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# Paediatric Diabetes: Information-Seeking Behaviours of Families

## Abstract:

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## Abstract

The Internet provides patients and their families with ready access to on-line health related information. However, this information is not always accurate, understandable or provided by health professionals or advocacy groups. One hundred children with Type 1 diabetes mellitus, or their parents, attending a paediatric diabetes clinic during September to November 2011 were invited sequentially to participate in this questionnaire-based survey of Internet use in searching for diabetes-related information. Sixty-seven (67%) returned completed anonymised questionnaires: 36/67 (53%) were categorised as socio-economic groups C1/C2. Of the 67 families who returned completed questionnaires, 64 (96%) had a home computer and 62 (93%) had home Internet access; 27 (40%) rarely, and 40 (60%) frequently, searched on-line for diabetes-related information. Key search terms were not provided by respondents. There appears to be considerable internet use in seeking health related information for children with Type 1 diabetes mellitus. Clinicians should make efforts to direct patients and their families to websites that present accurate and current information.

## Introduction

As the incidence of Type 1 diabetes mellitus (T1DM) is increasing, particularly in children, the availability of therapeutic options and technological support for patients is also increasing. For example, T1DM can now be treated via continuous subcutaneous insulin infusions (CSII), augmented by continuous glucose monitoring systems (CGMS), and an increased range of insulin, insulin delivery instruments and glucose monitoring systems. Some of these options require access to a computer and the Internet for optimum use. For many children and parents, the Internet is a vast source of answers to health-related questions<sup>1,2</sup>, but retrieving appropriate and accurate data can be difficult<sup>3,4,5</sup>. Examples of reasons for inaccurate data include information that is out of date, or not updated frequently. Furthermore, information may be appropriate to some but not all individuals with a particular condition. Finally, information retrieved online may be difficult for parents and families to apply without the guidance of their clinical care team. And information sourced on-line from unvalidated third parties may be difficult for the diabetes multi-disciplinary team to explain or apply.

Our paediatric T1DM clinic is located in a university-affiliated regional centre, providing care to patients from both urban and rural backgrounds and from a representative sample of socio-economic groups. Approximately 250 children and adolescents with T1DM attend this clinic. Within this context, the aims of this study were, within attendees at our paediatric clinic: i) to survey the attitudes and approaches to Internet searches for diabetes-related information (DRI) of children or parents of children with T1DM; and ii) to explore the difficulties encountered when performing these searches.

## Methods

Ethical approval for this study was obtained from University Hospital Limerick Research Ethics Board. A pre-validated questionnaire was administered prospectively to study subjects by a single investigator (ES). Any child with T1DM, or their parent(s), attending the paediatric diabetes clinic at University Hospital Limerick during September to November 2011 was eligible for inclusion and invited to participate. Questionnaires were completed during clinic time. All questionnaires were anonymised. Inability to read or speak English were exclusion criteria. Where families had more than one child with T1DM, only one questionnaire was completed per family. Socio-economic demographic data were determined from the highest reported level of parental education. The results were entered anonymously into a database for further analyses. Summary statistics were applied.

## Results

The one hundred families invited to participate represented approximately 40% of families attending the clinic. While no-one refused to participate, only 67 completed questionnaires were returned, from 64 families with a home computer including 62 with home internet access. The patients with T1DM had a mean age of 11.5 years (-3.6), and a mean duration of T1DM of 3.4 years (-2.9). Their mean HbA1c levels were 8.9-1.4%.

Of the 62 families with home internet access, forty-eight accessed the Internet daily and nine weekly. Of the nine families who searched weekly, eight rarely searched for DRI. Of the 48 families who searched the Internet daily, 17 (35.4%) and 3 (6.2%) families rarely or never searched on-line for DRI, respectively. DRI is searched for by 27/48 families who searched the internet daily, including 3/48 (6.2%), 16/48 (33.3%) and 8/48 (16.6%) who searched for DRI information daily, weekly and monthly, respectively. Of 62 families with home Internet access, 28 (45%) did not use any specific phrases or words to search DRI. Eight families (12.9%) felt that the on-line information they retrieved was not useful, and the most common reason cited was that information was related to Type 2 diabetes mellitus. Information volunteered by families included that they would value a chat rooms for children with T1DM and that they found dietary information particularly difficult to retrieve on-line. Most families, 36/67 (53%) were from the C1/C2 socio-economic group. The remainder of families included 14/67 group D, 2/67 group A, 11/67 group E and 5/67 group B. Of the 27 families who searched the Internet at least once per month for DRI, the highest level of parental education (either parent) was third level in 14 cases, finished second level in 11 cases and some second level in 3 cases.

## Discussion

Since the internet was first launched, the potential health benefits to the population were recognised to be one of its great opportunities. However, access to this information is not equal to all people. Factors which might affect the quality of a website for health related information include when the site was updated, who hosts and contributes to the site, especially if there is a professional patient advocacy group involved, and references to the evidence for information being provided. In one study, the evaluation of chronic inflammatory bowel disease related online information suggests that the quality of websites and information is very variable, but frequently poor<sup>7,8</sup>. It is certainly possible that T1DM related websites are similarly variable in quality, but further research is required. One option to improve the utility of internet searches for families might be for diabetes health care teams to provide lists of suggested websites, suitable for both children and for their parents.

This survey was by questionnaire, administered by a single investigator assessing the approaches adopted by children and families seeking diabetes-related information on-line. Disappointingly, despite conducting this study in our clinic waiting room, a relatively small number of children and families returned questionnaires. Nonetheless, this number comprised approximately one quarter of the paediatric diabetes patient cohort in the Mid-West region. Thus, these results are probably representative of the wider population throughout Ireland. This study has limitations. It is a relatively small study utilising a retrospective questionnaire. There are potential sources of bias in child/parental recollection and it is possible that families answered questions in a manner which they perceived to be helpful to the researcher. However, data were anonymised. Further, it was beyond the scope of this study to evaluate how parents and families decide if information retrieved is relevant to their own child.

The results of our study suggest a need for diabetes-related on-line information to be filtered for children and parents, to allow children and their parents the optimum opportunity to retrieve information which is high quality and appropriate for their child. Encouragingly, a large proportion of respondents described attempts at home to gather knowledge from the internet, indicating a willingness to learn and to supplement information directly provided by the diabetes team. Furthermore, it is encouraging that the spectrum of maximum parental education among those searching for information was wide, and included parents who had not completed second level education. Clinicians should consider providing patients and their families with a portfolio of websites which have content informed and monitored by specific professional groups. Specific to T1DM, these groups might include professional organisations or hospital networks which operate specific information sites for families, and high quality patient advocacy groups.

In conclusion, despite the high proportion of families with home Internet access, relatively few searched on-line for information on T1DM and those who did search, described frustrations with their search results. Furthermore, very little information was provided on how searches were performed. Several families used recognised websites, such as those supported by diabetes organisations. However, little is known about the quality of information on unregulated sites<sup>1,9</sup>. Physicians should be aware of information-seeking behaviours of families, and seek to help families retrieve accurate and relevant information<sup>10,11</sup> perhaps in the first instance, by directing families to sites operated by professional diabetes organisations. This study suggests a willingness of families to search for information, among those with internet access, but also that these families experienced difficulties retrieving information.

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