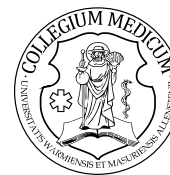




Polish Annals of Medicine

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SUPPLEMENTARY MATERIALS

Nieroba E, Larysz D. 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. *Pol Ann Med.* <https://doi.org/10.29089/2019.19.00078>.

Appendix 5. How members use the 'Craniosynostosis' Facebook group.

Variable	N	Percent
How did you find the group		
my child's doctor recommended it to me	10	18.5
parents of another ill child recommended it to me	10	18.5
my friend(s) or family recommended it to me	0	0.0
I found it on my own	34	63.0
other	0	0.0
When did you join the group		
immediately after my child's diagnosis	30	55.6
just before my child's operation	2	3.7
just after my child's operation	8	14.8
other	14	25.9
Why did you join the group (multiple-choice question)		
to learn more about my child's illness	46	85.2
to make contact with other parents of ill children	43	79.6
to seek advice regarding the care of my child	38	70.4
to share my personal experiences with other parents (e.g. regarding treatment)	31	57.4
to learn the experiences of other parents (e.g. what treatment was like, what specialists they recommend)	47	87.0
to talk with other parents about this illness	37	68.5
other	0	0.0
Frequency visit online support group		
more times a day	11	20.4
about once a day	17	31.5
more times a week	21	38.9
about once a week	3	5.6
more times a month	2	3.7
about once a month	0	0.0
less than once a month	0	0.0
Duration visit online support group		
less than 10 minutes	18	33.3
10–30 minutes	33	61.1
31–60 minutes	2	3.7
more than 1h	1	1.9
Are you active in the group, e.g. do you post, comment, etc.		
I only read posts and comments, and rarely or never make them myself	13	24.1
I sometimes post or comment	34	63.0
I often post or comment	7	13.0
I always post or comment when I visit the group	0	0.0
Do you know of other craniosynostosis support groups on social media		
yes	10	18.5
no	44	81.5