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An Online Monogenic Diabetes Discussion Group: Supporting Families and Fueling New Research

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Abstract

Many online support groups are available for patients with rare disorders, but scant evidence is available on how effectively such groups provide useful information or valuable psychosocial support to their participants. It is also unclear to what extent physicians and researchers may learn more about these disorders by participating in such groups.

To formally assess the utility of the Kovler Monogenic Diabetes Registry online discussion group for patients and families affected by K_{ATP} channel-related monogenic neonatal diabetes in providing psychosocial and informational support, and in identifying concerns unique to patients with this rare form of diabetes.

We qualitatively analyzed all 1,410 messages from the online group that consisted of 64 participants affected by K_{ATP} channel monogenic diabetes and 11 researchers. We utilized the Social Behavior Support Code to assign each message to a support category and deductive thematic analysis to identify discussion topics addressed by each message.

44% of messages provided/requested informational support, whereas 31.4% of the messages contained psychosocial/emotional support. The most popular topics of postings to the forums were diabetes treatment (503 messages) and neurodevelopmental concerns (472 messages). Participation in the discussion led researchers to modify survey instruments as well as design new studies focusing on specific topics of concern, such as sleep.

We demonstrate that an online support group for a monogenic form of diabetes is an effective informational tool that also provides psychosocial support. Participation by researchers and care providers can inform future research directions and highlight issues of patient concern.

Introduction

Monogenic diabetes constitutes approximately 1–2% of all diabetes in the US [1]. When diabetes is diagnosed within the first 6 months of life, there is invariably a genetic etiology,

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with mutations in the K_{ATP} channel the most common cause of permanent neonatal diabetes [2,3]. K_{ATP} channel closure is one of the key steps in insulin secretion. Diabetes in these patients results from inappropriate activation of mutant channels which fail to close in response to rising plasma glucose and consequent intracellular ATP [4,5]. The majority of patients with K_{ATP} channel-related diabetes can be treated with oral sulfonylureas, permitting insulin secretion through ATP-independent closure of mutated channels [2,3]. This discovery has allowed several hundred patients worldwide to experience improved diabetes control and quality of life allowing easier treatment with pills instead of injected insulin. However, many questions remain about the long-term effectiveness of this treatment, the optimal dosing of the sulfonylurea drugs, and associated extra-pancreatic problems. The rarity of this disease makes it such that many endocrinologists, diabetes educators and primary care physicians are less familiar with the disease or treatments, and often cannot provide answers to their patients' questions.

The internet has become a readily-used source of health information [6,7]. However, internet-based health information is frequently maligned by the medical community with studies indicating that health information on the internet varies in quality and may be difficult for the general public to interpret accurately [8,9]. Nevertheless, there are many benefits to web-based medical information, including broadening the distribution of information and allowing for more personalized medicine [10].

The current study examines one form of internet health information: an online support community. We aim to demonstrate that an online support group for monogenic diabetes can be beneficial to both patients and care providers or researchers. The online support group discussed in this paper has been used to provide effective psychosocial support, gather useful information about the concerns of patients, and generate novel research hypotheses.

Methods

Subjects with diabetes diagnosed before one year of age consented to participation through the University of Chicago Kovler Diabetes Center Monogenic Diabetes Registry (http://monogenicdiabetes.uchicago.edu/registry/) through which longitudinal information regarding the diagnosis and treatment of diabetes, and other medical information is collected through surveys and medical records [11]. The Registry includes a separate consent specifically for participation in online support groups. This was to ensure that all participants were aware that research could be conducted through the discussion group and that discussions could eventually be published in a de-identified fashion. All subjects were consented for participation through protocols approved by the Institutional Review Board at the University of Chicago.

Patients and families of individuals with K_{ATP} channel mutations amenable to sulfonylurea therapy began corresponding via email in 2006. This informal email correspondence was formalized into an email-based online support group hosted by a University of Chicago listserve in April 2010. Our research group invited all families in our Registry known to be affected by K_{ATP}-channel mutations. By design, all participants had an accurate, validated diagnosis of this unique form of diabetes. This enhances the internal validity and credibility of the study. The listserve format helped to ensure that all participants had been consented and that each would receive all messages from the group. The listserve structure also allowed for ongoing access by all participants to the online archive of all previous messages. Only messages sent via the listserve created in April 2010 were included in the present study. Families who participated in the email list were aware of researcher/provider participation in the group, and consented to have the emails read and analyzed for research purposes as part of an IRB-approved protocol. The research was carried out according to The Code of Ethics of the World Medical Association (Declaration of Helsinki). The email-based format was chosen for its expediency and privacy; the group membership is restricted to those who have consented and been added by the study investigators. Postings are not anonymous, but can be read by all participants who can choose to remain anonymous if they do not wish to post anything. Study physicians moderate all discussions and, when needed, may post responses that clarify the latest known information on any given topic.

All messages were read and analyzed using qualitative methods. Cutrona and Suhr developed the Social Support Behavior Code that characterizes five types of social support [12]. These types of support are informational (facts, advice), emotional (concern, sympathy, or empathy), esteem (compliments, confidence in abilities), networking (messages of inclusion in a group or outreach), and tangible (offering or requesting object, money, etc. or offering/requesting to perform tasks). All messages were coded according to these five categories. Additionally, deductive thematic analysis was used to create a coding framework to assign each message to one or more particular topics and/or subtopics relevant to this monogenic diabetes support group [13].

Results

There are 103 people identified with K_{ATP} mutations in the Monogenic Diabetes Registry. As of May 2014, 75 people were subscribed to the list, of whom two were patients (both female), 62 were parents of children with a K_{ATP} mutation (12 fathers, 50 mothers), and 11 were researchers, physicians, and staff associated with the Monogenic Diabetes Registry.

Since the creation of the listserve in April 2010 until the time of this study (May 2014), 1,410 messages had been sent, and all were included in the present analysis. 55 patient or family participants (74.3% of all subscribers) posted at least once to the email list, while study researchers and staff posted 83 of the 1,410 messages. Of the 55 participants who posted, the average and median number of postings were 25.6 and 13 respectively, with a range of 1 to 123 postings. 58.1% of the users who posted at all, posted at least 10 times.

Analysis of categories of support provided

Of the 1,410 messages sent, 1,254 (88.9%) of messages contained at least one of the five types of support outlined by the Social Support Behavior Code: informational, emotional, esteem, networking, and tangible. Of these, informational support was the most common support provided or requested by the message senders: 44.0% of the messages contained informational support (Table 1). The comments made in the postings suggested that subscribers used the support group in lieu of or in supplement to information from their physicians.

> “Hearing so much about the other kids is invaluable in helping us to nail down [my child’s] best way to take his meds”
>
> “Very good information and a BIG relief to find people who actually knows [sic] about the disease and is [sic] dealing with it”

The second most common type of support was networking (17.6%). Most networking messages were messages welcoming new members into the group. As the list was structured as a closed private group in which postings were not anonymous, subscribers used their real identities when posting and connections could subsequently be made off-line among subscribers who desired to do so.

> “When you’re here for a visit let me know. I would love to meet you.”

Additionally, the subscribers to the group were eager to raise awareness about monogenic diabetes so others could be diagnosed sooner and switched from insulin to sulfonylureas. Several of the networking messages discussed ways to contact the media or advocate for their disease. Lastly, the Kovler Diabetes Center hosts conferences for families affected by monogenic diabetes, and discussing plans around the time of these conferences was a common topic of conversation.

Esteem support was the next most common type, with 17.5% of messages containing esteem support. A common example of esteem support occurred when one parent posted to the email list with good news about a developmental milestone that their developmentally-delayed child has reached. A number of participants responded to this original email with messages of congratulations.

> “These are amazing progress reports all!! Makes me so excited and hopeful!”
>
> “Great news! I’m so happy for him.”

Emotional support was the fourth most common type of support, with 13.9% of messages containing emotional support.

> “I know it must have been a difficult day for you. I hope you know that you were not alone that day, or now. You had and do have many people’s thoughts and prayers with you.”

Emotional support tended to be associated with negative events (a child passed away, a child severely sick and in the hospital), whereas esteem messages tended to be associated with positive events. Our results would therefore suggest that subscribers were less likely to post negative events than positive events.

Tangible support was the least common type of support, with only 9.2% of messages providing tangible support. An example of tangible support is one parent offering his expertise in writing IEPs (individualized education programs) for their children.

Topics of discussion

> “We love our endo, but sometimes he’s a bit short-sighted… he tends to focus on the glucose control, as he would with typical diabetes patients, whereas we also

> have developmental/emotional/educational/social issues that might be associated with [our child's] mutation."

The two broad topics that were most prominently discussed were diabetes management and neurodevelopmental and behavioral concerns (Table 2).

Diabetes management

Diabetes management included things like sulfonylurea dosing, side effects, and how changes in diet, growth, or illness affect blood sugars. A total of 382 messages related to this theme (Table 2). Messages on this topic could fall into any of the support-type groups. For example, because patients with K_{ATP} channel mutations take sulfonylureas in much higher doses than are typically prescribed for patients with type 2 diabetes, group members posted messages about struggling with pharmacies or insurance providers questioning the high doses.

> "And insurance won't pay for [all the pills] because they can't imagine anyone her age taking so many. I have to get the endo to write a letter. They aren't terribly expensive, but it still angers me. We are not talking about a controlled substance here. Do they think I am selling them? Stocking up for armageddon?"

Additionally, sulfonylurea use in children is rare and the optimal dosing of the drug is still undetermined. There were frequent informational messages from families reporting their experience with different ways their treatment had been done (presumably in conjunction with their own prescribing physician). In 2014, one member voiced concern about possible side effects from taking very high doses of sulfonylurea, which led a number of other members in the group to post their doses and relative lack of side effects. Through this exchange, participants in the group discovered how wide the range of doses was.

Neurodevelopmental and behavioral concerns

A total of 345 messages pertained to neurodevelopmental and behavioral symptoms associated with some K_{ATP}-channel mutations. The mechanism, prevalence, and severity of these problems in K_{ATP}-channel related neonatal diabetes are not fully understood. This aspect of the condition takes a significant emotional toll on the families of these patients. Mothers of children with developmental delays frequently posted to the email list for support.

> "It is a struggle. I cry many nights wishing that my son would just be able to have a conversation with me and praying that [my daughter] will be ok."

Additionally, members used the support group for information about things like navigating school for children with learning disabilities, the choice of medications for seizures, therapy for behavioral issues, and the effect of sulfonylurea dose on developmental delays. The subtopics are listed in Table 2. Members of the group who tried different interventions to help with these behavioral or developmental problems reported their experiences back to the group. For example, since it has been suggested that higher doses of sulfonylureas may be able to cross the blood-brain barrier and treat some of the neurologic symptoms, one family independently found a lab that would measure the concentration of sulfonylurea in their child's CSF and reported the results back to the group.

Miscellaneous topics of discussion

282 of the messages discussed miscellaneous topics. These topics included the genetics of the disease, discussion of care providers (e.g. transitioning from a pediatric endocrinologist to an adult endocrinologist, or struggling to find a doctor who was willing to learn about the disease), and discussion of non-diabetes medications. 135 messages mentioned various other topics ranging from the biology of K_{ATP} channels to frostbite. Some of these topics are listed in the footnotes of Table 2.

Impact on research focus

The online discussion group has had a significant impact on research at the University of Chicago. Researchers at the Kovler Diabetes Center have adjusted the Monogenic Diabetes Registry and pursued new research paths as a direct result of this discussion forum. Modifications included clarifications and/or additions to survey instruments on the basis of the topics mentioned in this forum. Certain areas of concern discussed by the group, such as sleep issues, had not previously been known to be associated with these mutations but subsequently became a new topic of investigation.

4. Discussion

Value of a patient discussion group for a rare disease

Our study demonstrates that patients and families are benefiting from connecting with individuals who share their experiences and challenges via an online support group. About a third of the messages posted to the support group in this study provided emotional support or esteem support. Nearly half of the messages in our support group provided or requested informational support. A study by Nambisan (2011) showed that the ability to use the group to effectively seek information correlated with participant's perceived empathy of the group more so than messages of social support [14]. Therefore, in addition to conspicuous emotional and psychosocial support, information provided by online support groups is a significant source of support. This effect may be even more powerful for rare disorders such as ours for which reliable information is more difficult obtain. In contrast, one might expect an online support group for a more common disease, like Type 1 diabetes, would be less heavily-weighted toward information support because information about more common conditions is already plentiful. Our study thus highlights the utility of online discussion groups as an important source of support and information for families and patients with rare genetic forms of diabetes.

Internet-based health information is sometimes met with skepticism by the medical community. This study demonstrates that one form of internet-based health information in particular – a closed online support community – can play a key role in better interacting with and providing care for patients. Other online discussion groups have allowed patients affected by the same medical condition to connect, learn from, and support each other through their common experiences. Since online support groups are quite common [15], it is essential that the medical community establish a firm understanding of the impact of this medium on patient health and behavior.

There are many platforms available to support online support groups. Our listserve-based support group is one of the most private. More public options include online message platforms or social media platforms, such as Facebook, which can be tailored for a particular cause or interest, whether medical or not. Additionally, there are websites that are open to the public designed specifically for the generation of disease-specific online support group. These websites include PatientsLikeMe.com and the QuantifiedSelf.com. Each type of platform has its own set of advantages and disadvantages: while our listserve-based support group is well-moderated, and has a well-validated cohort of patients (ensuring that all participants indeed are affected by the disease in question), it is not freely accessible to the general public (a patient must first be in our Registry in order to be invited to the forum). Facebook, on the other hand, is more accessible, but does require a Facebook account, participants do not verify that they have the disease in question, and is more public thereby raising privacy concerns.

Several studies suggest that online support groups may be a beneficial tool in providing psychosocial/emotional support for patients dealing with such conditions as irritable bowel syndrome, Huntington’s disease and depression [16–18]. The support provided by these groups can extend beyond emotional support; many of these groups also provide informational support. Certain online networks are designed specifically to facilitate the exchange of information support. Websites such as PatientsLikeMe, 23andme, or QuantifiedSelf allow patients to compare each other’s health data, treatments, outcomes, and experiences in order to optimize their own health care. A study of PatientsLikeMe reported that participation on the site led to changes in health behaviors and outcomes [19]. Online support groups are particularly conducive to what is known as “participant” or “patient-driven research.” [20]. An oft-cited study of PatientsLikeMe demonstrated that patients with ALS on the site started their own patient-run experimentation with an off-label use of lithium to slow the progression of the disease and posted their results on the site [21]. However, such a desire on the part of the patients to move research forward more rapidly has not always been coupled with participation by researchers who can ascertain the scientific veracity of any potential change in understanding of or treatment of a disease.

Previous reports have promoted the concept that online patient discussion groups may not only allow patients and families to learn from each other, but also allow researchers and care providers to learn from the support group postings [20,22]. Our study demonstrates that it is, in fact, feasible for patients to actively participate in fostering the research direction. In addition, care providers can glean knowledge about the unique concerns of patients with the disease in question, which then better informs their clinical practice. Lastly, by participating in the groups, care providers have a trusted resource to which they can direct newly-diagnosed patients.

Lastly, this study demonstrates that providers and researchers can use the information provided by these online support groups to gain insight into patient concerns that often are not manifest in an individual patient-doctor interaction. A quarter of the messages discussed concerns of diabetes management, which is to be expected in a diabetes support group. Nearly an equal number of messages discussed neurologic and developmental concerns. These messages, a collection of experiences from multiple patients, can be used to gain further insight into the nature, severity, and treatment of a poorly understood aspect of these forms of monogenic diabetes.

Study limitations

The patients that participated in this study are not a representative sample of all patients with this form of monogenic diabetes. Participation in the support group was voluntary, and thus, self-selection bias precludes this from being a random sample. Additionally, the interpretation of the postings is skewed toward the people who post most frequently, and may not represent the experience of the "average" person with monogenic diabetes. Lastly, we were only able to code the messages based on what was explicitly said in the message. If there was an implied subcontext in the message that other members of the group might understand, we could not account for it, and therefore some messages' codes and intentions or impacts might not align.

Future directions

The patients and families participating in the group were surveyed to elicit feedback on the effectiveness of the current support group and suggestions for improving the support group's format and usability, as we consider changing the format of the support group. In response to the survey question, "Please list how the Monogenic Diabetes Discussion Group has impacted you," replies were overwhelmingly positive, with comments such as, "It's nice to know we are not alone," and "I do read everything and it has given me more knowledge about what I need to discuss with my doctor."

In light of positive feedback our research group has received from the support group, we are developing an expanded password-protected web-based platform for discussion groups that will allow inclusion of patients and families affected by any of over 20 different genetic causes of monogenic diabetes. We will continue to monitor these support groups for information that could suggest new research hypotheses. The expanded platform and greater numbers of participants will allow us to better understand differences and similarities that may be shared among those with the various forms of monogenic diabetes.

Concerns raised by the support group have led to a variety of ongoing formal research investigations by our group, including studies about sleep neurocognitive functioning.

Conclusion

In this study, we have demonstrated that an online support group is a useful way to connect patients and families affected by a rare form of diabetes, allowing for unique emotional support and informational support that their doctors often cannot provide. More importantly, we suggest that researchers and care providers can benefit from participating in online support groups in order to better fuel research hypotheses on the impacts, manifestations, and mechanisms of poorly understood disorders. We see online support groups as an invaluable resource for the development of research hypotheses that are inspired directly by patients.

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Table 1

Type of support provided by or requested in the online discussion group according to the Social Support Behavior Code Categories.

Support Category	No. of messages (% of total of 1410 messages)
Information	621 (44.0%)
Networking	249 (17.7%)
Esteem	247 (17.5%)
Emotional	196 (13.9%)
Tangible	130 (9.2%)
No Support	156 (11.1%)

Table 2

Occurrences of discussion of topics and subtopics in the monogenic

Topic of Message	**Number of Messages**
Diabetes Management	382 (27.0%)
Blood sugars	150
Diabetes Medications	320
Diet	34
Neurodevelopmental/Behavioral Concerns	345 (24.5%)
Developmental Delays	163
Behavior	107
School	70
Seizures	53
Sleep	49
Toilet Training	32
Miscellaneous	282 (20.1%)
Non-diabetes medications*	69
Care Providers	54
Genetics	38
Other**	135

* The majority of non-diabetes-related medications discussed were anti-seizure medications and ADHD medications; messages discussing these medications were counted as both “Non-diabetic medications,” and either “Seizures” or “Behavior”. Other medications discussed were stool softeners and antibiotics.

** Includes KATP-channel biology, nosebleeds, illness/surgeries/infections, bowel movements, macroglossia, gluten sensitivity, eczema, frostbite, hypothyroidism, cord blood transfusions, GI symptoms, medical ID bracelets, and transient neonatal diabetes, among other things