



Research paper

The Internet as an additional source of information on rare illness. A Facebook support group for parents of children with craniosynostosis as a case study

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ABSTRACT

Introduction: Empirical studies show that belonging to a support group contributes to patient and caretaker empowerment. They also show that support groups significantly help parents and caretakers of ill children reduce stress and better handle the illness.

Aim: The aim of the study is to expand knowledge of how social media support groups function, and what impact they have on members.

Material and methods: Data was collected using online surveys conducted on 54 respondents.

Results and discussion: In particular, the respondents experienced empowerment in terms of ‘exchanging information’ and ‘finding recognition.’ Thanks to the online group, they felt better prepared to meet with their doctors. They identified with other members of the group, and considered the information posted thereby to be understandable and valuable. The stories of other parents helped them realize they were not alone.

Conclusions: (1) Most group members were mothers. (2) Above all, the members were seeking information, not emotional support. (3) Doctors were the main source of information on the disease. (4) Analysis indicated that ‘exchanging information’ was most strongly correlated with empowering outcomes, while ‘helping others’ was least correlated. (5) It was difficult for members to evaluate empowering outcomes.

1. INTRODUCTION

Patient empowerment refers to a new type of patient/care-taker and doctor relations. ‘Empowerment reflects the belief in patient autonomy and the right and responsibility of patients to access health information and to make their own health-related decision.’¹ Patient empowerment is a process in which patients take responsibility for their own health. The Internet is a tool in patient/caretaker empowerment processes.²

Research shows that the Internet is one of the most important sources of information on illness for patients and their loved ones.^{2–7} This knowledge affords patients a more subjective and autonomous position in relation to their doctors. Research shows that users of online support groups most often seek emotional and informational support.^{8–12} The mutual assistance between members of online communities, in particular emotional and informational assistance, may have a positive effect on patient empowerment processes.^{1,4,13–18} The following empowerment outcomes have been identified: being better informed, enhanced social well-being, greater confidence in relationship with physicians, greater acceptance of illness, greater confident in treatment, greater optimism and control, improved self-esteem.^{1,19}

Research on how parents of ill children use online support groups shows that they are seeking contact with persons who have had similar experiences. This helps the parents manage their own situation.^{4,10,21–22} Informational support is essential above all for parents who consider information from doctors regarding their child’s illness to be insufficient, especially when the illness is rare.^{4,21,22} Parents often feel obliged to prepare for visits with doctors in order to better defend the interests of their children.^{21,23,24}

Craniosynostoses are a heterogeneous group of congenital defects resulting in an abnormal and pathological skull structure. There is premature closure of one or more skull sutures in 1 of every 2000 live births. This always causes deformation of all skull structures, including the face. The above frequency of occurrence means that craniosynostoses are classified as rare illnesses. These abnormalities in skull structure could lead to developmental disorders, delayed and disharmonious speech development, and various speech impediments. All children with craniosynostoses experience slightly impaired motor development. These symptoms call for interdisciplinary treatment. Due to the fact that these disorders are rare, most specialists do not have experience in the treatment of children with craniosynostoses.

2. AIM

The subject of this study is the community that comprises a closed Facebook support group for parents of children with craniosynostoses. The group was formed in 2015 and has 581 members. As far as we are aware, there is no other research in Poland on the topic of online support groups for parents of children with craniosynostoses.

The aim of the study is to expand knowledge of how social media support groups function, and what impact they have on users. More specifically, we will focus on: (1) who joins online support groups and for what reasons; (2) and how participation in such groups affects patient empowerment (i.e. the extent to which users experience empowering processes and empowering outcomes, is there a statistically significant relationship between empowering processes and empowering outcomes).

3. MATERIAL AND METHODS

Data was collected using online survey. In May 2018, with the consent of the administrator, a link to a questionnaire was posted on the webpage informing members that research on the significance of online support groups was being conducted among parents with children with craniosynostoses. Respondents were informed of the aims of the study and assured anonymity. Data was collected from the 10th to the 20th of May, 2018.

Respondents were asked about their basic demographic characteristics, their ill child, and how they used the Facebook support group.

The empowering processes and outcomes of parents with children with craniosynostoses were analyzed using tools developed by Uden-Kraan et al.¹ Due to the fact that our research was conducted among parents of ill children instead of patients themselves, some questions had to be modified. The difficulty and intelligibility of the questions was examined in a pilot study.

Empowering processes were analyzed using 4 scales: ‘exchanging information,’ ‘encountering emotional support,’ ‘finding recognition,’ ‘helping others.’ Each prompt had 4 possible responses: seldom to never, sometimes, often, and very often. Empowering outcomes were analyzed using 4 scales: ‘being better informed,’ ‘feeling more confident in the relationship with the child’s physician,’ ‘improved acceptance of the illness,’ ‘increased optimism and control over the future.’ Each prompt had 5 possible responses: completely disagree, disagree, it is difficult to say, agree, and completely agree.

Cronbach’s α was used to assess the reliability of each scale. The list of prompts for each scale and Cronbach’s α can be found in Appendixes 1 and 2 (online supplementary files).

4. RESULTS

4.1. Participant characteristics

The study was conducted on the group of 54 persons, 95% of whom were women. Their average age was 32.25 (SD 4.4). The respondents generally had higher education (51.9%), a rather stable material situation (80.8%), and lived in a large city (38.9%). Half of them were professionally active, and over 53.0% had one child. The respondents had gathered information on their children’s illnesses primarily from spe-

cialist doctors (94.4%). The Internet (63.0%) and parents of other ill children (79.6%) were less frequent sources. Details are presented in Appendix 3 (online supplementary files).

The majority of the respondents were parents of boys (59.3%). The average age of the children was 25.8 months (SD 19.8). The most frequently occurring types of craniosynostosis were sagittal craniosynostosis (37.0%) and metopic craniosynostosis (31.5%). Less frequent types were: complex (14.8%), genetic syndrome (9.3%), unicoronal (7.4%). In the study group did not occur types as follows: bicoronal, lambdoid; 65.0% of the children had undergone surgery. Their average age at the time of operation was 12.6 months (SD 8.1). Their irregular head shape was first noticed by their parents (48.1%) or doctor (general practitioner – 5.6%, pediatrician – 11.1%, other specialist physician – 22.2%). Details are presented in Appendix 4 (online supplementary files).

4.2. Participants' use of the Facebook group

Most of the respondents indicated that they had found the group on their own (63.0%). Over half joined the group right after their child had been diagnosed with craniosynostosis (55.6%). Just over half visited the webpage at least once per day (51.9%), and most spent no more than 30 minutes at a time on the webpage (61.1%).

Most respondents joined the group for practical reasons, i.e. to acquire more information on their child's illness; 87.0% wanted to learn the experiences of other parents (e.g. what treatment was like, what specialists they recommend), and 85.2% wanted to learn more about the disease. Details are presented in Appendix 5 (online supplementary files).

4.3. Construct empowering processes

Most activity process in the online support group was directed towards 'finding recognition' and 'exchanging information.' The averages for each scale are presented in Table 1, and the distribution of responses to each question is presented in Appendix 1 (online supplementary files).

4.3.1. Exchanging information

For almost all the respondents, the information obtained from other members of the group was understandable (94.5%) and valuable (76.0%). Most of the respondents claimed that the information posted to the group was not new for them (85.2%), and that it generally did not supplement the information they obtained from their doctors (53.7%).

Table 1. Mean score for empowering processes.

Scales	Mean (SD)
Exchanging information	2.68(0.44)
Encountering emotional support	2.06(0.49)
Finding recognition	2.89(0.53)
Helping others	2.21(0.56)

Comments: Questions to each scale are presented in Appendix 1 (online supplementary files).

4.3.2. Encountering emotional support

The declarations of the respondents indicated that emotional support from the group was not a universal phenomenon. 'Often' or 'very often' the respondents received encouragement (66.7%), consolation (62.9%) and support during difficult times (53.7%) from other members of the group, yet 98.0% of the respondents claimed to 'seldom to never' have face-to-face meetings.

4.3.3. Finding recognition

The respondents identified with other members of the group, who helped them feel that they were not alone in their struggle (92.6%), and that their experience was similar to that of other parents (72.2%).

4.3.4. Helping others

The respondents declared that they 'seldom or never' or only 'sometimes' felt like they set an example for others (75.9%), offered advice or support (64.8%), or shared their experiences with the illness of their own child (53.7%).

4.4. Construct empowering outcomes

Most activity outcomes in the online support group was directed towards 'being better informed.' The averages for each scale are presented in Table 2, and the distribution of responses to each question is presented in Table A4 in supplementary materials.

4.4.1. Being better informed

The respondents indicated that one of the benefits of participating in the online group was the feeling of being better informed. They declared that they felt better informed (81.5%), that they better understood their child's illness (77.8%), that they had more (and accurate) knowledge, which helps them to better deal with the illness (72.2%), and that they had a real picture of the illness (70.4%).

4.4.2. Feeling more confident in the relationship with child's physician

Thanks to their membership to the group, the respondents felt that they were better prepared for meetings with specialist doctors (72.2%), that they better understood the information provided to them by the doctors (64.8%), and that they had more courage to talk with the doctors (61.1%).

The respondents were additionally asked to evaluate contacts with specialist doctors, who they generally believed paid them sufficient attention. Over 66.0% were 'rather sat-

Table 2. Mean score for empowering outcomes.

Scales	Mean(SD)
Being better informed	4.03(0.90)
Feeling more confident in the relationship with child's physician	3.42(1.19)
Improved acceptance of the illness	3.45(1.13)
Increased optimism and control over the future	3.54(1.16)

Comments: Questions to each scale are presented in Appendix 2 (online supplementary files).

isfied' or 'definitely satisfied' with the time devoted to them during visits. The same percentage of respondents indicated that their specialist always answers their questions exhaustively, and 65.0% of respondents declared that the specialist always uses understandable language.

4.4.3. Improved acceptance of illness

The respondents generally declared that membership in the group allowed them to reconcile with their child's illness, and that it is easier for them to tell others of the illness, or ask for help.

4.4.4. Increased optimism and control over the future

Most of the respondents indicated that thanks to membership in the group, they have more faith in the future, that their attitude towards the present is more positive, and that they feel they have more control over what is happening with their child.

4.5. Relationship between empowering processes and empowering outcomes

Almost all processes taking place in the online support group are significantly correlated with the outcomes experienced by group members (Table 3). The correlation between individual variables is nevertheless weak or fair. The strongest correlations (more than 0.5) were between 'exchanging information' and 'increased optimism and control over the future,' 'encountering emotional support' and 'being better informed,' and 'exchanging information' and 'improved acceptance of the illness.' On the basis of the data collected, we can claim that there are no or very weak statistically significant relationships between 'helping others' and empowering outcomes.

4. DISCUSSION

The respondents declared that their main reason for joining the group was to seek information on their child's illness, both in terms of facts, and the experiences of other parents (e.g. which treatments work best, which specialists they recommend, etc.). As other studies show,^{2,21} patients and their caretakers seek alternative sources of information when they are not satisfied with that provided by their doctor. Furthermore, every additional piece of information is particularly valuable for parents of children with rare diseases, even if this

can lead to information overload and be an additional source of stress.^{23,24} Research^{4,25} also shows that additional online information is sought mainly by women. Our study confirms this, as women constituted 94.4% of the respondents. The respondents' rarest motives for joining the group were sharing their own experiences and talking with other parents.

To study caretaker empowerment, we used a tool that allows analysis of both empowering processes and empowering outcomes.¹ The data collected shows that the respondents experience empowering processes and empowering outcomes in many areas and to various degrees. The strongest experience of empowerment was visible in the areas of 'exchanging information' and 'finding recognition' (Table 1).

They desire medical knowledge, and attach less weight to emotional support (Appendix 5 in online supplementary files). The results not only show that they less expect emotional support, but also that they do not receive much of it (Table 2). Of the 4 areas of empowering processes, 'encountering emotional support' was indicated as the less important. In contrast with the parents of children with autism spectrum disorder,⁹ whose main reason for posting in a Facebook support group was sharing their personal experiences, the parents of children with craniosynostoses primarily sought online support to exchange medical knowledge. There was a relatively low indication that they did so for the purpose of 'helping others.' The majority of the respondents were 'lurkers,' who were not very active in posting or discussion – a necessary condition for the sharing of personal experience and providing support to others. Similar conclusions were reached by Uden-Kraan et al.¹

In this study, the most empowering outcomes were a result of respondents' 'being better informed.' This has also been confirmed by other studies of online support groups.^{1,26,27} Although the information posted to the group was rarely new, the respondents still saw it as valuable, and usable, and above all understandable. We assume that this knowledge can generally help users feel better informed, and in turn help them better deal with their child's illness.

Analysis of the 'feeling more confident in the relationship with the child's physician' scale clearly showed that access to online information does not automatically affect doctor–patient relations. The respondents were still dependent on doctors, as they lacked systematized medical knowledge (this was also indicated by their responses in the 'exchanging information' section). However, the additional knowledge did help them feel more comfortable when meeting

Table 3. Pearson correlation coefficients for the relationships between the empowering processes and the empowering outcomes.

	Being better informed	Feeling more confident in the relationship with child's physician	Improved acceptance of the illness	Increased optimism and control over the future
Exchanging information	0.426*	0.476*	0.506*	0.568*
Encountering emotional support	0.511*	0.280**	0.280**	0.447*
Finding recognition	0.473*	0.305**	0.373*	0.460*
Helping others	0.288**	0.215	0.168	0.336**

Comments: * $P < 0.01$; ** $P < 0.05$.

with the doctors. It is also worth noting that many respondents had difficulty indicating what effect membership to the group had on them. Most notably, they responded with ‘it is difficult to say’ when asked to assess whether membership helped improve relations with their doctor (27.8%), and reduce dependence on his or her opinion (22.2%).

The results of this study cannot be generalized to all online support groups for at least a few reasons. Firstly, the research sample was relatively small, and consisted of persons similar to one another, i.e. women with a higher education, living in larger cities, and with a good or very good material situation. Secondly, the study focused only on parents of children with craniosynostoses. Thirdly, the questionnaires were completed voluntarily, and thus by only the most committed members of the support group.

5. CONCLUSIONS

In many ways, the conclusions confirm those of other studies on members of online support groups:

- (1) The members of the ‘Craniosynostosis’ group were mainly women (in study group 86.0% members are women).
- (2) Their main reason for joining the group was to expand their knowledge about their child’s disease and how to treat it. Informational support was more important than emotional support.
- (3) Doctors were the main source of information on the disease.
- (4) Analysis indicated that ‘exchanging information’ was most strongly correlated with empowering outcomes, while ‘helping others’ was least correlated.
- (5) It was difficult for respondents to assess empowering outcomes. On the basis of the data obtained, we assume that online information cannot be treated as a simple means to the autonomy of patients and their caregivers.

Conflict of interest

None.

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Supplementary materials

Additional materials for this paper (Appendixes 1–5) are available online: <http://www.journalssystem.com/paom/Association-between-depression-symptoms-and-Mediterranean-dietary-adherence-in-adults,113547,0,2.html>.

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