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**Evaluation of an Online Peer Support Network for Adolescents with Chronic Kidney Disease**

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### Abstract

This study reports on the development and evaluation of an online social support network for adolescents with chronic kidney disease (CKD). Twenty four adolescents were enrolled in a 6 month online intervention in which asynchronous and synchronous online peer support was facilitated. Online dialogue transcripts were analyzed as were post-intervention qualitative interviews with network participants. Findings identify both benefits and challenges of online social support for adolescents and provide guidelines for future support initiatives. The study supports online support as a valuable resource for adolescents with CKD.

Background

Chronic kidney disease (CKD) is occurring at an increasing rate worldwide. Prevalence rates indicate that approximately 20 million Americans or 1 in every 9 U.S. adults has chronic kidney disease (National Kidney Foundation, 2007). Children with CKD present a range of health challenges and often experience a series of comorbidities and adjustment issues. Beyond implications associated with daily care needs, CKD is reported to evoke a range of challenging emotions for patients and their families (MacDonald, 1995; Nicholas, 1998; Nicholas, 1999). Adolescents with CKD are profoundly affected by the disease and exhibit varying levels of stress associated with CKD (Nicholas, Koller, & Picone, 2004). These findings are consistent with the literature examining the impact of chronic illness on adolescents which identifies adolescents with chronic illness to be a population at risk for emotional and mental health challenges (Drotar, 1999; Snethen, Broome, Kelber, & Warady, 2004; Woodgate, 1998a).

Adolescents with CKD experience concerns associated with their condition and perceive, in varying degrees, limited social outlets or opportunities to discuss these issues and stresses. Stresses include concerns about illness and treatment, missed developmental milestones, feeling 'left out' of health-related information, peer relationships (Nicholas, Koller, & Picone, 2004), educational and cognitive deficits (Snethen, Broome, Kelber et al., 2004), and worries about the future (Nicholas, 1998; Nicholas, Koller, & Picone, 2004). Peer networks are typically relied upon by adolescents and may become a source of or contributor to identity formation, a sense of 'belonging', and differentiation from parents (Nicholas, Koller, & Picone, 2004).

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Yet for adolescents with CKD, peer interaction sometimes is impeded due to decreased energy and demands of care. These adolescents may be left with diminished social networks, resulting in isolation and a lack of meaningful peer relationships (Nicholas, Koller, & Picone, 2004). Moreover, the number of children with CKD is relatively sparse; hence, geographic dispersion limits peer-based connection with others adolescents with CKD.

The desire among adolescents with CKD to connect with peers, coupled with scattered geographic home locations of patients, invite the development of innovative approaches that foster accessible peer support among adolescents with CKD. Online approaches using the Internet offer promise in facilitating an accessible social network for these adolescents. This form of technology can facilitate and sustain a meaningful social network that is not limited by geographic distances and scheduling restrictions associated with CKD treatment.

Toward this end, a six-month online peer-based network for adolescents with chronic kidney disease was implemented and evaluated. Research questions addressed adolescents' experience in using the online network, issues discussed in the online network, and perceived benefits and challenges experienced within the network.

### The Intervention

Upon receipt of informed consent, participants were placed on an e-mail list of network members. This process followed a careful registration process in which a mailed identity verification was sent to participants, verified by them, and then returned to Ability Online via Canada Post. Prior to online access, the name of each participant was

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then reviewed by the local hospital social worker in order to confirm their involvement in that renal program. Once participants' identities were confirmed and online registration was processed, they were: (1) enrolled in the online network, (2) assisted in accessing the network by the facilitator, as needed, (3) welcomed 'online' by the network facilitator, and (4) invited to read and post messages on the online support network a minimum of once per week for a period of six months. Participants were also invited to participate in live chats hosted by the online support network. This newly-created network was monitored by an MSW-trained facilitator with clinical research experience in a pediatric setting.

The network was hosted by *Ability Online*, an internationally-renowned electronic messaging network with over 4,000 users. *Ability Online* specifically provides a safe forum of online peer support for children, parents and families affected by pediatric chronic health conditions, disabilities and special needs. The network employs stringent state-of-the-art online safety processes including monitoring and privacy mechanisms. Website and electronic capture of information on the network implements, "password protocols and encryption software to protect personal and other information (that is) received online" (Ability Online, 2004). Within the online network, participants were invited to raise issues, questions and responses as desired with a general focus on adjustment to CKD. In addition to the online discussion forum, adolescents were also invited to take part in live chats which were held in the last month of the intervention.

## Methods

Data collection included transcript analysis of online network dialogue and post-intervention qualitative interviews with participating adolescents. A comparison group was not used due to the qualitative nature of this study and the focus on online processes and experiences. There is limited literature and current research on adolescent experiences of living with CKD and the impact of online social support for this population; therefore, open exploration of participant experiences and perceptions can provide valuable knowledge and insight.

### Network Transcript Analysis

To understand important elements of online network process as well as the substantive issues that mattered to participants as discussed in the online network, the verbatim transcripts of the networks (initial comments, inquiries and replies) were reviewed. Transcripts were analyzed for substantive content (e.g., experiences), network/group process and development (e.g., participation, group dynamics, flow, relationship/alliance-building), and ways that peer support was enacted (e.g., different uses of the network [browsing, posing questions, replying], and the types of support identified [informational, emotional, offering of tangible support] (Dunham, Hurshman, & Litwin, 1998; Nicholas, 2003a).

For qualitative analysis, computer software (NVivo) was utilized to assist with analysis of interview transcripts resulting in concept saturation and theme generation. This content and process analysis identified important areas for knowledge building in

terms of identifying and examining important issues to consider in future social support networks for adolescents with CKD.

Reliability of emerging themes was demonstrated through qualitative rigor, including the use of (1) multiple reviewers of all data and subsequent reviewer consensus regarding coding schemas; (2) referential adequacy (sufficient evidence of codes based on text quotes); (3) negative case analysis (systematic search for evidence disconfirming or differing from emergent themes); (4) peer debriefing (follow-up with experts in the field to address the viability and clinical relevance of emergent findings); and (5) member-checking (review of emergent themes for confirmation, by a panel of at least four participants, selected by participant interest/willingness in member checking) (Lincoln & Guba, 1985).

#### Post-Intervention Qualitative Interviews

Participants were interviewed about their perceptions of the online support intervention. McCracken's (1988) long interview method was utilized for qualitative interviewing. This approach invites open expression of participants' perceptions while ensuring thorough coverage of common topical areas. An interview schedule outlining broad, open-ended questions explored: perceived outcomes of the network; experiences and perceptions; processes of peer support within the network; elements that contributed to and/or limited beneficial outcomes; and the experience of using technology for peer support. Interviews were audio recorded and conducted in-person at a convenient location for interviewees. Following verbatim transcription of interviews, qualitative

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analysis, assisted by computer software (NVivo), resulted in concept saturation and theme generation.

### The Sample

Twenty-four adolescents with CKD (mean age of participants was 15 years) participated in the online network. Participants were drawn from databases of adolescents with CKD at three pediatric health sites in central Ontario, Canada. Upon study initiation, 16 participants had received a kidney transplant, 4 received peritoneal dialysis, 2 were on hemodialysis, and 2 were receiving pre-renal replacement therapy. In addition, a purposive sample of ten network members was interviewed following the intervention. Participants were selected for interviews based on a range of variables such as age, gender, location and availability for the interview. Participants were introduced to the study by receiving an advertisement describing the study from a local health care provider, and a follow-up contact was made by a research coordinator. All potential participants were informed that their participation was entirely optional. Ongoing access to support was made available throughout the intervention through the participants' local hospital social worker as well as having access to a toll-free telephone number that reached the network facilitator.

### Results

Participants demonstrated a range of engagement in terms of either (a) logging in and lurking, (b) logging in and posting or (c) participating in the live chats. Topics shared in the online forum included discussion about participants' home community, family, pets, gender, employment, age, activities and interests, and school (e.g., school

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name and location, grade, like or dislike of school, classes and assignments).

Participants' discussion in some cases led to specific discourse about kidney disease. In addressing their experiences with kidney disease, participants identified personal issues and challenges such as their experience of dialysis or transplantation and the varying emotions experienced. They conveyed empathy, offered tangible help or advice, and vented feelings about managing kidney disease in the context of their daily lives.

For example, a 15 year old girl wrote to the group, *“Hi my name is Abby and I have just started Grade 10 and I'm loving it. I live in a family of four (people) and two dogs. I love playing street hockey with my big brother, and neighbors. In school I'm trying to learn so hard how to play the clarinet in music class. I have had my kidney transplant already for about 13 months now. I was so scared when I first found out that my kidney was starting to fail and found out that I was going to be needing a transplant. Now I have been through a lot of different things, but this was the scariest thing that I had to ever face. If u would like any help with wanting to know what to expect then u can leave me a message, lets hope u know how. Thank u for reading, Abby”* (original spelling not changed, all identifying information including participant's name, has been changed).

In response, another participant commented, *“Hi Abby, my name is Jenny and I know what you are going through with your kidney transplant. I had one when I was four years old because the doctor told my parents that I had no kidneys when I was born, but I am doing ok now. I have had my kidney transplant for 12 years now. I am very lucky to be alive. Hope to talk to you soon bye, Jenny.”*

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Analysis of the online discussion board suggests that adolescents not only wanted to learn from others, but also desired to share their own stories, experiences and wisdom gained as they had dealt with kidney disease. This theme became more explicit during post-intervention interviews in which one teen described how she benefited from hearing about the experiences of another teen participating in the online forum: *“She (the peer in the online network) is a year older than me I think, so I just had a few questions about like, how her parents were, if they were more protective, because I had had an interesting week when my parents didn’t let me go anywhere because I hadn’t been feeling great. I just wanted another girl’s perspective. That was helpful. She said she had talked to her parents about it and then she got a cell phone and then it was easier to just go out and always have that contact.”*

Adolescents spoke about wanting to share their experiences and supporting others, as exemplified below: *“Because I’m doing fine with my experiences, I’d love to give advice to a younger girl or guy who’s just like, going to have a transplant. Like, I’d find that cool...Just give them more advice...Like, with my personal life because I find it’s affected a lot too ...”*

In forging supportive peer relationships, adolescents with common interests appeared to connect more quickly and frequently than others who had more difficulty finding common ground. Particularly in the discussion board, adolescents who participated in the online discussions most frequently either lived in the same city, were close in age, or had met briefly in person. This may speak to the importance of effective and strategic matching for adolescent online support participants and raises the potential value of facilitator support in ensuring mutual interests and points of connections.

### Live Chats

Discussion during the three live chats tended to revolve around participants' interests including movies and video games, with kidney disease following these earlier topics of mutual interest. Participation in live chats was reportedly limited by the time available and was restricted by heavy weekday schedules (i.e. homework, extracurricular activities and part-time employment). For some adolescents, live chat interactions presented challenges in following the conversation due to the rapidity of moment-to-moment dialogue, the number of individuals participating, frequent interruptions in the flow of conversation, and challenges resulting from posed questions that went unanswered. However, despite challenges for a few teens, the interactivity with their peers provided by online dialogue was appreciated as a beneficial resource and support.

### Post-Intervention Interviews

Several participants described little support from healthy peers and alternatively sought support from other adolescents with CKD. One adolescent explained the general lack of understanding and compassion from healthy peers, stating, "*My health is my number one priority, which a lot of my friends don't get*". Adolescents described strongly valuing the online support received from others and participants described a desire for continuation of the group for multiple reasons, as exemplified by participants below.

*"To help other kids that are suffering from this disease... I could help them and tell them what my experience with that is."*

*"To share my experiences and to show people who are about to have a transplant how it's not as scary as the doctors might make it seem."*

*"It would be cool to talk to the kids who are on dialysis and they're waiting for their kidney - it would be good if we give them information about what happens when you receive a kidney transplant, what are the side effects and whatever experiences that we*

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*should share with them, and when we were on dialysis how did we suffer and other stuff like that.”*

*“If I go [online] one-on-one, I’ll go with a dialysis kid because the dialysis kids are more curious to have a transplant. The people who have had transplants don’t need any more experience because they already have a kidney. The kids who are on dialysis, they need some more experience or they need some person who advises them to be careful about the mistakes we’ve made, you don’t want them to repeat.”*

*“Dialysis to transplant would be a good match [for online interaction]. There are a lot of differences. When you’re on dialysis you’re not that strong and you can’t do stuff, you can’t play games, you can’t swim. But when you’ve had a transplant, life is easier.”*

As illustrated in these examples, participants valued and anticipated opportunities to share their experiences and assist others within online communication. While they described enjoyment and benefit from listening and learning from others, they also valued being able to offer both emotional and informational support to others. Toward this end, the online forum allowed participants the opportunity to reflect and share lessons learned and expertise gained. In pursuing this communication, adolescents expressed a general preference for the posting forum over the live chat. However they felt that a live chat option was appropriate for additional, separate one-on-one chats with peers from the larger online context.

Some participants suggested incorporating personal profiles on the website that would allow participants to know one another by sharing personal information such as age, gender, interests, school-related information and photos. A few participants expressed concern over both their safety, right to privacy, and anonymity online; however, they sought a balance between safety/anonymity and fostering connection with others through “putting a face to the name” and sharing personal information if they so chose. One teen stated that personal information online would foster connection:

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*“Just make [the network] more personal. (Having personal bios) would be so much easier because then you will get those little things about people such as, where they live, how old they are, if they’ve had a transplant or even just want kind of music they listen to. If you find someone who listens to the same music you can have an hour conversation just from that. You just have to find one little thing that is similar. Even like, age - just finding out their age because if they’re in the same age group then you can talk about school.”*

While participants ranged in their views about divulging personal information, they consistently looked for topics or characteristics of mutual interest among one another. To the extent that they were able to find issues in common, they tended to forge meaningful and supportive relationships, both giving and receiving information, support and advice. Facilitating such a process of connecting adolescents appears to be an important consideration in fostering engagement in online support.

### Discussion

These data clearly convey that adolescents with CKD experience difficult challenges and concerns that can, in part, be mediated by an online support resource. The participants in this network – many of whom lived substantial distances apart from one another – were able to come together virtually, and meaningfully share key elements of their lives and experience with CKD. They conveyed to each other both challenges and adjustments made in incorporating CKD in their daily lives and were able to utilize the online network to discuss areas of mutual interest. Some participants’ desire for more personal information, face-to-face contact or pictorial/biographical descriptions of participants, reflects their continuing attempts to identify who’s who in the network. We view this desire as developmentally appropriate and evidence of beneficial network

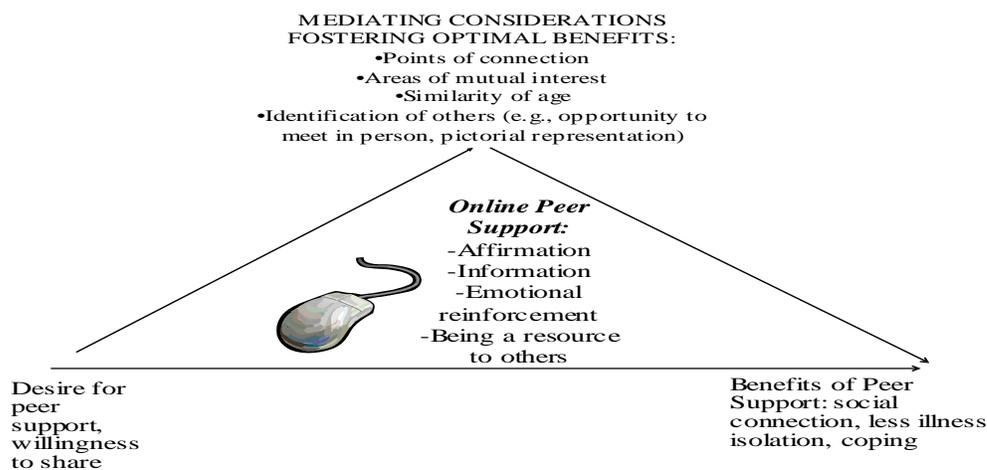
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impact as it demonstrates participants' interest and engagement, desire for ongoing meaningful network contact, and positive peer support among the group.

This online resource assisted participants by facilitating them in hearing and sharing some of their challenges; increasing connection with peers journeying a similar health experience; and providing knowledge gain and empowerment. Consistent with other literature, the accessibility and flexibility offered by this online support, facilitated friendship formation and social network creation, and reduced social isolation (Galinsky, 1997; Nicholas, 2003b; Weinberg, 1995). The text-oriented electronic mail format was generally reported to more effectively facilitate dialogue, particularly in cases in which cognitive or keyboarding functioning precluded the rapid processing necessary for the live chat modality.

In considering future interventions of online support for youth with illness, several mediating considerations emerge in fostering optimal benefits, as illustrated in Figure 1.

Figure 1:



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Findings illustrate both perceived benefits of the support network for adolescents and challenges particularly related to the delivery of online support. For instance, comfort with the synchronous, live chat varied. Also, some participants relied on research staff for troubleshooting help for website navigation and password access. Accordingly, it is advisable that technological support/education be integrated within online support as well as methods of online communication that match the preferences and abilities of the target population. Supporting participants in finding common ground and points of mutual interest also would serve to enhance and support participants' engagement and potential achievement of beneficial outcomes. Those developing and facilitating an interactive online network for children and adolescents with a health condition such as CKD should seek to maintain participant safety and confidentiality and ongoing psychosocial and technical support should be delivered by a trained group moderator.

Facilitating an online network for children with a relatively rare disease such as CKD presents challenges in implementation and evaluation. For instance, the research team necessarily drew from multiple centers in order to garner an adequate sample for both network quorum establishment and sample sufficiency. However, online approaches mitigate this concern by overcoming geographic barriers hence including potential participants regardless of home location. In this study, the wide range of ages (12-18 years) presented challenges in that substantial developmental differences and priorities were noted across the adolescent age span. As a result, future online network formation may be enhanced by establishing reasonable age cohorts for participation.

Conclusion

This study illuminates the value of an online support intervention, suggesting that an online network is beneficial and appreciated by participating adolescents.

Accessibility, ease of communication, connection with peers, and a sense of privacy appear to contribute to adolescents' use of, and benefit from, online support for adolescents with CKD. They further illuminate challenges in online support provision for adolescents, yet these challenges do not appear to outweigh the potential benefits of this emerging form of peer support. Accordingly, online support for adolescents appears to be a promising endeavor worthy of further study.

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