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

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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 socioeconomic 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.