

Dissertation Abstract

An Online Community of Women with Spinal Muscular Atrophy (SMA) as a Psychological and Social Self-help Support Group

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Area and objective of the research and its scientific justification

The subject of the research is the activity of women with spinal muscular atrophy (SMA) participating in an Internet forum, as well as their opinions on the forum and the support they receive. The author outlines the problems that concern the community and the way the forum works, particularly in the context of the support given and experienced by the participants. The overall aim of the research is to describe and understand the online community of a private forum for SMA women who form a psychological and social support group for each other. The practical objective, which may prove helpful when providing assistance to people with similar conditions, is to identify the available Internet resources SMA women can use to cope with their health problems and life issues. The research project formulated the following questions: What is the image of the online community developed by SMA women? What topics and problems are discussed in the forum and how do the forum members want them resolved? How do the forum members describe their adaptation to the conditions of the disorder and how do they tackle the advancing physical limitations? What kind of problems do they receive support for and what support do they offer to other forum members? What role does the online forum play in the lives of SMA women and how important is it to them?

Research methodology

The research was conducted among women suffering from SMA who are members of an Internet forum called Kobiety SMA (SMA Women). It is a Facebook group made up of around 180 women, however the number of active members who comment on posts is usually between a dozen and 20–30. The forum members are adult women with and without children; they are married and single; they live in cities or villages, they work, study or are not employed. Most of the women who took part in the survey are in the wheelchair and require assistance with daily activities. Also, most of them are gainfully employed, which is not so common for people with a disability. The research methods involved ethnographic participant observation combined with gathering texts for analysis, an online survey for the forum members, and in-depth biographical interviews.

By analysing the content of the forum, the author identified twelve themes: personal assistance, hobby, passions, abilities, professional work, rehabilitation, specialists, treatment, travel, in-person meetings of the forum members, everyday matters, sexuality, dating, romantic relationships, motherhood, dependence and autonomy in the disease.

In order to show who the forum users are, what their participation style is like in the group's activities on Facebook, and what the forum is for them, the author carried out a survey using Forms to which 30 of the women responded. She also conducted in-depth biographical interviews, however – due to pandemic restrictions – only one interview was conducted face-to-face and in eleven cases the Zoom videoconferencing application was used.

Research outcomes and conclusions

The undertaken research made it possible to gain insight into a private online forum – SMA Women – which is a unique space on the Internet, serving the purpose of a psychological and social support group for its members. The results of the research demonstrate that the online forum enables the women to communicate, give and receive support and engage in various social activities. The women join the group by coincidence, through a reference elsewhere on the Internet, however most often through a recommendation by another forum member. A lot of the women have been members of the Facebook group for several years. Quite a few of them tend to check the forum on a daily basis. Most of the surveyed women claim they speak up from time to time on topics that they find interesting, however there are also forum members who remain silent readers of the posts (so-called lurkers). It was found that a lot of forum members keep in touch outside the virtual world and maintain real-life relations. Although the posts on the forum concern various topics, the most

common ones relate to treatment and rehabilitation, as well as sexuality, romantic relationships and motherhood. Nearly all respondents seek advice on how to cope with the limitations imposed by SMA and they seek emotional support in challenging life problems. The forum members support and help each other with problems and dilemmas, make it easier to face various challenges created by SMA. The forum plays a major role in the members' life. It is their source of the most comprehensive knowledge about their disease and an invaluable source of assistance in situations that may initially seem hopeless to them. The women appreciate being a part of a community, especially as they are able to find relevant advice and tips in the posts to help them live better. The forum members themselves point out that it is the only place where they really feel understood and where their fellow forum users have become like family to them.