The role of an online community in improving the wellbeing of geographically dispersed young people living with an illness or disability

Kylie Johnson1, Felicity McMahon1, Elizabeth Kelly-Dalgety1
1Starlight Children’s Foundation

Abstract

Online social support is a valuable resource for connecting, supporting and empowering young people who are living with an illness or disability and who are unable to access traditional means of peer-based support. In 2008 an online community was established to respond to the needs of adolescents and young adults (AYA) with a serious/chronic medical condition who were experiencing isolation from their peers and community. The issue of isolation was particularly evident for AYAs living in rural communities. An increasingly centralised model of specialised acute care meant that many AYAs were hospitalised away from their home community. Returning home was often challenging as it interrupted positive relationships developed in hospital with peers facing similar issues. Decreased energy, demands of care and time spent recuperating also impacted on their relationships at a time when these were crucial.

The online intervention was designed to increase social inclusion, and enhance members’ sense of community and connection through participation in a range of activities including online chat, blogs, community forums, video streaming, and games. The program has been evaluated with participants across a range of illnesses/disability, age, gender and socio-economic status from metropolitan and regional areas of Australia utilising online surveys and focus groups, participant interviews, observations, and content analysis of transcripts and the website.

Focusing on the development and evaluation of a national online moderated social support program for AYAs (10-21 years) living with a serious illness, chronic condition or a disability the evaluation investigated: (1) the ways in which participation in the intervention impacted on members’ wellbeing, sense of identity and embodiment, (2) the role of moderators in supporting and maintaining a cohesive online community, and (3) ways for improving the delivery, member benefits, and longevity of the program. The results demonstrated that the intervention enhanced participants’ psychosocial outcomes, provided members with a strong support community, and encouraged greater acceptance and integration of members’ illness and/or disability with their identity. The results were stronger for those members experiencing higher levels of isolation from peer-based support communities. Based on the evaluation the program has recently undergone a series of changes, expanding its membership to include United States and Canadian AYAs living with a serious illness or disability.

Introduction

There has been a marked increase in chronic health conditions and disability among adolescents and young adults (AYAs) worldwide.1 In Australia it is estimated that 60 per cent of young people aged between 12-24 years have at least one long-term health condition and 7 per cent of 15-24 year olds a disability, with twelve per cent of young Australians requiring ongoing specialist and tertiary care for a medical condition.2,3 Having a serious chronic illness or disability can negatively impact on the wellbeing of AYAs, adversely affecting a young person’s ability to engage in social activities, recreation, education and employment, which in turn, can limit their opportunity for development and social inclusion.2,4 It is not surprising therefore that young people with a serious chronic illness or disability are at a higher risk for negative psychosocial outcomes e.g. lower overall life satisfaction, poorer mental health, and lower self-efficacy, than their healthy peers.5

Emerging research has shown that peer support can play a critical protective role against many of the psychosocial adversities faced by AYAs with a chronic illness or disability. Interaction with peers and participation in peer support programs have been shown to enhance the self-concept, self-esteem, friendships, and quality of life of young people with a chronic health condition or disability.6,5 However
not all AYAs living with a chronic illness or disability have ready access to peer support and peer-based programs. Of particular note are those AYAs residing in rural and remote regions of Australia. An increasing centralised model of specialised care means that many AYAs with a serious chronic illness or disability receive treatment away from their home community. Returning home is often challenging as the positive relationships developed in hospitals with peers faced with similar issues are harder to maintain outside the treatment centre. Limited resources at an individual and health service level, and longer travel times coupled with decreased energy, demands of care, and time required for recuperating, significantly reduce the AYAs’ capacity to access peer support services—all at a time when peer support is fundamental to supporting and improving the AYAs well-being. In addition, depending on the medical condition or disability of the AYA, limitations in mobility and speech may impede face-to-face or telephone communication with peers.

Increasingly, Internet technology is being used to enhance access to peer support for AYAs with a chronic illness or disability. Emerging research has highlighted several benefits of using this technology to facilitate a sense of community and social support among AYAs with a serious chronic illness or disability. Additional benefits have included increased social acceptance and confidence, improved moral support, connectivity, positive mood, and general well-being, as well as a decrease in loneliness.7-9

The Starlight Children’s Foundation recognised that by using the newer online technologies and the potential of online communities that there might be better ways to increase and maintain the positive connections made by peers when they met in a health setting or who were experiencing similar life experiences but were geographically dispersed or were unable to access traditional means of peer-based support.

**livewire.org.au—connect, support, empower**

Established in 2008, livewire.org.au is an online community connecting young people aged 10-20 years old living with a serious illness, chronic condition or disability, and their siblings, to help increase their social inclusion and enhance their sense of connection and community.

Young people are able to become a member of livewire.org.au by signing up on the public site where they fill in an online membership form. If on this form they indicate they meet the criteria of having a long-term health condition or disability (i.e. longer than six months) and their membership is verified by a parent and a health professional known to the AYA they can join the community.

The features of the livewire.org.au online platform include:

- Online chat
- Blogging
- Community groups
- Articles
- Member profiles
- Music
- Games
- Competitions

Livewire.org.au members are guaranteed a high level of safety. The online program employs stringent signup and identity checking procedures, and adheres to strict guidelines which require members under the age of 18 to agree to not share personal information that would enable another member to contact them outside of the livewire.org.au online program without the consent of a parent. In addition all online activities are moderated by experienced facilitators trained in adolescent health and well-being.

Prior to October 2011, livewire.org.au hosted live chat sessions for two age groups: for members aged 10-15 years and for those aged 16-21 years. In October 2011 livewire.org.au’s online chat function
merged with that of Starbright World (USA and Canada) another online community dedicated to improving the well-being of AYAs with a serious or chronic illness. In compliance with Starbright World USA requirements a decision was made to change the membership criteria, and as a result, members must be 13 years of age before they can access the chat room. The chat room is accessible and moderated 24 hours, seven days a week. Livewire.org.au members between the ages of 10-12 years are able to access most of the other features on the livewire.org.au site.

In addition, the livewire.org.au platform enables other organisations to set up their own livewire.org.au group allowing the organisations a safe option to connect and share information with young people that utilise their services providing them with event updates, resource information and support relevant to their condition, e.g. Asthma Australia and Disability Sport and Recreation.

Program evaluation

In 2009 Starlight engaged the services of the Centre for Everyday Life, Murdoch University, to undertake an independent evaluation of the impact of livewire.org.au on its members’ well-being, sense of identity, and embodiment.10 The evaluation was undertaken in three stages:

- **Stage 1**—A review of the available literature and research in the field
- **Stage 2**—An online survey (n=35) and online focus group (n=14) with members; analysis of livewire.org.au content e.g. blogs, chat transcripts
- **Stage 3**—Interviews about and observations of how members moved around and engaged with the livewire.org.au site, along with members’ use of various technological interfaces (n=18).

Key findings

The evaluation demonstrated that the livewire.org.au online community powerfully supports the personal and social well-being of its members. Livewire.org.au members reported:

- Their online friendships were more dependable and enduring than their offline friendships, referring to their online friends as ‘true friends’, which is friends who understood and accepted their chronic illness/disability.
- Livewire provided them with an opportunity to positively integrate their illness and/or disability with their identity providing them with a sense of ‘normalcy’, i.e., though illness and disability are present they are not focal to online chats.
- Livewire provided a ‘space’ where they were able to talk through and make important life decisions with the support of their peers, e.g. whether to undergo difficult treatment or procedures.
- Participation in livewire.org.au was viewed as an important function in the process of ‘transition’ for some members, as these members shifted from identifying with chronic illness and disability to becoming young adults in the ‘real world’.
- That online safety was defined as freedom from prejudice and marginalisation on the basis of their illness and/or disability and that livewire.org.au provided a safe place for sharing.
- That chat hosts (online moderators) are fundamental to the success of the livewire.org.au community.

In addition, the evaluation also highlighted that the benefits of livewire.org.au are stronger for members experiencing higher isolation from peer-based support communities.

In short, the evaluation found that livewire.org.au enabled young people living with a serious chronic illness or disability to experiment socially in a safe, moderated setting, and that these factors in turn helped foster meaningful relationships. The social connection, sense of friendship and community and
safety that are nurtured in livewire.org.au appear to contribute directly to members’ enhanced sense of well-being, including members’ capacity to adapt to adverse life circumstances, accept their illness or disability, to engage and form meaningful relationships, and to live fuller lives.

The findings support the results from other similar studies, notably, how being a member of an online community specifically established to support people with a serious health condition or disability can provide access to a larger social network of others who share similar experiences and values. The successful functioning of such an online community can reduce members’ isolation, improve mood, confidence and self-acceptance, while also providing significant moral support.7-9

Building on the initial study of the livewire.org.au program a second evaluation was completed in March 2013. This evaluation investigated in more detail the role of the chat hosts (online moderators) in supporting and enhancing members’ experience of livewire.org.au.11 The results of the second evaluation will be released in May 2013. The initial findings of the second evaluation have highlighted that the chat hosts are key to the success of livewire.org.au because they:

- are integral to the flow of conversation and activity that occurs in the chat sessions and are central to the smooth running of the chat room
- seek out opportunities to support members to learn more about themselves and others
- support the development of members’ skills so that they can socialise more effectively with peers
- demonstrate a range of positive personal attributes including charisma, empathy, ‘fun’, respect and professionalism
- use a variety of strategies to address a range of challenging situations

In addition, the second evaluation also highlighted the importance of recruitment and training to ensure that the chat hosts are provided with the skills and expertise to facilitate member participation.

The findings highlight a model of care that is different from traditional online moderated spaces established for people who are living with an illness or disability e.g. rather than assuming the role of ‘expert’ in livewire.org.au, chats hosts provide a range of organisational, social, and intellectual roles. Fundamentally chat hosts are seen by members as both confidant / ‘friend’, as well as a mentor and a leader with skills and knowledge that they can contribute to the chat room. Chat hosts understand the importance of their role in connecting, supporting and empowering members.

Future directions

Livewire.org.au has grown over the past five years and is an evolving program. Feedback provided by members of livewire.org.au through this evaluation is being used by Starlight to continually improve and develop the services provided. An example of this is the recent development of livewire.org.au’s ‘over 21 mentoring program’. Here some members who have reached the age of 21 have the opportunity to gain skills in leadership within the site. The members are provided the opportunity to mentor younger AYAs and are assigned set tasks, e.g. writing blogs (once a week), leading activity in the chat room (two hours a month), to further develop their communication and leadership skills while also providing a gentle path for transitioning out of the program. Training in facilitating and promoting peer support is provided in the context of the chat room.

Conclusion

Online social support programs such as livewire.org.au are a valuable resource for connecting, supporting and empowering young people who are living with an illness or disability and who are unable to access traditional means of peer-based support. AYA online peer support programs have the capacity for reducing isolation, increasing the availability of social support, and ultimately improving the well-being of members. The programs offer promise in establishing and providing easier access to social
networks that are not limited by geographical location or the restrictions imposed by illness or disability at time when AYAs with a serious chronic illness and/or disability, especially those residing in rural and remote areas of Australia, have limited access to tailored peer support programs. The provision of evidence-based, structured online peer-support networks and programs can go some way in providing meaningful support to AYAs who otherwise would struggle to access peer support.

References