

PatchWorx: Connecting Unhealthy and Disabled Children in an Online Community

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Clinical Medicine & Research

Volume 1, Number 3: 259-260
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www.mfldclin.edu/clinmedres

ABSTRACT

PatchWorx (PatchWorx, Inc., Menlo Park, CA) is a nonprofit Web-based community for young people facing illness and disability (<http://www.patchworx.org>). Teresa Middleton, founder and president of PatchWorx, Inc., believes the PatchWorx online community helps children develop the skills necessary for them to successfully cope with their illnesses. Through computer-mediated communication (CMC) via the PatchWorx Web site, children practice information seeking, problem solving and proactively finding social support.

INTRODUCTION

PatchWorx Inc. was founded by SRI International's (<http://www.sri.com/>) associate director emeritus Teresa Middleton. In 1998, Middleton had received SRI's Mimi Award (established in memory of Marian [Mimi] S. Stearns, former SRI Vice President of the Health and Social Policy Division) in recognition of her contributions to mentoring and supporting colleague career growth at SRI. The award included a six-week paid sabbatical that Middleton used to begin development of the PatchWorx community. PatchWorx was incorporated as a nonprofit organization in 2001.

PatchWorx recently received a three-year grant from the Technology Opportunities Program of the United States Department of Commerce to expand its operations and create a national "Circle of Support" for children. Requirements for this grant included compliance with privacy and security measures. PatchWorx is compliant with the Health Insurance Portability and Accountability Act (HIPAA).

During the three-year grant, PatchWorx will establish long-term partnerships with clinics, hospitals, rehabilitation centers, Ronald McDonald Houses, children's camps and schools around the world, to serve as sites that identify children who will benefit from PatchWorx. These sites will also facilitate obtaining parental permission for the child to join the PatchWorx community, monitor their participation and help recruit adult volunteers.

The PatchWorx Web site lists the partnerships that have been established and recognizes their dedication to promoting the PatchWorx community. For example, The National Cristina Foundation was integral to the implementation of the community. The National Cristina Foundation continues to donate refurbished computers to children who otherwise would not have access to the Internet.

THE PATCHWORX ONLINE ENVIRONMENT

Supervised by adult volunteers, the PatchWorx Web site is a safe, secure online environment that encourages children to minimize the obstacles of distance and disability through CMC. PatchWorx online activities include discussions through moderated chat, bulletin boards, member-submitted poetry and artwork, an e-mail listserv, online games and responses to questions from Patches, the site's mascot.

According to Middleton,

More than a half-a-million children in the United States between the ages of 5 and 18 suffer from a critical illness or a serious disability. Many are isolated and alone because they are hospitalized or homebound and feel that only other youngsters facing similar challenges understand. PatchWorx gives them the ability to connect with one another, exchange information and become more proactive in their own care.

HOW CHILDREN USE PATCHWORX

The PatchWorx Web site can be accessed from any computer with an Internet connection, at no cost to the user.

The chat room is open at scheduled times and is always monitored by a trained moderator. Other sections of the site, such as the message boards, games, Kid's Quilt and Ask Patches are always open.

Middleton hypothesizes that the interactive opportunities of CMC through the PatchWorx Web site will help children alleviate feelings of isolation. Online communities can be effective resources to gain knowledge by enabling users to participate in an interactive process with information and people. PatchWorx provides a venue for children and their families to have the opportunity to meet others who understand their physical situations and emotions. Middleton explains,

Many children facing critical illness or disability feel alone, and are lacking social and peer support. This is particularly true in these days when many family and youth-related support systems are weakening...We designed PatchWorx to help these kids reach each other across the barriers of distance and disability and, through developing friendships, find new ways to deal with their challenges.

CONCLUSION

Every day, the messages from the children using PatchWorx indicate that the Web site makes a positive impact on their lives. One member wrote,

I am so glad I joined here. I already met a lot of neat people in the chat rooms and I think it is helping me deal with being sick so much.

Another PatchWorx member said,

I am grateful that I have a place to come where people understand and where I don't have to worry about my differences being so obvious. I don't know what I would have done this past year, or now, without this place.

For More Information about PatchWorx

Inquiries may be emailed to patchworx@patchworx.org or contact Teresa Middleton at 650-859-3382, tmiddleton@patchworx.org. Visit the PatchWorx Web site at <http://www.patchworx.org>.

For More Information about

SRI International and the National Cristina Foundation

Several generous organizations partner with and/or sponsor PatchWorx, Inc. Two mentioned in this article are SRI International and the National Cristina Foundation.

SRI International (<http://www.sri.com/>) is one of the world's leading independent research and technology development organizations. The nonprofit research institute performs contract research and development for government agencies, commercial businesses and nonprofit foundations.

National Cristina Foundation (<http://www.Cristina.org/>)

Provides computer technology and solutions to give people with disabilities, students at risk and economically disadvantaged persons the opportunity, through training, to lead more independent and productive lives. NCF works in the United States and abroad to ensure that used computer technology resources that no longer meet an enterprise's needs are given a second productive life as a tool for developing human potential.