How a Facebook Group Creates Feelings of Belonging

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INTRODUCTION

This research will explore the rhetoric used about one specific Facebook user group and its members, by the members of the group, to find how that rhetoric affects members' feelings of belonging and group identity.

Facebook is the most popular Social Networking Site (SNS) with over a billion users worldwide. It is available in almost every country, to anyone with an Internet connection. To become part of Facebook, a series of decisions must be made by every prospective user. Each user must create a public profile, an online face with which to interact with the online world. The user must choose how to identify herself or himself, and then may choose to join one of thousands of existing Facebook user groups.

Facebook itself is used as a channel of communication on an individual's public profile page, but it is also a facilitator for self-inclusion and self-identification through these user groups. These groups are formed for diverse reasons, but all are inclusive based on some stated criteria with which the new member must first agree. The group studied here is one formed by people affected by a rare type of disorder, orphan diseases known collectively as Fatty Oxidation Disorders (FODs). I am a carrier of one such FOD, and the mother of a child with an FOD. I am also a member of the Facebook user group, FODSupport, which will be studied here.

Facebook user groups are populated by members who identify with the group stated aims or with its inclusion criteria. In closed groups, administrators review each request to join the group, and accept or reject the request in order to maintain a group identity. Facebook users

who self-identify as disabled by an FOD seek out, or are guided to by medical professionals, the Facebook user group FODSupport. This group is associated with FODSupport.org, a web site which distributes medical information and promotes research into FODs. FODSupport.org is available to the general public, while the Facebook group requires administrative approval to join.

Since FODSupport.org publishes research papers, project updates and other hard medical data, it is not necessary for the FODSupport Facebook group to be a comprehensive source of medical information. The utility of the Facebook group can thus be separated from the utility of the web site, and it becomes possible to see the Facebook group as a unique artifact of study.

The Facebook group has become the social hub of the FOD online community. Those in the group are forced together by an unwanted, shared rare diagnosis. No one wants to belong to the group, yet members actively work to create and maintain a sense of belonging, for the benefit of the group as a whole, for new members, and for their personal well-being. For them, it is essential to have a community of others with which to share the everyday experience of living with the constraints of an FOD. Because these disorders are so rare, that interaction must occur online

Many of the published research findings indicate that the amount of time spent on Facebook, or the number of Facebook friends, cannot adequately measure the effect of Facebook on a user's self-image, satisfaction, or state of depression (Ashwini et al). It appears that the quality of the individual interactions on Facebook is a better indicator of the effect on a user.

The rhetoric used in the Facebook group frames the relationship of its members to the larger society. Words are used to highlight the differences between typical parents and FOD parents. Comparisons are often made between 'us' and 'them' when asking for advice from group members, when a member has a question for which the typical parent response would be useless for an FOD parent. Another use of the 'us' and 'them' comparison is when discussing family dynamics, and these conversations become more frequent and emotional around holidays.

The emotional support given by the group is significant, because according to group members, it is only through the group that they receive understanding and realistic suggestions for improvement. The common phrase used is, to "get" the FOD family life. Outsiders do not "get" it.

Hospitals, school administrators and teachers are definitely part of the 'them' opposing the 'us' of the group. When the school year begins, the conflict between the schools and the FOD parents becomes a rhetorical battleground. Language is carefully crafted in Individualized Education Plans (IEP) which every child needing special accommodations must apply for, and which far too many school districts work hard to deny. The wording of a protocol letter to be presented to an emergency room during a medical crisis is worked out within the group, and revisited after a crisis to determine whether the language used forced the actions needed while at the hospital.

Rhetoric is managed as part of the disease, because with rare diseases it is through the word choices alone that information is available to help these families. People dealing with an FOD in

the family can never assume that the teachers, school administrators, emergency room doctors or anesthesiologists they contact will have any information about that specific disease. Thus, word choices are often discussed in the FODSupport Facebook group to ensure the necessary outcome in specific circumstances.

Because managing the language used about the FOD is critical to surviving with the disease, members of FODSupport Facebook group are perhaps more specific than others about their word choices in general conversation. When posting about their relationship to the group as a whole or to other members, it is not uncommon to hear that the group has been a lifesaver, or that the group has helped avoid a medical crisis. Synonyms for gratitude abound. Each time these are posted, it cements the bonds between group members a little bit more solidly. It is the word choices made by group members in all these conversations which make up the text of this research.

This paper will explore the language used by members of the FOD group, when discussing the group itself and when describing the group to new members, as a means of understanding the method by which the sense of belonging is fostered within the group. The working hypothesis is that the group members use language that distinctly and definitely creates a sense of membership and belonging in a select group.

METHODS

The artifact examined was the posts placed on the Facebook group page, FODSupport... These posts were scanned for comments relating to the group itself, membership, and belonging. The word choices used by group members in these posts were recorded. In addition to recording

the spontaneous references, several messages were posted asking for group members to respond with short descriptions of how the group develops and maintains a sense of belonging and community. An additional request to members asked for specific words which describe what the group means to them.

Limiting the examination to these specific texts allowed for a close look at the importance to members of having a sense of belonging to this group. By eliminating extraneous text, it was possible to find the specific words used by group members to help each other find that same sense of belonging.

THEORETICAL FRAMEWORK

When compared to the society in which they live, families living with an FOD patient are different in many ways. Because the diseases require dietary vigilance and often, durable medical equipment, the everyday lives of FOD families are very different from that of an average family. The FOD family is most often unable to attend many events or participate in organized activities, especially those for children, since FOD children are at high risk from common infections. A child using an implanted feeding tube and pump, for example, will likely not join a soccer team and will miss out on the camaraderie and opportunity for socializing after the games. Parents of these children are out of the loop of typical parental interactions, missing out on everything from PTA meetings to scout camping trips. These parents have very few opportunities to discuss their parenting experiences with anyone else. If we think of the myriad conversations a typical parent has with other parents about things affecting their families, and then think of the limited involvement an FOD parent has with other adults, it is

clear that there is a need for interaction with other FOD parents. FODSupport Facebook group conversations provide that interaction online.

Studies have proved that there is a positive psychological effect from using social networking sites (Oh et al, 2014). For users whose life is different from the norm because of a rare medical condition, these sites offer the best opportunity to interact with others whose lives are similarly affected. This acquisition of social support from others through a social networking site, and in this case, through a Facebook user group, is one of the most important reasons for using social networking.

In the paper, How Does Online Social Networking Enhance Life Satisfaction? The Relationships Among Online Supportive Interaction, Affect, Perceived Social Support, Sense of Community and Life Satisfaction, Hyun Jung Oh, Elif Ozkaya, and Robert LaRose argue that the type of social networking sites people use predicts psychological outcomes of use, more so than a measure of the amount of time spent on social networking sites such as Facebook. Their findings clearly show that the perceived level of support from an interaction, rather than the number of interactions, is what leads to feelings of belonging.

The need to belong is universal. In the paper, Why Do People Use Facebook? Ashwini Nadkarni and Stefan G. Hofman posit that Facebook use is driven by the need to belong as well as the need for self-presentation. For the disabled community, the need to belong is obvious; many do not feel as if they belong in the larger society and seek out the cohesive groups of like people on Facebook to find that sense of belonging. These same people have had to identify as belonging in that group before requesting membership, and thus their self-presentation has

distinguished them as different even before they may find a community of like individuals. For both needs, the belonging and the identification of self, the Facebook group is a source of satisfaction.

Nadkarni and Hofman identify three capabilities of social networking sites. They discuss the ability of Facebook to construct a public profile, the ability to identify other users with whom a connection is shared, and the ability to observe interactions within a group. They find that each of these is essential for a user to achieve satisfying interactions and attain a sense of belonging.

We rely on social support from others. We need to belong. Self-esteem and self-worth are tied to the need to belong, and within the disabled community that self-worth may be difficult to maintain in the face of discrimination or disapproval from others. We are not simply identified as belonging to a group or in a place and left with that identification for life. Belonging, and self-identification, are lifelong processes. Life, especially life with an FOD, involves changes.

Aimee Carillo Rowe discusses this process in Be Longing: Toward a Feminist Politics of Relation. In this work, she suggests that our identification of self is a manifestation of our surroundings and experiences, not a result of a single starting point. Members of the disabled community would agree; whatever the self-identification a parent may have had to start, prior to learning that a child has a metabolic disorder, the self becomes identified as the parent of a disabled child very quickly and all anchors are lost. The parent no longer belongs in the community with healthy children. A re-examination of self, and a new self-image, is necessary. The need for a place to belong, just to be and not have to constantly compare of contrast with the lives of others, drives many to Facebook groups, and ultimately to the FODSupport group.

Belonging is often a matter of privilege. The person may be unaware of this, with the invisibility of such privilege accepted as the norm. But as Rowe says, "That which is most often invisible to groups of privilege is often most visible to those who occupy marginalized viewpoints." Members of the FOD community see themselves as marginalized by their medical disorder, by the attitudes of their peers toward them, and by the overt and institutionalized discrimination shown toward the disable person. They often feel invisible. To these people, belonging, or the search for a place to belong, is a deliberate process, one they are forced to undertake with every change in medical status or within the family. Belonging thus becomes a work in progress, a process, not a destination.

The rhetoric used in the Facebook group constantly reiterates this process with every report of changes in medical status or, too often, report of another death from the disease the group shares. The rhetoric within the group at such times contains the most frequent references to belonging and the value of the group itself. The nature of the shared loss from the disease creates the need to restate the value of the group. In this sense belonging becomes the process of longing for a place to belong even if, as in this case, the place is one which no one wants to be.

Additional work reviewed for this paper includes blog posts written by members of the disabled community at large, not just those with an FOD. These posts were interesting for what they did not contain as much as for what they did include. It is clear that there is a difference between the members of the FOD community and the disabled community at large. Because FODs are so rare, the experience of people dealing with them is not shared with other disabled people. FOD families do not have the kind of public awareness of the disease they face as do families

with breast cancer or childhood leukemia. The FOD families do not meet with the same level of understanding and acceptance as these other groups, and thus the Facebook community becomes even more important to them. All roads it seems, lead to Facebook.

Searches for published research on the utility of Facebook groups for people dealing with disabilities, or rare disorders, resulted in a disappointing lack of information. There is research on the effect of Facebook use on the sense of belonging, on the sense of life satisfaction, and many other psychological outcomes. There is not any research on the value of Facebook groups and their specific value in fostering a sense of belonging in a community of people with a rare disease. These small populations use Facebook in ways that are different from the use described in existing research. More research is needed on how Facebook groups can affect the lives of people living with rare diseases.

Several requests for information on the emotional value of Facebook were placed on the Facebook group, FODSupport. The words most frequently used to describe how group members feel about the group included supportive, understanding, inspirational, educational, connection, and reassuring. Of the thirteen responses to one request, eight included the words, "I am not alone." References to the "us vs. them" problems faced by families dealing with uninformed doctors and school administrators were frequent. Another frequent comment was the ability of the group to "get" the life of an FOD family, as compared to outside friends, neighbors and family who most definitely do not "get" this life.

Within the group, a death occurred while these texts were being observed. In response to the notification of the members' death, group members posted messages of sympathy and urged

the surviving family members to remain part of the group, with comments that often include the words, "belonging" and references to the value of these family members to the group as a whole. Several comments were posted stating the member's anger at yet another death, which initiated conversations about how the group has been involved in the grief process of the survivors of other members who have died. The group takes care of its own.

Recent posts in welcome of a new member as introduced by the group administrator included comments that this group offers the only opportunity to belong to a group that requires no explanation of life with an FOD, another reference to the fact that the ability to "get" the details of such a life is invaluable to group members. While this is an "us vs. them" comment, it should not be taken as being exclusionary for any perceived benefit. It is simply a statement of fact, as experienced by someone who is part of the "us" and thus knows how difficult it is to explain us to "them."

The need to belong to a group that requires no explanation and which welcomes new members without reservation is clear in the language used by these new members. Gratitude and relief are the most frequently described emotions; gratitude that the group welcomed the new member, and relief that the member has finally found a place to be with families who are different in the same way as the new member is different from the outside world.

Most patients and families will never, in daily life, meet another person affected by an FOD. For these families, the disorder is the cause of isolation and separation from society. The Facebook group is often the only opportunity, the one single source, for discussion with other affected

families. On the group pages, why members use the group, and what benefit they gain from using it, are often topics of conversations.

When asked what the most important aspect of the group is to them, members most frequently posted that the group has "Saved my sanity." This is not merely a humorous comment. Many of the group members have had accusations of Munchausen by Proxy disorder, a psychological disorder in which parents choose to make their healthy child appear sick in order to serve the parents emotional needs. These accusations become voided once the child is diagnosed with the FOD, but they leave scars. For these people, finding the group is a validation of their own worth as parents, a negation of the Munchausen accusation. For those members who have not faced an accusation of Munchausen by Proxy, the joke is that sanity is only available within the group, where there is a safe place to vent and complain about the strange combination of medical, legal, and social restrictions that life with an FOD involves.

Words used by group members to describe the group itself are almost always positive. If there is a group member who does not feel positively about the group, he or she has never stated that publicly. Requests to members to share their least favorite aspect of the group resulted in no responses at all. Either there is nothing at all to complain about, or members feel so overwhelmingly positive about the group in general that they are not willing to share any complaint they may have.

The international members of the group are most grateful of all. They may be the only known patient with an FOD in their country, and may have no hope of ever meeting another FOD patient. Their expressions of gratitude are often repeated for the benefit of new members and

are especially poignant. Using translation software makes conversation challenging, especially when working with languages used by small populations such as Danish, but the positive comments and expressions of gratitude are clear.

Group members work to make the group feel like a special place. There are frequent references to "us" and to "FOD Family" as well as specific word choices such as "FOD warriors" to describe young patients. The overwhelmingly positive comments and lack of complaints support the conclusion that the members of this group value it very highly and are willing to work to maintain the group identity. Unlike many other Facebook user groups, there has never been a major disagreement between users. No one has ever left the group over a personal disagreement with another member. The group cooperates in refraining from hate speech or personal attacks.

ANALYSIS

The intent of this paper was originally to analyze the language used by these group members and determine which words were used specifically to support the feeling of belonging. In examining posts to the group page, it became clear that in some way, every one of the group posts supported this sense of belonging. There was not a single thread which did not have messages of support and reminders to remember that the original thread poster was a valued member of the group. Not one thread from a member upset about an "us vs. them" problem with the outside world went unanswered. Almost all responses included messages of support and solidarity, and reminders of how much help the group offers.

The effect of these positive interactions online is to create a strong feeling of community and sense of belonging. Due to the nature of the rare disorder they share, members of the group are highly motivated to maintain cordial relationships with each other. Because there is literally no other place to go, the group maintains supportive behaviors and motivational posts for each other's benefit.

According to belongingness theory, individuals develop and maintain positive social relationships in order to experience a sense of belongingness. Every time a Facebook encounter results in a positive affect, the user reinforces the positive feedback loop from self-image to interaction to satisfaction and belonging. Online social connections, like offline social connections, result in positive outcomes including lower depression and anxiety, and increased subjective well-being (Grieve, et al).

The connections created within the group are critical to the creation of social bonding, especially for those members who are unable to make traditional social connections offline. Those using Facebook for the purpose of friendship and connections are likely to succeed in making connections (Grieve et al) and all indicators are that these Facebook interactions can be an important part of an individual's self-esteem.

CONCLUSION

Members of the Facebook user group FODSupport are able to create and maintain close personal bonds to the group by reinforcing the positive aspects of group interactions through use of positive word choices. Group members are highly motivated to maintain the group

cohesiveness; of the more than one billion Facebook users, there are only one thousand members of the FODSupport group worldwide.

There is published research on the use of Facebook in other situations and for other populations. There does not appear to be any specific research on the subject of rhetoric used by members of a Facebook group to nurture a sense of belonging and group identity. Given the popularity of Facebook conversations, the extent to which they replace face-face conversation, and the isolation of families with FODs, this appears to be a subject which needs further investigation.

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