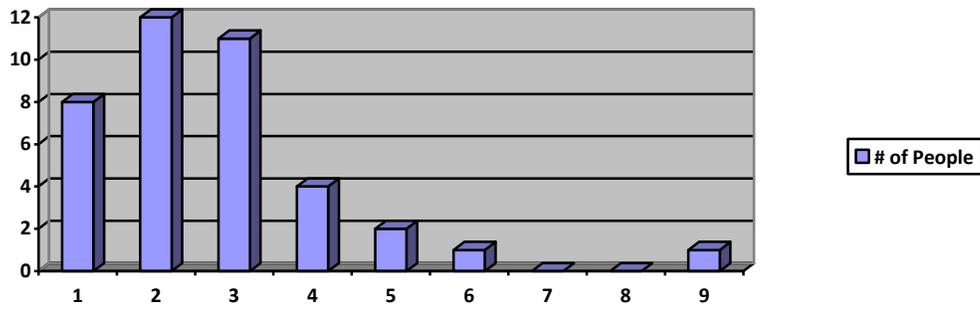Note: Outlier at 23 responses not shown

Figure 2. Number of People Posting in Response to Original Posts

Within these communication groups, it is quite striking to note the lack of any open conflict within the group. There was not one observed instance of contradicting or correcting any other user personally. Only information posted as recommendations by clinicians, and openly identified as so, was challenged. However, no personal attacks on other users were ever made. This is quite different from some other group sites in which open conflict is quite common.

The general attitudes expressed in the group towards other users were of total support. Postings included "you're in our hopes and prayers", "we are all thinking about you", "welcome to the EE family", etc… Even when topics that tend to be highly contested in the field from the medical side were discussed, disagreement never occurred. Users often confirmed the shared experiences and difficulties of caring for a child with EoE.

This was seen in conjunction with a high level of sharing on the part of users. Disclosure was highly personal despite the site being entirely public and accessible to non-members. Users would post their child's test results, symptoms, and diets on a regular basis. More intimate information was also posted concerning personal feelings and concerns. This was often met with reciprocated disclosure as one might expect in a well functioning support group.

In addition, new users were not screened. Anyone could join the group and immediately begin posting. However, there were many more members than active participants in the time that the group was observed. As stated before, there were 50 total users in the text but the site reports 781 members. That is just over 6% of the group. This means that many more people were potentially monitoring the site for content than those who were actively posting. In addition, the site can be accessed as open content online. Given the level of access that many others have, the intensity of disclosure is important to comment on.

It is also notable that there was no clear moderation of posting. This meant that content was relatively unregulated and unstructured. No one posted explicit discussion questions but instead posting was based largely on personal concern for caregivers and this potentially led to broader content in the threads. The format of the networking site means that there is no clear end to threads. Posters could continue posting on an original as long as they desired. It appeared that some threads ceased when the issue discussed in the original posting was resolved but others were simply abandoned or even never responded to. There was no prompting to "complete" these threads.

Discussion

Content Themes

Previous research has described functions of ESGs but has been limited in a description of potential relation of the content to clinical experiences. ESGs are becoming ever more popular and as such should be assessed as sites for navigation of medical experiences. Mickelson (1997) observes characteristics of ESG users vs. characteristics of participants in a traditional support group. Wright and Bell (2003) theorize that in fact the experience within an ESG is quite distinct from that of traditional support groups in the type of networks they create. Radin (2006) argues that this is a positive modern shift away from more paternalistic emphasis in care environments. She connects this back to larger trends in health care. This analysis looks to extend these arguments by describing how ESGs are used in order to address interactions with doctors.

In review of the text it is clear that content is grouped in distinct ways. There is a high degree of overlap between the first three themes: good doctor, bad doctor, and medical advice. However, practical advice appears in relative isolation. This suggests that good doctor, bad doctor, and medical advice represent a distinct category from practical advice.

On one hand, practical advice involved one party: the parent/caregiver. Parents therefore addressed other users in their roles as parents. The combination of themes involved multiple parties: the parent/caregiver, the patient, and the clinician. When a complaint was raised about a clinician, parents could not challenge the medical professional from their roles as parents. Doctors and nurses still have medical authority in such a situation. However, once the parent assumed the role of a EoE expert, they could position themselves in such as way so as to confront the doctor about any concerns through the doctor's own channels: medical knowledge.

In the text, medical advice was often overlapping with the bad doctor theme. It appeared to be insufficient to simply state that the doctor or nurse or therapist was wrong but that parents felt the need to present evidence contrary to clinician's assertions. While the medical advice was instrumental in itself, it also served the function of implicitly challenging medical professionals. This allows parent to go beyond their roles as parents which have typically been centered around being compliant with medical advice from traditional health providers to be in control of the interaction within this specific setting to a certain degree.

This could be largely a function of the condition itself. Various specialty centers around the country have different standards of care and treatment. In traditional support groups, due to geographic grouping, participants would most likely be seeing the same treatment programs. However, in the electronic support groups geographic barriers are removed and parents from all over the country can communicate. Therefore parents communicating in this group often have different treatment plans that work in different ways for them. When one parent describes something that is working for their child that does not align with another family's care, this can cause issues when one is labeled as wrong. It is simply such a new condition that there is no single academically/medically justified answer.

Yet, frustration with care providers was not only addressed with postings of academic and medical character, but also carried a highly emotional weight. This was seen in clear contrast to the postings made in the other three theme areas. Parents used intense language to describe poor relationships and described further action in several instances to move forward with formal complaints or action against providers. This suggests that these interactions were quite meaningful to parents and that when they went poorly it was highly impactful to parents.

This could be due to the role that parents play as intermediaries between clinicians and their ill children. Parents are in the unique position of being gatekeepers of their child's health while having a heavy reliance on a third party for information. Thus, they must make the decisions without necessarily have a high level of medical expertise. They are highly invested as parents and this leads to intense emotions when the highly dependent relationship with the physician goes poorly. This is distinct from when parents deal with practical advice where they operate simply in their roles as caregivers and are in control to a much higher degree. Therefore this supports Barker's (2008) notion of hesitant dependency in which patients/caregivers desire the agency to be in control of their health but must yield in many ways to the expertise of clinicians.

This suggests that the while the content of the interaction between parents and clinicians is very important that the character of the interaction can be just as significant if not more so. The negative clinical experiences were often described as involving doctors that did not listen and did not honor the experiences of the parents. These doctors did not engage in patient centered communication and the consequences stayed with parents in an intense and long lasting way into the support group.

Yet there were a small number of examples of clinicians who were able to achieve a sort connection with their patients' caregivers to the extent that they were praised by users. While good doctors were not often discussed, when they were it was in a highly complementary manner. These characterizations suggested that the clinicians did engage in patient centered communication by commending their ability to connect on a personal level.

Thus there appeared a sort of polarization of good and bad doctors. This was observed within the same message string. A bad doctor was countered with a good doctor. As stated before, these characterizations were clear and strong. In addition good results were tied to good doctors and bad results were tied to bad doctors. Outcomes are a primary concern of both caregivers and clinicians and therefore the connection to characterization of clinical staff should be emphasized.

However, good doctors were not characterized by their treatment types, tests, etc… but via their interpersonal communication behaviors. These included respecting the experiences of parents and caregivers as opposed to being solely focused on the medical treatment. In addition, users described good doctors in their follow-through and clarity of explanation. Finally, they were able to consider the whole experience of the family and address various needs.This built trust and exemplifies patient centered communication. On the other hand, bad doctors were talked about in terms of their inability to communicate and listen. They were described as not considering the assessment and understanding of the parents as well as failing to build trust in the relationship.

It is important then to acknowledge the crucial roles that doctors play in coloring the experience of caregivers and patient. This is not exclusively done via medical knowledge conveyed but in the quality of the communication exchange. The ESG provides a space for

parents to reclaim ownership over the medical interaction by engaging in a medical discussion. However, there continues to be tension evident in the description by parents. Frustration with these providers stems largely from the role that parents must take on.

While it could potentially be dangerous for parents take on the roles to give medical advice, more attention should be paid to what this analysis suggests about the clinical interaction. Parents/caregivers utilize the ESG as a space to talk about what goes wrong in these interactions and navigate the experience. Given the unique characteristics of ESG users identified in previous research, this population is more likely to report having a lack of social support. As seen in the content of the ESG, when clinical experiences go wrong, there is lingering, residual frustration from parents. Therefore, while all interactions should move toward PCC, parents without less social support should be a population of more emphasis.

Interaction Patterns

The observations made of this ESG support the work of previous researchers in characterizing ESGs as spaces for weak tie networks to develop as spaces for support and information exchange (Wright & Bell, 2003). This work more broadly reflects Wright and Bell's argument that in their very nature ESGs will be distinct from traditional support groups. These differences are grounded on observations of "communicative clustering" and lack of explicit moderation.

First, within the text there clear patterns in the distribution of groupings for users around a single post. While the group itself was quite large as was the participating group in the time frame analyzed, only two to three users would post on a single topic thread. Thus a limited number of members would be actively participating at any time. The small dyads or triads posting on one original comment would were isolated conversations. This would be distinct from

a traditional support group in which members are sharing a space and are encouraged to participate and listen to others. In the ESG users can either read without posting as "invisible" participants or can ignore whatever posting they like without being chastised for doing so.

This could happen for several reasons. First, the original post could serve as a sort of "flagging" device. It indicates the topic of discussion and if a potential user does not identify with the first posting they may move on. Thereby members can make decisions about what they would like to read, to post on, or create. There is no need to be present and available for all the members' posting as might be true of group communication in traditional groups. Users then can engage in selective participation.

More people can then watch over the conversation without indicating this to the rest of the group. The mini-conversations may in fact have all 781 group members following even though only two to three individuals are actively posting. Yet it would be highly unlikely that the entire group is involved in every single interaction as observers. It would take a high degree of commitment and time to read through every posting. This again makes the ESG distinct from the traditional support group in which members indicate their presence as listeners and observers through their presence.

While this topical flagging could be occurring to alert users to the content of the interaction, much of the response trend could be dependent on the time that the posting was made. On the site the content is organized by the date and time of the original posting. Later postings will move further down the page and eventually far enough away from the most current to the point that it is only accessible via a history link. Therefore some of the response clustering could be simply dependent on when the original post was made and when the potential poster decided to check the page. Again, a comparison can be made here with traditional support

groups. In the latter, there is a high degree temporal and geographic dependence. Group

members physically share a space at a designated time. Members share and that information

cannot be accessed outside of the space in which the group met. However, in ESGs members can

post and leave the site. There is not the need for immediate response or shared physical space.

However, users can go back into a history of shared information to access what they find

valuable. Yet, they may still be somewhat constrained temporally in this format of

chronologically listing postings.

Another important note in a comparison of ESGs and traditional support groups is the

lack of explicit moderation. There was not an identified leader of the discussions and no obvious

attempts were made to control other users postings by any single group member. In addition,

there was never prompting to share from "silent" members. Those that did not actively

participate by posting were not asked if they wanted to contribute. This is distinct from the

implicit pressures to contribute in the traditional support group where the small group size and

shared physical space makes not participating relatively difficult. The ESG also removes the

constraints that often fall to the moderator of traditional groups of turn-taking and space sharing.

There is an informal understanding of how to use the site as no instructions are posted. This

lowers the need for negotiation and makes sharing more flexible.

These constraints could also have an effect on the lack of conflict observed in the group.

There is again not the need to compete over communicative space when the posting potential is

extensive. In addition, one might conclude that the group is doing quite well in performing the

function of being a supportive communication space. The discussions all have the underlying

concern of a child's health and welfare. The parents and caregivers share this interest and openly

support others in this pursuit and the difficulties that come with coping when this goal is not so

easily reached. This represents a certain camaraderie among the users who all share the role of caretakers for their sick children. The group studied represents a positive use of ESGs for social support.

Practical Implications

While this positive dimension was observed within the group, there are certain aspects of the ESG that point to areas for improvement. First, communication concerning clinical interactions suggests that it is extremely important in defining the experience of care for families and caregivers. This supports previous research on other populations (Epstein & Street, 2007; Krumholz & Herrin, 2000). One of the implications for clinicians is the continued pursuit of engaging in PCC. This can enhance the relationship and prevent the frustrating experience for parents of being frustrated with their care providers. The reward for quality communication is positive characterization and long lasting positive framing of the experience.

Providers might also look to explore fully public sites for support and communication such as the ESG studied. This would be ethical given the nature of the content as public. Such use would help doctors and other clinicians to identify lapses in their own roles in the creation of a clinical experience. It could also help clinicians to identify misinformation that is disseminated in disease specific circles. This could aid in supporting a more compliant population and thereby support a healthier group of ill children. Finally, accessing ESGs could help providers to identify the needs of the caregivers that may not come up in medical appointments and face-to-face visits. This method of monitoring ESGs is far less intrusive than sitting in on a traditional support group. It allows the medical professional to remain invisible and therefore is less likely to change the perceived conditions of posting to potential users.

More ESGs should also be made available for parents. This could include healthcare institutions sponsoring groups or users creating their own. As stated before, the ESG allows parents to reclaim some power in their fragile role and to support each others in their difficult position as parents of ill children, without many answers. It also supports more flexible communication and consumption of information than the traditional format. Users are not pressured to contribute, caregivers are able to confirm each other as experiencing something real and challenging, and there are decreased temporal and geographic barriers. While Mickleson (1997) notes that ESG users are different from traditional support group participants in several ways, one of her observations is that the ESG users perceive themselves to have less social support. They are more isolated and have less resources and are therefore more vulnerable. This group then should be supported with more social resources available online.

These should be publicized in clinical encounters as coping resources. Users with less social support are less likely to have friends or family available to refer them to potential tools for dealing with the stresses and concerns of caring for a child with a major illness. This should be especially true to families or parents more specifically that the clinician deems high risk for being socially isolated. Using this casual referral strategy, providers could normalize seeking support and could help build trust in their own relationship with the family. Thus instrumental support as well as emotional support could be provided.

If this was not enough, clinicians should also be motivated by these findings to pursue better relationships with patients and families because the parents or caregivers that do not deem the interaction to be satisfactory could be communicating openly and strongly about negative feelings for the doctor online. As a result, a negative relationship with one parent could lead to a negative view by many if the caregiver in question is advertising the quality of the care online.

These findings suggest that given the emotional intensity consequent to poor experiences, users may be highly motivated to share their view of providers in ESGs. Therefore, clinicians should be aware of the potential ramifications of poorly communicating with just one family.

On the other hand, these findings also suggest that good doctors will be rewarded via similar mechanisms. Patients participate in their own ESG referral networks that point others in the direction of providers that they have had positive experiences with. As a result, beyond the welfare of the individual families, clinical communication can have very real consequences for the doctor alone.

Future Research

In order to better describe this group and the dynamics within it, a useful study would involve in depth interviews with users. This would explore reasons for use, consequences of use, perceptions of other users, and perceptions of the clinical relationships. This would be important in speaking to the self-concept of users and the perceived benefits/consequences to participating in an ESG. This could also be useful in determining how this population might be different than other caregivers that did not use ESGs.

While these findings only represent one specific condition, these concepts should be explored in additional disease populations. The relative newness of the condition does appear to load onto certain dynamics within the group, especially in conflict over medical advice. However, the general concept of using medical advice in order to challenge the medical provider should be observable beyond this population as in ESGs. In addition, expression of frustration with clinical providers as related to communication events should be explored further. The examples within this text suggest that negative experiences can be very impactful and when ESGs are used this expression is easily shared.

Future research should also look at ESG use and passive use vs. active use. Observations made of this ESG showed that communication was clustered where only a few users were participating in active communication around a post at one time. In addition, only about 6% of total group members were posting in a six month period. This suggests low active use but it is possible that other members are lurking and receiving the information in the posting without contributing. While only open participation can be viewed and observed as a text, it would be valuable to explore attitudes and use patterns by non-posting members.

Conclusion

Research regarding ESG use is crucial as medicine moves out of the exam room into a larger experience that is constantly being negotiated. Patients and caregivers must determine how to engage with providers with a sense of autonomy while at the same time acknowledge their dependence on medical providers. ESGs are a space for patients and caregivers to form a collective and support one another's concept of their experiences with illness. They are then extremely important in understanding and addressing the disease experience.

As a researcher, I have worked with this population of patients and families for two years. I have seen many of the frustrations, complications, and stress that families as a whole must deal with. I have also had the fortune of working with a very strong team of providers. From my observation, their use of PCC has dramatically improved the experiences of many families. However, in working with these families I heard various stories of difficulties with other programs. It appeared that some programs were offering a great deal of support beyond treatment and forming relationships with families while others were not fully recognizing this component of the disease experience and this was greatly impacting families. This led me to investigate this population in the ESG.

Thus, not only are these findings relevant for my current professional role, but I hope that I can employ them as a future clinician. As a communication and sociology student, I have long believed in the value of humanist orientations in a variety of settings. I feel that this is particularly important in medicine. It is a highly emotionally charged and high stakes science that needs to consider the person and the body. I hope to be the type of doctor that can treat patients as people and effectively communicate that value to them. This research supports the necessity of such an orientation and practice.

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