

ORIGINAL ARTICLES

An online monogenic diabetes discussion group: supporting families and fueling new research



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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 and 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. (*Translational Research* 2015;166:425–431)

Abbreviations: ADHD = attention deficit hyperactivity disorder; ALS = amyotrophic lateral sclerosis; ATP = adenosine triphosphate; IRB = institutional review board; KATP = ATP-sensitive potassium

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INTRODUCTION

Monogenic diabetes constitutes approximately 1%–2% of all diabetes in the United States.¹ When diabetes is diagnosed within the first 6 months of life, there is invariably a genetic etiology, 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 adenosine triphosphate

AT A GLANCE COMMENTARY**Perrone ME, et al.****Background**

Despite the expanding number of online support groups, 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.

Translational Significance

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.

(ATP).^{4,5} Most 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 extrapancreatic 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 present study examines 1 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 dis-

cussed in this article 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 the age of 1 year 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 e-mail in 2006. This informal e-mail correspondence was formalized into an e-mail-based online support group hosted by a University of Chicago listserv 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 listserv format helped to ensure that all participants had been consented and that each would receive all messages from the group. The listserv structure also allowed for ongoing access by all participants to the online archive of all previous messages. Only messages sent via the listserv created in April 2010 were included in the present study. Families who participated in the e-mail list were aware of researcher/provider participation in the group and consented to have the e-mails read and analyzed for research purposes as part of an institutional review board-approved protocol. The research was carried out according to The Code of Ethics of the World Medical Association (Declaration of Helsinki). The e-mail-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

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