

Editorial

Considerations for using virtual communities for psychosocial support in pediatric transplantation: An editorial

The use of Internet technology for health information has increased exponentially over the last decade of the 20th century (1, 2). Further, this point in history has been described as the first when humans became overloaded with the production and dispersion of health information (3). Various communication technologies take place online, including chat rooms, instant messaging, topic forums, blogs, message boards, and social and professional networking sites (i.e., facebook, linkedin). The commonality among these technologies is that they allow for real-time interaction among individuals without necessitating the presence in the same physical locale. Virtual communities integrate all of these communication tools but are prominently known for their use of avatars. An avatar is the user's representation of him/her or an alter ego, displayed in the form of a three-dimensional model that may look like and/or act like the individual user, and can be moved around in the background. According to the 2007 Pew Internet and American Life Project, 55% of youth (12–17 yr) use virtual communities (4).

Zora, the virtual community software created by Bers et al. (5), was designed as an intervention specifically for adolescent transplant patients. The goal of this innovative web-based environment is to provide an opportunity for adolescents to creatively express their identities and concerns related to chronic illness, offer a means of support and increased social networking, and promote a sense of community. Zora incorporates a webpage, instant chat system, and a 3-D world that can be manipulated by the participants. One unique feature of Zora is that an entire city is created around the topic of managing an organ transplant – participants can write stories about their transplant experiences, express their fears and frustrations, share their

hopes and accomplishments, and receive additional education on topics such as adherence to medical regimens and transition to college. Zora allows adolescents to take ownership of the project by creating a personalized experience that is meaningful to them, perhaps helping them take control over the chronic illness in a way that may not be possible in their life. At the same time, there are ongoing opportunities for collaborative group activities and oversight by a team leader.

What are the advantages?

There are many potential advantages to the use of virtual communities such as Zora with medical populations. Most in-person social support interventions are limited by small sample sizes for a number of reasons. Coordination of schedules because of daily time commitments of adolescents such as school, illness management tasks, time with peers, and extracurricular activities may interfere with regular attendance at a group. Being able to log into the virtual community even for a few minutes at a time that is convenient may be more appealing, particularly for adolescents who may prefer to interact online late in the evening when an in-person support group is not feasible.

Practical barriers to support access in a chronic illness population include transportation, accessibility, and cost. Patients may live far from the health care site, and whereas attendance at transplant clinic is necessary for illness management, making an additional trip to the hospital for a support group may not be feasible. Some patients may not have a means of transportation or may not want to incur additional costs inherent in travel, particularly adolescents who still rely on family members to get around. Inability to travel

when not feeling well or the opposite dilemma expressed by adolescents, not wanting to come to the hospital when they are feeling well, pose additional challenges that can be addressed by a virtual support group. Adolescents can thus interact with other transplant recipients from a more comfortable home environment.

Virtual communities enable adolescents to anonymously communicate with others who have similar health problems, which may promote a greater expression of thoughts and feelings (6). Internet-based support also has benefits for those who may be socially awkward or shy and may otherwise avoid social interactions; virtual communities allow them to participate in social networking in a way that may feel more comfortable. Virtual support systems also offer the usual advantages of support groups such as reducing isolation, providing a sense of belonging to a community, enabling members to share ideas and problem solve with peers, and increase adolescents' social network in general (6). Thus, virtual communities are able to overcome barriers and offer many additional advantages over in-person support groups.

What are the potential challenges?

Despite the advantages that virtual communities can offer chronically ill adolescents, a variety of limitations must also be considered. First, some patients may experience significant emotional distress while discussing or acting out their transplant experience in the virtual space. Perhaps, the somewhat distanced experience of living via an avatar in a virtual world may give patients the courage to disclose things they would not have otherwise. What if a patient reports suicidal ideation or intent? What if a patient discloses a recent experience of sexual abuse? Similarly, there may be instances of cyber bullying that may lead to feelings of victimization and isolation (7). It is not uncommon for these situations to arise during support groups, but the challenge in a virtual community is how to assist patients in a clinically responsible and timely fashion to keep them safe.

Second, if a virtual community incorporates any sharing of personal health information among its members, making sure the site is HIPAA compliant would also be wise. Another question related to privacy is whether the transplant program can monitor who has access to the virtual community. It would be essential to keep the community safe and secure, which would require the usage of usernames and passwords distributed directly from transplant clinics or

hospitals. Administrators would need to monitor the site to ensure that only members of participating transplant centers are allowed access.

Lastly, there are several practical considerations to the use of virtual communities among adolescents. In order to benefit from a virtual community, adolescents must have access to a computer and the Internet, which may be a barrier for teens of lower socioeconomic status. It could be argued however that adolescents could utilize this site from their school or local library if there was not a computer in the home. Recently, the National Institutes of Health suggested a reduction in "screen time" (i.e., computers, TV) to promote healthy lifestyles for children and adolescents. Many in this age group replace daily physical activity with time spent in front of the television or computer. As such, it would be important to limit the amount of activities taking place within the virtual community, so as not to decrease physical activity among patients with chronic illness in real life or detract from social involvement with peers.

Recommendations for consideration

The use of virtual communities to support pediatric transplant patients is a new area that warrants further research, particularly to examine the costs and benefits of virtual interventions for this population. For instance, comparing psychological adjustment, illness-related coping, and perceived social support between patients enrolled in a virtual community support group relative to those enrolled in an in-person support group or a standard care group would help determine its effectiveness. Additionally, patient satisfaction with using such programs should also be assessed more extensively.

Several suggestions are provided to help maintain the safety and quality of virtual communities with pediatric populations. First, there should be a means for monitoring access to the virtual community to ensure that only patients who meet specified criteria for age and health condition have access. Should the site be center-specific so that the administrator knows all participants or should the site be open to all transplant centers? A national virtual community for transplant patients would increase the amount of interactions and offer greater support, but would be more difficult to maintain and would require more safeguards.

Second, there need to be clear guidelines for participants with regard to patient privacy and confidentiality. The websites should be password-protected, with passwords distributed by

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the transplant center directly to their patients. This would protect patients from having others enter the virtual community and may help patients feel more comfortable sharing personal information on the site. Most in-person support groups ask participants to keep all discussions confidential and not to discuss outside of the group; similar rules in a virtual community would encourage respect for privacy.

Third, it is imperative to have a specific plan for how to deal with crises including threats or thoughts of suicide or homicide, major depressive episodes, or accounts of abuse. Minimally, a disclaimer should be posted that the site will not be monitored in real-time and a list of resources should be made available. In some situations, the administrator of a virtual community may need to break confidentiality in order to make a mandated report to protect the patient. As in individual psychotherapy, the participants should be educated about this possible breach of confidentiality during the informed consent process. The policy can be posted on the website, perhaps on a discussion board so that expectations are clear for participants.

Lastly, the sites should post guidelines of appropriate behavior as well as consequences for inappropriate conversations, cyber bullying, or harassment. Behavior among avatars, verbal comments, and postings should be monitored regularly. Administrators also need to be cautious about participants sharing inaccurate medical information or negatively influencing others' behaviors with regard to medication adherence. There should be a plan for how participants who

experience or witness negative interactions can inform the site administrator. This could be carried out with an e-mail system, but efforts should be made to make the reporting process anonymous perhaps via a "suggestion box" link. Although such behavior may be less likely given that many transplant patients using the site may already know each other, guidelines of behavior would set clear expectations for a supportive and safe environment.

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