Canadian Society of Nephrology/ Société canadienne de néphrologie CSN/SCN

CANADIAN JOURNAL OF KIDNEY HEALTH AND DISEASE
Journal canadien de la santé et de la maladie rénale

Original Research Article

Changing Needs for Information and Support in an Online System for Parents of Children With Kidney Disease

Canadian Journal of Kidney Health and Disease
Volume 4: 1–12
© The Author(s) 2017
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/2054358117714999
journals.sagepub.com/home/cjk
SAGE

Maury Pinsk[1] and David Nicholas[2]

Abstract

Background: Pediatric chronic kidney disease is psychologically, financially, and physically demanding on parents providing care. Parents often feel isolated because of the rarity of the condition, and geographic isolation often compounds this perception in Canada. Many parents seek assistance online for both information and social support.

Objective: This study examines an online portal, titled "Ability Online," which was designed to provide support and information to a diverse group of parents using chat facilities, bulletin boards, and e-mail. Specifically, we sought to identify how the technologies offered in this system related to the support and information seeking needs for parents. Secondary aims of determining possible reasons for attrition over time were explored as well.

Design: Mixed methodology sequential exploratory design using the qualitative methodology of descriptive interpretation.

Setting: Telephone interviews.

Patients: Twenty parents of pediatric patients with chronic kidney disease from four Canadian centers who engaged in an online social support system "Ability Online."

Measurements: Interview transcripts generated from 20 taped phone conversations were reviewed from parents who engaged in the online system, and the themes derived from these transcripts served to generate semistructured interview questions that focused on their use of, and perceived benefit from, this technology for social support. Follow-up telephone interviews were then conducted with a 6-person subset of the original group in an effort to further define the impact of technology on their experience. This same smaller cohort provided data on social supports, caregiver satisfaction, and caregiver stress.

Results: Many parents experience a progression through which their needs for knowledge and support change over time. Specifically, parents describe a transition from pure information seeking, to seeking parental interaction, mutual support and collaboration, and ultimately to advocacy. Parents described how technology could be used to address those needs.

Limitations: Our cohort was slightly more educated and representative of more urban populations than published data reflecting the population of North American pediatric patients living with kidney disease.

Conclusions: Our data suggest themes of technology use influencing the goals of online support seeking. While our findings are preliminary, further study may inform Web designers to identify the changing needs of participants in designing such online support networks, and minimize the reasons that participants fail to adopt, or terminate their online experiences.

Keywords

patient informatics, parent support, Internet, nephrology, pediatric

Abrégé

Contexte: L'insuffisance rénale chronique (IRC) chez les enfants impose un fardeau physique, psychologique et financier aux parents. Ces derniers, qui doivent prodiguer des soins à leurs enfants, se sentent très souvent isolés; d'abord en raison de la rareté de cette maladie, mais également parce qu'au Canada, l'isolement géographique contribue souvent à accroître cette perception. Beaucoup de parents se tournent alors vers le Web pour s'informer ou pour obtenir du soutien.

Objectifs de l'étude: Cette étude s'est penchée sur *Ability Online*, un portail Web conçu pour informer et offrir du soutien au groupe hétérogène de parents d'enfants atteints d'IRC qui utilisent les forums de discussion, les différents babillards et le courriel. Concrètement, nous avons voulu savoir si les technologies offertes dans ce réseau satisfaisaient les besoins des parents en termes de recherche de soutien et d'information. L'étude visait également à explorer et à cerner les raisons pour lesquelles certains parents décidaient de s'en retirer au fil du temps.

Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (http://www.creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage).

Type d'étude: Un modèle exploratoire, séquentiel et à méthodologie mixte, où on a utilisé une méthodologie qualitative de l'interprétation descriptive.
Méthodologie: L'étude a été réalisée au moyen d'entretiens téléphoniques
Participants: Un total de 20 parents d'enfants atteints d'IRC provenant de quatre centres urbains au Canada, et qui fréquentaient le réseau de soutien social d'*Ability Online*.
Mesures: Les transcriptions de vingt conversations téléphoniques enregistrées lors des entretiens faits auprès de parents fréquentant le réseau ont été analysées. Les thèmes retenus dans ces transcriptions ont servi à produire un entretien semi-dirigé dont les questions mettaient l'accent sur l'usage que les parents faisaient de cet outil pour obtenir du soutien social et sur les bénéfices qu'ils en tiraient. Un entretien téléphonique subséquent a été conduit auprès d'un sous-ensemble de six personnes du groupe original, pour tenter de mieux définir l'impact de cette technologie sur leur expérience. Cette cohorte réduite a fourni des données sur le soutien reçu, de même que sur le niveau de satisfaction et le stress vécu par les aidants naturels.
Résultats: Plusieurs parents ont mentionné avoir observé une progression de leurs besoins de connaissance et de soutien au fil du temps. Plus précisément, ils ont constaté la transformation de leur besoin initial d'information en une recherche d'échanges avec d'autres parents, puis en soutien mutuel et en collaboration, pour finir en mobilisation. Au cours de ces entretiens, les parents ont également précisé la manière dont cette technologie pourrait être utilisée pour répondre à ces besoins.
Limites de l'étude: Notre cohorte était légèrement plus scolarisée et représentative d'une population urbaine que les données publiées précédemment sur la population d'enfants nord-américains atteints d'insuffisance rénale.
Conclusions: Nos données proposent des domaines d'utilisation de la technologie qui pourraient influencer les objectifs de recherche de soutien social en ligne. Nos résultats sont préliminaires, toutefois, une étude plus approfondie servirait à guider les concepteurs de sites Web pour qu'ils soient en mesure de mieux cerner les besoins des participants et de suivre l'évolution de ceux-ci dans la conception de réseaux de soutien en ligne. De plus, on suppose que cela aiderait à réduire les irritants qui font en sorte que les participants hésitent à adopter ces sites Web ou mettent fin à leur expérience en ligne.

Received December 17, 2016. Accepted for publication May 12, 2017.

What was known before

Online support systems in chronic kidney disease, particularly in pediatrics, are largely unstudied.

What this adds

This study describes the online information seeking behavior of parents, and how these behaviors change over time with increasing knowledge and experience of their child's disease.

Introduction

Chronic kidney disease (CKD) is an increasing health concern worldwide, with an estimated 7.2% of the world population older than 30 years diagnosed with kidney failure.[1] Children make up approximately 3% of the total population with renal failure receiving dialysis or transplantation therapies.[2] Although the population of children with CKD is relatively small, the burden of care for families and support systems is heavy. Children require multiple medications, dietary and fluid restrictions, and have comorbid conditions that complicate care. However, there is some suggestion that children exhibit some resilience with the burden falling to parents and caregivers. Madden et al investigated children's adaptation to chronic renal disease and their mother's response and resilience.[3] Despite the fact that children were identified by their parents as having increased risk of psychological problems, the children themselves did not. The parents, however, self-reported increased psychological stress and mental health issues than parents of normal controls.[3] Children with CKD in fact show very few behavioral and social difficulties. The perception that they may internalize psychological symptoms is based on parental reports,[4] and may indicate that parents experience significant mental stress themselves. In a systematic review of 12 qualitative

[1]Section of Pediatric Nephrology, University of Manitoba, Winnipeg, Canada
[2]Department of Social Work, University of Calgary, Alberta, Canada

Corresponding Author:
Maury Pinsk, Department of Pediatrics and Child Health, Rady Faculty of Health Sciences, University of Manitoba, FE009, 840 Sherbrook Street, Winnipeg, Manitoba, Canada R3A 1S1.
Email: mpinsk@hsc.mb.ca

studies of parents of children with kidney disease, Tong et al reported that aside from parenting roles typical of care for a healthy child, parents of a child with kidney disease experience significant further burden.[5] They reported that parenting a child with CKD "demands a high-level health care provider, problem solving, information seeking, and financial and practical skills at a time when the capacity to cope is threatened by physical tiredness, uncertainty, and disruption to peer support within and outside the family structure."[p. 349]

The result can be significant isolation and stress to the caregiver. Fielding et al evaluated anxiety, depression, and psychosomatic complaints in siblings and parents of children with kidney disease, confirming that the children show good resiliency with scores that are not different from normal controls. However, both fathers and mothers showed significantly higher anxiety and depression than with control scores, indicating that the burden of caregiving is great.[6]

In managing pediatric CKD, the families often require intensive resources to help them cope. Most pediatric nephrology centers in Canada offer social workers to help navigate the system of financial supports to access travel, medications, psychology, and family counseling. Those fortunate to live in urban centers often have access to support groups and counseling services provided at the base hospital. Those who are more rural often do without those services. In Canada, 81% of the general population lives in an urban setting, but the distribution is heterogeneous across the provinces with urban dwelling rates ranging from 47% to 86%.[7] Thus, depending on the province of residence, access to services in Canada can be limited significantly by geographic isolation.

It becomes intuitive that allowing parents and caregivers a venue to voice concerns and feel heard may provide support and ease the burden of care. Ability Online[8] was developed to provide a networking support system for patients and families dealing with disabilities. Initially conceived in 1991 by Dr Arlette Lefebvre, a child psychiatrist at the Toronto Hospital for Sick Children, the online environment has grown to serve a larger community of predominantly children and adolescents dealing with disability and chronic disease. In 2007, Ability Online was studied in the context of providing support for adolescents with CKD,[9] and more recently has been the subject of study in evaluating the use of the online system to provide support to parents of children and adolescents with kidney disease.[10] The online system provides a password-protected environment where parents, children, and adolescents can interact using a closed system of instant messaging, forums, and chat rooms. In addition, the site provides additional resources for parents and family to maximize their child's functioning and abilities. To provide an environment unique to parents of children with kidney disease, Ability Online created a closed system to invited parents caring for children with kidney disease. Using the technology supports available, parents created the content and drove the discussions in the online environment, in effect, creating an online community to best meet their needs.

Historically, support environments impose obstacles to efficacy. Galinsky et al found that in a survey of 227 social work professionals, obstacles to adults seeking group therapy resources included inaccessible transportation, geographic isolation, time constraints, illness or caregiving responsibilities, reduced mobility due to physical or mental illness, and communication difficulties.[11] Galinsky et al conducted the study in the context of discovering advantages to the use of telephone- or computer-based group therapy, which, in the opinion of the survey participants, appeared to circumvent these obstacles. Specifically, the use of asynchronous communication methods such as e-mail or bulletin boards afforded convenience of participation, while the afforded anonymity of some communication portals appeared to facilitate the sharing of personal or potentially embarrassing communication between participants. Galinsky et al also noted disadvantages in the use of technology, such as the loss of visual or social cues in communication leading to miscommunication, the loss of intimacy as might be necessary to console, the perception of further isolation of participants, and issues with technology failure limiting access or participation.

Despite potential pitfalls in technology, the use of online support systems for parents has been successful in terms of perceived support, knowledge acquisition, and satisfaction. Scharer reviewed the status of Internet-based communication for parents caring for children with mental illness. She concluded that parents will utilize Internet-based communications[12] and that in general there is great potential for electronic communication to meet the needs of parents seeking additional support mechanisms.[13] In fact, successful Internet support systems have been implemented for a variety of populations and health states, including maternity and parenting,[14-19] cancer,[20] diabetes,[21] mental health,[22] CKD,[10] and HIV.[23] Despite the positive outcomes reported in these studies, in each of these online systems the assessed outcomes were either an assessment of support, or an assessment of satisfaction without formal assessment of usability.

The issue of usability becomes important because despite promising efficacy trials, some Internet-based support systems show remarkably poor adherence. Eysenbach reports that Internet-based interventions are often studied without attention paid to attrition of user participation.[24] Some interventions, which arguably are more intensive than chat room communication with a peer support system, show that less than 1% of enrolled participants in programs for self-management of depression or anxiety disorders complete the program.[25,26] Wangberg et al studied three different Internet-based interventions (smoking cessation, diabetes self-care, and maintenance of a personal health record) to determine whether nonadherence was a disease-specific phenomenon. In all three groups, attrition was high, and self-reported intent to use the online systems did not correlate with what was

actually done.[27] Of particular interest, adherence to the programs was correlated with high self-efficacy in the smoking group, but not in this diabetic group. Other researchers have found positive correlations between self-efficacy and adherence to behavior modification programs in the context of non–Internet-based interventions,[28,29] suggesting that intrinsic personality or resilience may be a predictor in participation and completion of such programs. These associations between self-efficacy and adherence may be pertinent in the context of similarly employed Internet-based interventions.

In summary, parents of children with kidney disease are at profound risk for social isolation and burnout. Although there is promise in providing that support through an Internet support system, there appears to be intrinsic social and mental health issues that will determine if and/or how the individual accesses a support system. Exploring salient considerations such as parental perceptions of support, caregiver burden, and sense of community in the context of a usability analysis may more acutely highlight design issues that limit the sustainability and potential impact of an online support system for this population.

Methods

We used a mixed methodology sequential exploratory design[30] with the aim of assessing perceived quality of support and the usability-employed technology. With this approach, one methodology is used to inform a second or further method, thus creating a more comprehensive exploration and description of the observed phenomenon. This is a novel approach because the technology delivery was assessed and contrasted with the subjective experience as it was used in a support network for parents. The research was organized into two phases:

Phase 1: Initial cohort

The Phase 1 interviews focused on the nature of support received online. In the course of those interviews, several usability issues were assessed. The initial analysis and description of technology impact on social support systems formed the basis and design of the follow-up structured interview script used in Phase 2 of the study.

Participants for Phase 1 of the project were recruited from an existing multicentered cohort using Ability Online. The participants represent a convenience sampling of parents of children with CKD recruited from 4 pediatric nephrology clinics across Canada (2 from eastern Canada and 2 from western Canada). Inclusion criteria were (1) caregivers of a child 0 to 18 years of age with stage IV or V(d) CKD (as defined by nearing dialysis with renal function <30% of normal, or on dialysis), or having received a kidney transplant; (2) sufficient interest in learning about online utilization; and (3) an expressed willingness to post messages to the network a minimum of once per week. An exclusion criterion was severe mental health issues related or unrelated to adaptation to kidney disease, as identified by the referring physician. A total of 20 participants participated in telephone interviews, and along with the interview transcripts, the online postings were reviewed. All participants signed a consent form as part of the initial study to allow secondary analysis of their data and follow-up contact to participate in future studies, which was approved by ethics boards at the respective centers. The interviews and postings were analyzed using a systematic qualitative inquiry analysis technique—interpretive description. The rigor of the analysis was achieved by the following: (1) The reliability of the emerging themes was verified using secondary review (D.N.) of the primary coding and thematic analysis (M.P.). (2) Themes were identified only if there are sufficient codes derived by multiple dialogue excerpts from the participants supporting the code and theme derivation. (3) The themes identified in the first thematic analysis were brought forward for assessment and validation in Phase 2 of the study.

Phase 2: Validation cohort

Semistructured interview scripts were developed from existing validated instruments of usability[31] and further informed by qualitative interview data obtained from parents using the online support network in Phase 1. This was done as part of thematic validation, as well as to obtain targeted information on site usability, and relate these issues back to the perception of the online system as a social support network. Three survey instruments were also used assessing caregiver satisfaction,[23] degree of social support,[32] and sense of community.[9,33] A demographics questionnaire was administered after the interviews to provide a context to understanding the data. A comprehensive sampling approach of all 20 participants from Phase 1 was attempted to participate in a follow-up phone interview. Of the original 20 participants, a convenience sample of 6 participants was available and agreed to complete the telephone interview. Each participant discussed and submitted verbal informed consent before participating in the interview.

The approval for this phase of the study was granted through the University of Alberta Human Research Ethics Board. Interviews were audio-recorded and transcribed verbatim into transcripts for subsequent analysis.

Interviews

Setting. All interviews and survey instruments were administered over the telephone.

Data Collection Tools and Procedures

The telephone interview script is included as an appendix. The Social Support Scale[32] was validated against several personality scales, as well as measurement instruments of loneliness and social competence. However, only the quantity of

social support (N) was assessed in this study, as the satisfaction scale (S) has shown to have significant skew in small sample sizes by the authors.[32] Satisfaction was instead measured through the Caregiver Satisfaction Scale,[23] which was initially developed to measure degree of caregiver stress and burnout in HIV caregivers and was reported by the authors to be robust in smaller cohorts. However, the instrument was modified for parents of children with kidney disease. These instruments were selected as they reflect salient characteristics in this population of parents of children with kidney disease, and further reflect considerations associated with online social support, based on the preliminary online support data and clinical experience. None of the instruments were piloted in a population of parents with CKD prior to use as each instrument has content validity and was validated in other populations.

Data Collection

Telephone interviews were audio-recorded using Camtasia Studio (version 1.2.2; TechSmith, Okemos, Michigan) and transcribed for importation into NVivo 9 (QSR International, Victoria, Australia), qualitative research data management and analysis software. The initial interviews were conducted by a research assistant hired by D.N. and took approximately 90 minutes to complete. The follow-up interview in the validation cohort was conducted by M.P., occurred within 1 year of the initial interview, and took about 1 hour to complete. In addition, online postings were taken verbatim from the bulletin boards and coded as if they were a transcript, incorporating the identical methodologies to identify areas for thematic analysis.

Questionnaires were all administered to the validation cohort by M.P. over the phone. Questionnaires were scored as follows: The 6-item Social Support Questionnaire (SSQ-6)[32] has numeric responses to each question, with the respondent identifying individuals in their social network who are able to provide specific supporting functions. There is, in theory, no maximum score to the instrument. The results were validated against 11 existing measures of social functioning in the original paper. The responses to questions are then summated, and the final score is indicative of the size of the social support system for the individual. The validation cohort for the instrument was comprised of university undergraduate students. The score range for each question item was 2.92 to 5.46 with an mean of 4.25 for the overall instrument score (ie, on average, the validation cohort reported 4.25 unique individuals providing support in any of the instrument functions in their social network). The Caregiver Satisfaction Scale[23] is a 14-item scale scored on a 7-point Likert scale examining both satisfaction and stress items for caregivers. The validation cohort for this instrument was health care workers caring for patients with HIV/AIDS. The Satisfaction subscale had a mean score of 29 ± 5.9, whereas the Stress subscale has a mean score of 24.3 ± 5.7 in the original validation cohort. The maximum score for each of Satisfaction and Stress subscales is 49. The original Sense of Community Scale[33] is an instrument of 7 items, each scored on a 5-point Likert scale that assesses an individual's sense of belonging within a community with a theoretical maximum score of 35. The original validation cohorts included a randomly selected population within a community endorsed an average of 3.45 community items, whereas those of a community-engaged cohort of residents who attended an open house on a hazardous waste plant locating within the community scored an average of 8.22. The scale has been validated against instruments of self-efficacy and self-esteem, and correlates with longevity within the community and greater involvement in community organization. The scale was modified to ask about an online community, but the content of the scale was otherwise unchanged.

Data Analysis

Semiquantitative data from social support, caregiver, community assessment, and demographic instruments are presented descriptively in Table 1, and are used in the context of augmenting the qualitative data as well as adding depth to our understanding of the sample. Comparison populations were included from the literature as comparators.[23,32-34]

Qualitative data were analyzed using the tradition of interpretive description. Interpretive description is a qualitative methodology described by Thorne et al[35] as an approach that is "grounded in (nursing's) our own epistemological foundations, adherent to the systematic reasoning of (nursing's) own discipline, and yield(s) legitimate knowledge for (nursing) practice. It is a practice that sits on the boundary of quantitative research and qualitative research."[p. 172] The qualitative aspect seeks to describe a phenomenon from diverse sources of information, often iteratively, and then brings that description toward a quantitative position by interpreting the phenomenon in the context of knowledge and theory of applied practice. The qualitative interpretive method provides a means of examining behaviors of information seeking and attaining social support in the context of online system usability. The addition of quantitative data is meant to provide a descriptive context, putting the qualitative themes identified into context with geography, caregiver stress and satisfaction levels, as well as socioeconomic status.

Results

Demographics

Participants were recruited from 4 Canadian pediatric renal centers. From the original 20 participants (Phase 1), 14 of 20 were female compared with 4 of 6 in the follow-up cohort (Phase 2). The Phase 1 cohort had a similar distribution of rural representation to the Phase 2 cohort, with 40% and 33%, respectively, living more than 100 km away from the treating hospital. This is in keeping with estimates of the general

Table 1. Demographics and Social Assessment Scores of Study participants.

		Validation cohort	Comparator population[23,32-34]
Gender (male/female)		2/4	NA
Age, y			
20-29.9		0	NA
30-39.9		0	NA
40-54.5		6	NA
Income		N = 6	N = 24[a]
20-59 K		0	21%[a]
60-99 K		3 (50%)	65%[a]
100-169 K		2 (33%)	13%[a]
170-249 K		1 (17%)	0[a]
Employment		100%	NA[a]
Rural (>100 km from hospital)		33%	NA[a]
Education			
Postsecondary		6 (100%)	25%[a]
Postgraduate		0	58%[a]
Family structure			
Biological		6 (100%)	
parenting			79%[a]
Intact:separated		6:0	19:5[a]
Siblings to child		1.2 ± 0.4	NA[a]
Other children		0	
with complex care			NA[a]
Social supports assessment			
Average social support score (N) ± SD (range)	NA	3.1 ± 1.6 (1.1-5.3)	4.25 (2.95-5.46)[b]
Satisfaction score		45.5 ± 5.4	22.3 ± 9.5[c]
Stress score		20.5 ± 6.7	16.7 ± 8.0[c]
Sense of community score (scale 1-5), average ± SD	NA	3.1 ± 1.1	5.03[d]

[a]Mavis et al,[34] kidney transplant cohort.
[b]Sarason et al,[32] college student cohort.
[c]Ferrari et al,[23] HIV caregiver cohort.
[d]Bachrach and Zautra,[33] community hazardous waste exposure cohort.

Canadian population of 20% to 40% living in rural locations.[7] No other demographic data were available from the Phase 1 cohort. Demographics for the Phase 2 cohort are described in Table 1, and show that family incomes were shifted higher compared with a published but analogous cohort. Similarly, none of our parents in Phase 2 failed to complete high school compared with an established cohort. Unfortunately, the published cohort did not publish data on parental age. Family composition was similar between the Phase 2 and published cohort groups. Sample sizes are small, which only allows descriptive differences between our study group and a published cohort.

Participant Experiences and Perspectives

A range of perspectives related to Ability Online use were elicited in data collection and analysis. Emergent themes are as follows: (1) participant need for communication, information, and a "support trajectory" and (2) patterns of online communication behavior inform information delivery choice. These themes reflected the perspectives of experienced users from both phases of the project. Each of these themes is described below, along with illustrative text quotes from participants.

1. Participant need for communication, information, and a "support trajectory"

Both Phase 1 and Phase 2 users articulated that support and information needs changed over time. One user characterized the transition as follows:

> If I'm brand-new into this . . . it's not even that you need to participate by writing anything in, but it's really just to know that there is information that is somewhat valuable, because it's from experience rather than from a medical perspective, to support you and help you, and if something comes along that you really need to find out more about, you know that there's somebody there that's going to be able to answer that question for you from a human perspective.

Participants stated that the technology optimally facilitated informational gain in different ways at various stages.

One participant stated that self-directed immediately digestible forms of information were desired early on, and more exploratory, interactive, and supportive information was sought in the later stages of illness experience. In the following exchange, interviewer comments reflected a participant's identification of shifting knowledge needs over time. To this, the participant clarified this shift:

Interviewer (I): At the beginning, it sounds like you have a thirst for knowledge—so a lot of what I would call static information—like pages of text. What kind of information are you looking for now?

Participant (P): Now? Now is more the how can we give back, what can we do. How can we help, where can we get involved? A little bit of information I'm still kind of looking for—what does this mean down the road for us—we are in a good place now so we have some time—we are all positive—so now tell me what's going to happen, tell me where I can find that information to say, you know—share with other people who have gone through the two years on this medication—and did you relapse? Where is this? Where is that?

One participant introduced the possibility that once the acute issues have resolved and there is time to reflect, the support trajectory may move beyond simply offering support to others, and increasingly focus on effecting change:

> I was hoping to address—give doctors a better understanding of things that didn't work. We just had some procedural things that really should have been addressed better, that the hospital could do. I guess just in that sense. If it had been earlier on like before the transplant, or even shortly after the transplant, when you're really dealing with a lot of the emotions and things like that, I think it would have been helpful to communicate with different families about what they are going through.

As illustrated here, the need for support appears to be multifaceted, with shifts based on experience and prioritized need. Elements of this need at varying points entail communication, information sharing, and support.

2. Patterns of online communication behavior inform information delivery choice

Participants in both Phase 1 and Phase 2 expressed different communication strategies to meet their purposes for participation in the online network. These behaviors included unidirectional communication (reading webpages or "lurking"), asynchronous communication (bidirectional communication occurring at different times [eg, e-mail]), and synchronous communication (bidirectional communication occurring simultaneously [eg, live chat]), each of which are briefly described and exemplified below.

Lurking. In some cases, individuals did not post at all, in preference to reading ("lurking") the information that others posted and gaining support by learning passively from others' experiences:

> I'm not a big one on the on-line talking part as far as I'm concerned, but it was interesting to go in there and hear other parents' points of view or things they were going at, and you can say, "Oh, yeah, that sounds familiar," or "I kind of know what they're going through." You know, it was nice to relate to someone else. I went on just mostly to read for information to see what other families go—I don't even know if I put in a post; I may not have even put in a post.

Lurking appeared to be a significant part of the online experience. It seemed that in some cases, there was a perceived need to "get up to speed" with knowledge before launching into a conversation with others. In other cases, avoiding contact with others online related to the aim of processing the information in private:

I: In terms of you moving into other sections that were not (kidney) specific was it quite an intentional move, or did it happen by accident?

P: No it was intentional—it looked interesting, and I would go only there, but I didn't spend much time at all. But then someone who saw me on there would send me a message. And I didn't like that. It was kind of creepy.

I: Was that generally a feeling you had on the system, that you were more vulnerable to be contacted by people who you didn't want to be contacted?

P: Yes—once it happened, I didn't do that anymore. So if I found something else I would avoid going there because I wanted to avoid someone contacting me.

Asynchronous communication. When interacting with others online, all participants stated that they would use some form of asynchronous communication. Users who preferred asynchronous communication cited the ability to thoughtfully craft a response, and appreciated the convenience of entering and leaving the site depending on one's schedule:

> I thought it (the asynchronous site) was good, because you are able to type your whole response and then you can think about what you wanted to say, you can think about what you wanted to ask, and then they have time to word their response rather than just a face to face conversation—like you might think of something later after the conversation finished, you might add something like, "I should have said this or I should have said that"—I liked that part about it.

Synchronous communication. Those who preferred synchronous communication usually cited the need to obtain more immediate support or troubleshooting, rather than merely finding factual information. In many cases, they would

bypass the online system for a telephone conversation or, if located close by, a meeting in person.

> All of a sudden, I would think of something: "How are you supposed to do that?" or "How did you handle this?" especially on bad days where you didn't know how you were supposed to do it. Not that—she was an interesting woman; she was incredible. Two children with special needs, and both had been through transplants. She was just very—mostly, she just went, "Um-huh, yeah, isn't that hard." Often, she didn't even tell me anything else, she just—and I went, "Yeah, it's really hard." Just that was often enough, just to have somebody there who'd been through it, instead of calling my mom who I'd often phone, or talking to my husband about it; where they didn't know, she knew. They could support me, but they couldn't say, "I know."

The chat facility was the main source of synchronous communication in the online system. Among reasons parents favored, live chat was an immediacy of response to their queries. If able to participate in multiuser chat, participants appreciated the diversity in responses that occurred in this venue. However, when multiple users were on, others felt the topics remained too general to be of practical use:

> I think it's good to have a chat area—but I think it would be good to break down different areas that people might have issues with, so that they could very quickly go to an area and address really good experiences and experiences where they feel the (health) system could be improved.

The use of synchronous communication offline did occur among experienced users, usually in the form of telephone or person-to-person interactions. For others, synchronous communication was unsuccessful because of issues with online participation:

> I found when I went on, nobody else was. Then I read the conversations, and they all seemed to be—the bulk of them, from [a distant regional area]—and the sort of timing issue. (Due to distant regions in which participants lived, synchronous communication reflected the need to coordinate across time zones of up to 3 hours.) And it got to the point that I didn't bother going on because there was no one on with me.

Discussion

CKD often presents complex medical, social, and adaptive problems for children and their families. In assessing the behaviors and needs of parental users of Ability Online, parents indicated important requirements of the types of information, the modes of disseminating that information, and limitations of how the existing delivery model works.

The themes of the study are built upon the characteristics of the study cohort and triangulated data collection approaches based on multiple methods. Participants in Phase 2 of the study were generally educated, but older and earn high incomes than published comparable cohorts. This is in keeping with larger studies that show similar demographics in Internet use.[36] However, the continued proliferation of computer use in community living is causing the demographic accessing online health information to shift.[37] Indeed, estimates of adult American Internet usage have increased from 52% in 2000 to 88% in 2016.[38] Estimates of health seeking behavior have also grown from 71% of Internet users in 1988 to 88% in 2010.[39] This may be a result of successful Internet-based interventions that target health care needs of historically marginalized populations such as low-income rural families[40] and ethnic minorities.

Parental characteristics such as worry or anxiety, and not demographics, may be stronger drivers of Internet use and information searching. For instance in a cohort of 39 families dealing with pediatric encopresis, Magee et al showed that parental worry was the dominant factor in predicting access to an online intervention program despite varying severities of children's health.[41] Thus, while our cohort is typical of others that have been studied, there are other factors that may require consideration in the discussion of generalizability.

Anxiety and depression were recognized as a factor influencing online access to information and support. Our Phase 2 cohort had similar sized social support networks (Table 1) compared with the work of Sarason et al in a healthy college cohort of 4.25 people (range: 2.92-5.46).[42] This suggests that our Phase 2 group trended toward the low end of Sarason's scale but was still comparably supported to the comparator group. In contrast, the Sense of Community Scale scores, which showed the Phase 2 participants scoring 3.1 ± 1.1, compared with the index population of residents in a community fighting a chemical disposal site, with a score of 5.03. This suggests that the Phase 2 group may feel more isolated than a comparable group fighting a common threatening cause. The sense of isolation appears to be an intrinsic character of the participants, rather than a factor of geography, as the Phase 2 cohort appeared similarly distributed between urban and rural sites as national statistics describe.

The satisfaction component of Sarason's scale was not deployed, as the constructed Likert scale of 1 to 5 tends to skew in small populations, suggesting its utility in this study may have limitations.[32] Instead, Ferrari's[23] Caregiver Satisfaction Scale is considered a stable measure in small populations. Compared with a cohort of caregivers of persons with AIDS, Phase 2 stress scores were 20.5 ± 6.7 compared with 15.9 ± 9.3, and satisfaction scores 45.5 ± 5.4 compared with 22.3 ± 9.5.[23] This suggests that the cohort of Phase 2 parents shows comparable stress levels relative to caregivers of persons with AIDS in an era where HIV infection was a terminal disease. Conversely, Phase 2 participants reported higher degrees of satisfaction. In Ferrari's analysis, stress scores correlated with higher scores on the Beck Depression Inventory Scale, implying that higher scores on the stress scale predict an increased probability of depression in the caregiver. This analysis was not attempted in the study,

but the finding of high stress scores in our cohort may indicate a higher predisposition to anxiety or depression in the interviewed parents; this is a hypothesis which is supported by the work of other groups.[3] From Ferrari's work, the satisfaction scale scores remained stable over time; however, it is not clear how or if it moderates the stress score. In our cohort, higher satisfaction scores compared with caregivers of persons with AIDS may be biased because the line of questioning directly addressed a parent-child relationship. Accordingly, parents generally may have difficulty admitting a divestment in that relationship, and this likely was compounded by the fact that the interviewer in this study was a health care practitioner, although not directly involved in the care of the cohort children.

Support and Technology Can Form a Common Trajectory of Care

The concept of changing needs for support over time is a well-established paradigm. Bensley et al described an eHealth Behavior Modification Model that assesses the stage of change in behavior of an online user, and try to match the user with established websites reinforcing change at that stage of the trajectory.[43] Similarly, online grief support groups often document stages of grieving and the necessary supports that are required at each stage. In a study describing an online support group for grieving mothers with perinatal losses, a cohort proceeded through a "shared metamorphosis," representing recognized stages of grief in response to the staged supports offered.[44] These trajectories are not limited to recovery but include coping and development of advocacy.[45] This adds credence to what parents experience when receiving a chronic diagnosis in a child, irrespective of the perceived mortality or morbidity.[46] In this study cohort of parents caring for children with CKD, the needs were no different.

The construct of a support trajectory provides a framework for understanding the information content and its mode of delivery. Brazy et al described the information seeking behaviors of 19 mothers of premature infants, and noted that within the first month of the baby's birth, mothers spent anywhere from 10 to 20 hours per week information seeking.[47] Mothers required more information than was provided by the health care professionals, and health care professionals underestimated what mothers wanted to know. Mothers would therefore seek information from other sources including the Internet, noted in the theme "information hunger."[48] In our cohort, many recalled the need for information early in the diagnosis phase of kidney disease, noting that aside from using health care providers as resources, it was difficult to find information that was reliable, accurate, or pertinent. A significant reason for parents to not adopt the Internet for information gathering is the generally poor quality of information available to parents, including information provided by parent-run sites.[49] One solution is to involve health care professionals in the creation of the available information, particularly because health care professionals share these concerns about information quality. Semere et al studied 150 families and their attitudes to information on the Internet and found that more than 98% of families found the information to be helpful and reliable despite conflicting opinions from health care practitioners.[50] The authors used this as a call to arms to establish guidelines for health information quality.

The support trajectory also informs mode of delivery, which is partly assessable by user uptake (adoptability). Parents who used Ability Online for information seeking valued the accessibility of information and perspectives but were disappointed that the information provided was unstructured. Intense information seeking is commonly manifested among parents dealing with new diagnoses, and parents of children with kidney disease express the same desire for consolidated information of high quality. In studies where families are involved in deciding what basic information should be available, the format often used initially is a static page of data that could be reviewed at leisure and in detail.[51] As parents move through the process of managing the disease, the requirement to seek information through other means grows. Nordfeldt et al describe a web portal for diabetes management that incorporated searchable pages of information. Patients eventually transitioned to use the chat rooms and message boards to probe for information from other parents on more complex issues, or to help validate the information available on static pages and make it more personal.[52]

Limitations

Our study used an established cohort of participants in the Ability Online system. We identified after the initial interviews that demographic data would be helpful in qualifying the statements around information seeking in technology; however, we were unable to obtain these demographic data in retrospect. While we do not have this information to qualify all of the data, we did obtain the demographic information from the Phase 2 validation cohort. Our validation cohort did agree with the themes that we constructed, suggesting the generalizability of the data within the cohort. In terms of broader generalizability to parents of children with CKD, we identified that our Phase 2 cohort had higher incomes but lacked representation of those who only completed up to high school education. Our Phase 2 cohort also has a slightly more urban representation than the Phase 1 cohort, but we are unable to determine whether this is significant due to the small sample size. In terms of applicability to parents of children with CKD, we feel that the themes we describe represent the experience of online information seeking. However, we suspect, that like others, we may not be representing the views of a segment of the population who do not use the Internet for information seeking, perhaps due to low health literacy, low socioeconomic status, or other undetermined barriers.

Conclusion

Parents of children with kidney disease demonstrate common characteristics to users of other health-interest websites. Interviews of experienced users performing an assessment of the website provided valuable insight to the relationship between how social support and information gathering is conducted, and how it can be impacted by the choice of information delivery format. In addition to providing suggestions for design elements of an existing website, specific issues about online access to health care resources require further exploration, particularly as they relate to quality of online relationship and privacy contributing to attrition.

Appendix

Interview Script

Do you use any social networking sites like Facebook or Myspace?
How did you learn about computers/Internet? For example, have you taken courses, read, or experimented on your own?

What is the highest level of education that you have completed?

Ability Online
How comfortable would you say you are using computers? The Internet?
Did you find Ability Online was usable given your level of computer skills?
If not, what are some things that you found hard to do on Ability Online? (If necessary, prompt: for example, was there anything that you tried to do on Ability Online that you had to work around)
If not, what are examples of things that you tried to do but were never able to do?

When using Ability Online, did everything work well?
If no, what were some of the things that seemed to be awkward to do?

How did you learn to use Ability Online? (If necessary, prompt: for example, did you read online instructions/documentation, has someone explain it to you, trial and error)
How long did it take for you to feel comfortable using Ability Online?

When using Ability Online, did instructions or information make sense?
If not, what are examples of things that you found confusing?

Did everything work the way you expected it to with Ability Online?
If not, what were some examples of surprise responses that occurred when you tried to do something?

Did you feel that you could make changes to suit your needs to Ability Online? (Prompt, for example, some people find it difficult to read small text, and some systems allow you to change the text size to be more readable. Did you find Ability Online allowed you to do this if necessary?

Did you get a sense that the system adapted to how you used it? For example, when you tried to do a task, like post a comment, did it take fewer steps to do that each time you tried?

How well did you develop a sense of support using Ability Online, compared with, for example, a one on one conversation?

Is there anything that you noted with how postings work that made it more difficult to follow or develop a supportive relationship? If so, how would conversations be easier to follow for you?

How easy is it for you to identify different users participating in a conversation?
Is there anything that you think makes it hard to follow?
Is there anything that would make it easier for you?

Was there ever a time when you did not participate in a forum or conversation because the system was hard to use? Or prevented you from participating?
Did you persist until you got it figured out or did you give up?
If you persisted, how did you resolve the problem? For example, did you contact someone at Ability Online, read online information, talk with another user and so on.

How did the site look to you? Was it easy to read information from the screen?

How did you find the system was at identifying the start of a new conversation?

How easy was the system at organizing responses/dialogue within a conversation?

Was there ever a time when you felt you didn't want to share information in a forum?
If so, what reasons prevented you from sharing that information?
Would you/did you share that information with another user by e-mail?
If you held back information from posts or e-mails or participated less, under what circumstances or environment would you feel comfortable sharing that information with another user?
Would you share the information if you didn't have to transmit it electronically (ie, face to face conversation)?
If there is no situation where you would share that information, would you feel comfortable sharing that information at all with a trusted family member or a member of child's health care team?

Did you find that you had enough time to participate and keep up with the online discussions?
If not, what are some reasons that you had problems finding the time?

Do you feel that the quality of the relationships and support in any way influenced how easy you found the system to use? If so, please explain and give examples.

Did your participation decrease with time? If you found that your participation decreased over time, what would you give as reasons for this happening?

Ethics Approval and Consent to Participate

Ethics approval was obtained from the University of Alberta Human Research Ethics Board and consent from participants was obtained verbally before conducting the interview.

Consent for Publication

Consent for publication was obtained from all authors.

Availability of Data and Materials

There is no further data or materials available.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received financial support for the research, authorship, and/or publication of this article: The authors received financial support for this research from the Kidney Foundation of Canada.

References

1. Zhang QL, Rothenbacher D. Prevalence of chronic kidney disease in population-based studies: systematic review. *BMC Public Health*. 2008;8:117-130.
2. Fortin C, Williams B, Ivis F, Na Y, Hall N. *Treatment of End-Stage Organ Failure in Canada: 1998-2007*. Canadian Organ Replacement Register, ed. Ottawa, Ontario: Canadian Institute for Health Information; 2009. CORR Annual Report.
3. Madden S, Hastings R, V'ant Hoff W. Psychological adjustment in children with end stage renal disease: the impact of maternal stress and coping. *Child Care Health Dev*. 2002;28(4):323-330.
4. Hooper SR, Duquette PJ, Icard P, Wetherington CE, Harrell W, Debbie SG. Social-behavioural functioning in paediatric chronic kidney disease. *Child Care Health Dev*. 2009;35(6):832-840.
5. Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics*. 2008; 121(2):349-360.
6. Fielding D, Moore B, Dewey M, Ashley P, McKendrick T, Pinkerton P. Children with end-stage renal failure: psychological effects on patients, siblings and parents. *J Psychosom Res*. 1985;29(5):457-465.
7. Human Resources and Skills Development Canada. Canadians in context—geographic distribution. Human Resources and Skills Development Canada. http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=34. Published 2013. Updated August 16, 2013. Accessed June 2, 2017.
8. Unknown. Ability Online 2011. Publisher Unknown. http://www.abilityonline.org/. Published July 23, 2012. Accessed June 2, 2017.
9. Nicholas D. Edmonton, Alberta, Canada; 2010. Personal communication.
10. Nicholas D, Picone G, Vigneux A, et al. Evaluation of an online peer support network for adolescents with chronic kidney disease. *J Technol Hum Serv*. 2009;27(1):23-33.
11. Galinsky MJ, Schopler JH, Abell MD. Connecting group members through telephone and computer groups. *Health Soc Work*. 1997;22(3):181-188.
12. Scharer K. An Internet discussion board for parents of mentally ill young children. *J Child Adolesc Psychiatr Nurs*. 2005;18(1):17-25.
13. Scharer K. Internet social support for parents: the state of science. *J Child Adolesc Psychiatr Nurs*. 2005;18(1):26-35.
14. Drentea P, Moren-Cross JL. Social capital and social support on the web: the case of an internet mother site. *Sociol Health Illn*. 2005;27(7):920-943.
15. Lowe P, Powell J, Griffiths F, Thorogood M, Locock L. "Making it all normal": the role of the internet in problematic pregnancy. *Qual Health Res*. 2009;19(10):1476-1484.
16. Madge C, O'Connor H. Parenting gone wired: empowerment of new mothers on the internet? *Soc Cult Geogr*. 2006;7(2):199-220.
17. Nyström K, Öhrling K. Parental support: mothers' experience of electronic encounters. *J Telemed Telecare*. 2006;12: 194-197.
18. O'Conner M, Madge C. "My mum's thirty years out of date": the role of the Internet in the transition to motherhood. *Community Work Fam*. 2004;7(3):351-369.
19. Chan AHN. "Life in happy land": using virtual space and doing motherhood in Hong Kong. *Gend Place Cult*. 2008;15(2): 169-188.
20. Suzuki LK, Kato PM. Psychosocial support for patients in pediatric oncology: the influences of parents, schools, peers, and technology. *J Pediatr Oncol Nurs*. 2003;20(4):159-174.
21. Zrebiec JF. Internet communities: do they improve coping with diabetes? *Diabetes Educ*. 2005;31(6):825-828, 830-832, 834, 836.
22. Feigelman W, Gorman BS, Beal KC, Jordan JR. Internet support groups for suicide survivors: a new mode for gaining bereavement assistance. *Omega (Westport)*. 2008;57(3):217-243.
23. Ferrari JR, McCown W, Pantano J. Experiencing satisfaction and stress as an AIDS care provider. The AIDS caregiver scale. *Eval Health Prof*. 1993;16(3):295-310.
24. Eysenbach G. The law of attrition. *J Med Internet Res*. 2005;7(1):e11.
25. Christensen H, Griffiths K, Korten A, Brittliffe K, Groves C. A comparison of changes in anxiety and depression symptoms of spontaneous users and trial participants of a cognitive behavior therapy website. *J Med Internet Res*. 2004;6(4):e46.
26. Farvolden P, Denisoff E, Selby P, Bagby R, Rudy L. Usage and longitudinal effectiveness of a web-based self-help cognitive behavioral therapy program for panic disorder. *J Med Internet Res*. 2005;7(1):e7.
27. Wangberg S, Bergmo T, Johnsen J. Adherence in Internet-based interventions. *Patient Prefer Adherence*. 2008;2:57-65.
28. AbuSabha R, Achterberg C. Review of self-efficacy and locus of control for nutrition- and health-related behavior. *J Am Diet Assoc*. 1997;97(10):1122-1132.

29. Bandura A. Health promotion by social cognitive means. *Health Educ Behav*. 2004;31(2):143-164.
30. Creswell JW, Plano VL. *Designing and Conducting Mixed Methods Research*. Thousand Oaks, CA: Sage; 2007.
31. Perlman G. User interface usability evaluation with web-based questionnaires 2009. http://oldwww.acm.org/perlman/question.html. Accessed June 2, 2017.
32. Sarason IG, Sarason BR, Shearin EN, Pierce GR. A brief measure of social support: practical and theoretical implications. *J Soc Pers Relat*. 1987;4(4):497-510.
33. Bachrach KM, Zautra AJ. Coping with a community stressor: the threat of a hazardous waste facility. *J Health Soc Behav*. 1985;26(2):127-141.
34. Mavis A, Ertl A, Chapman S, Cassidy L, Lerret S. Vulnerability and chronic illness management in pediatric kidney and liver transplant recipients. *Prog Transplant*. 2015;25(2):139-146.
35. Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Res Nurs Health*. 1997;20(2): 169-177.
36. Cotten SR, Gupta SS. Characteristics of online and offline health information seekers and factors that discriminate between them. *Soc Sci Med*. 2004;59(9):1795-1806.
37. Zhao S. Parental education and children's online health information seeking: beyond the digital divide debate. *Soc Sci Med*. 2009;69(10):1501-1505.
38. Pew Research Center. Internet/broadband fact sheet. http://www.pewinternet.org/fact-sheet/internet-broadband/. Internet use over time. Published 2017. Accessed June 2, 2017.
39. Interactive H. "Cyberchondriacs" on the rise? http://www.theharrispoll.com/health-and-life/_Cyberchondriacs__on_the_Rise_.html. Published 2010. Accessed June 2, 2017.
40. Atkinson NL, Billing AS, Desmond SM, Gold RS, Tournas-Hardt A. Assessment of the nutrition and physical activity education needs of low-income, rural mothers: can technology play a role? *J Community Health*. 2007;32(4):245-267.
41. Magee JC, Ritterband LM, Thorndike FP, Cox DJ, Borowitz SM. Exploring the relationship between parental worry about their children's health and usage of an internet intervention for pediatric encopresis. *J Pediatr Psychol*. 2009;34(5): 530-538.
42. Sarason I, Levine H, Basham R, Sarason B. Assessing social support: The Social Support Questionnaire. *J Pers Soc Psychol*. 1983;44(1):127-139.
43. Bensley RJ, Mercer N, Brusk JJ, et al. The eHealth Behavior Management Model: a stage-based approach to behavior change and management. *Prev Chronic Dis*. 2004;1(4):A14.
44. Capitulo KL. Perinatal grief online. *MCN Am J Matern Child Nurs*. 2004;29(5):305-311.
45. Black AP, Baker M. The impact of parent advocacy groups, the Internet, and social networking on rare diseases: the IDEA League and IDEA League United Kingdom example. *Epilepsia*. 2011;52(Suppl 2):102-104.
46. Holmbeck GN, Alriksson-Schmidt AI, Bellin MH, Betz C, Devine KA. A family perspective: how this product can inform and empower families of youth with spina bifida. *Pediatr Clin North Am*. 2010;57(4):919-934.
47. Brazy JE, Anderson BM, Becker PT, Becker M. How parents of premature infants gather information and obtain support. *Neonatal Netw*. 2001;20(2):41-48.
48. Plantin L, Daneback K. Parenthood, information and support on the internet. A literature review of research on parents and professionals online. *BMC Fam Pract*. 2009;10:34.
49. Schaffer R, Henderson GE, Churchill LR, et al. Parents' online portrayals of pediatric treatment and research options. *J Empir Res Hum Res Ethics*. 2009;4(3):73-87.
50. Semere W, Karamanoukian HL, Levitt M, et al. A pediatric surgery study: parent usage of the Internet for medical information. *J Pediatr Surg*. 2003;38(4):560-564.
51. Sheets KB, Best RG, Brasington CK, Will MC. Balanced information about Down syndrome: what is essential? *Am J Med Genet A*. 2011;155A(6):1246-1257.
52. Nordfeldt S, Hanberger L, Bertero C. Patient and parent views on a Web 2.0 Diabetes Portal—the management tool, the generator, and the gatekeeper: qualitative study. *J Med Internet Res*. 2010;12(2):e17.