Classification of Patients Visiting Online Patient Support Groups on Disease-Types on The Basis of Support Variables

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Abstract: This study looks into how patients are grouped in Online Patient Support Groups based on the type of disease they have, using factors like homophily, perceived empathy, and perceived social support. The research explores how these factors differ among patients with rare, chronic, and life-threatening diseases. The data, collected from 700 participants between July 2020 and November 2022, were analyzed using discriminant analysis. The findings suggest that while there are noticeable but not strong differences in these factors among different diseases, patients with rare diseases tend to score higher. Despite the modest disparities, the analysis correctly identified disease types about 64.5% of the time, indicating that these factors can be helpful in identifying diseases among Online Patient Support Group users. However, more research is needed to fine-tune classification methods and account for the diversity within disease categories to enhance accuracy.

Keywords: Online Patient Support Groups, Rare Disease, Chronic Disease, Life-threatening Disease, Homophily, Perceived Social Support

1. Introduction

Recently, different types of social media platforms on the internet, such as blogs where patients share their experiences, online communities offering support, and websites dedicated to health topics, have become very popular for finding health information. A report suggests that about one-third of people who look up health information online have used these social media platforms as helpful sources. It's expected that more people will turn to these online social media platforms in the future to seek help and information from other patients [1,2,3,4]. As time has passed, online patient support groups have introduced various features aimed at enhancing social engagement among their users. These features include private messaging, live chat, and online social networking capabilities [5,6,7,8]. One of the recent updates comprised the integration of online social networking elements [9,10], which encompassed features like individual profile pages and friend lists [11]. The incorporation of these social networking functions was aimed at improving connectivity among users of online patient support groups [9,10]. Particularly when utilizing the internet, people make deliberate and proactive decisions regarding which web pages to access, based on their specific requirements. People who have specific reasons to use online patient support group sites are likely to use certain features on those sites more often than other people. As an example, in a study about online patient support groups for HIV/AIDS, it was found that some patients devoted more of their time to using features that involved talking and interacting with others (like discussion boards), while others focused more on using features that provided educational and informative content [12].

Rare diseases encompass a wide spectrum of severe or long-lasting conditions that lack a cure, cannot be avoided, and have no successful treatment available [13]. Rare diseases are defined as conditions that affect fewer than one person out of every 2000 individuals. Currently, there are about 7000 recognized rare diseases worldwide, and new ones continue to be discovered each year [14]. People diagnosed with rare diseases face similar challenges to those with more prevalent medical conditions. As a result of the physical and psychological symptoms they experience, they often need to adjust their family, work, and social responsibilities [15,16]. In contrast to individuals dealing with more widespread illnesses, those with rare diseases usually encounter significant extra hurdles due to the limited understanding of their condition and the strategies to handle it. For numerous individuals with rare diseases, achieving an accurate diagnosis can pose a substantial obstacle, and in certain instances, this journey may span several years [14].

Chronic diseases refer to medical conditions that are long-lasting and tend to progress slowly. These diseases can be managed but not completely eradicated [17]. They are the primary reason for disability and death on a global scale [18,19]. The rising number of long-term health problems on a global scale is creating a significant challenge for healthcare systems. This challenge includes a growing demand for extended hospitalization, frequent readmissions to hospitals, and visits to the emergency department [20,21]. As per a recent report on global health [22], over 70% of death across the world can be attributed due to chronic diseases like heart disease, diabetes, and chronic lung conditions. As chronic conditions typically last for an lengthy period, engaging in daily self-care becomes a vital aspect of effectively managing these persistent health issues [23].

A life-threatening disease has widespread consequences that impact an individual's physical, emotional, social, and spiritual health. Certain patients find that coping with such a condition heightens their self-awareness and provides a chance for psychological development and the strengthening of their relationships. On the other hand, some individuals find it challenging to discover a sense of purpose and meaning in their lives due to their condition, which can result in feelings of demoralization and hopelessness [24]. The Life-Threatening Illness Supportive Affective Groups Experience (LTI-SAGE) was established through the collaboration of six Catholic healthcare organizations with the shared goal of tending to the needs and worries of individuals dealing with life-threatening illnesses [25].

2. Literature Review

Currently, plantation drives are conducted by NGO, Government organizations or private companies. These initiatives mainly rely on funding via crowdfunding or corporate sponsorships.

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Volunteers are then assigned to plant saplings at suitable locations for the execution of these plantation drives. Citizens can opt to donate to these drives either through direct contributions to NGOs or by participating in crowdfunding campaigns. Some platforms allow them to choose the type of tree they want to contribute to. In India, a group of volunteers created a nonprofit organization to address the needs of people with rare diseases and offer them support and benefits they lacked called "Organization for Rare Diseases India" (ORDI; www.ordindia.org). ORDI's objective is to stand up for the shared concerns and champion the requirements of rare disease patients and various interested parties in India [26]. There is a website for the Seven-Pansy Rare Disease Community, which serves as the overarching national organization dedicated to supporting all individuals affected by rare diseases in China. (qsi-china.com) [27]. Many individuals with chronic illnesses show significant interest in utilizing phone-based and email/Internet-based telehealth services, irrespective of their health condition, accessibility challenges, age, or various other sociodemographic factors. We can make patients more interested in telehealth by making them feel better about using technology, telling them the good things about it, and answering their queries and worries about telehealth [28]. The significant number of people with chronic diseases who seek and use health information online may indicate a growing trend of using eHealth tools to manage chronic conditions. Healthcare professionals and educators need to keep exploring methods for connecting with and assisting patients in managing chronic illnesses via eHealth platforms. This includes making the most of online resources, patient portals, and mobile apps for disease education and tracking [29].

Online support groups cover a wide array of distressing issues, ranging from individuals with asthma to parents of autistic children, hearing-impaired teenagers to caregivers of children with Alzheimer's, survivors of sexual assault to students with dyslexia, people who have gone through early divorces to patients facing a specific cancer, and socially anxious adults to those attempting to quit smoking. Participating in an online support forum provides individuals with a lasting and reliable source of assistance. Within these forums, they exchange and receive information, offer and receive emotional support, connect with others, build personal relationships, and find a sense of friendship with people who understand their challenges. This helps improve their feelings of being different or alone [30]. Online patient support groups offer numerous appealing qualities. [31] highlighted that people seek a sense of community when they realize that community is a matter of choice rather than something they inherit. He contended that community can be more readily discovered, chosen, or initiated online. Moreover, individuals dealing with chronic illnesses or disabilities may discover that engaging in online support groups is a more convenient option compared to attending in-person meetings. Supporters of virtual support groups have proposed that participants value the anonymity and lack of face-to-face interaction in these communities. In such settings, individuals can be valued for the quality of their contributions rather than being judged based on their physical appearance or disabilities. While joining online patient support groups requires access to computer equipment and technical assistance, it eliminates limitations related to the size of local communities, geographical constraints, or the availability of social services. If it's confirmed that online patient support groups are both feasible and advantageous, they should be encouraged and broadened to improve accessibility and offer a wider range of communities for individuals to choose from [32]. Online support groups for patients are present in numerous medical specialties, and they can provide practical and emotional benefits. These groups bring together individuals who share similar experiences, providing exposure to information, treatment options, and effective ways to cope, while also offering access to valuable social support [33].

2.1. Chronic Disease

A chronic illness is a long-lasting condition that cannot be prevented through vaccination, does not resolve naturally, and is rarely completely cured [34]. The causes of chronic diseases encompass both factors that can be changed (such as tobacco use and an unhealthy diet) and factors that cannot be changed (like genetic predispositions), as stated by the World Health Organization (WHO). Typical chronic health conditions encompass heart disease, cancer, and diabetes. Although the frequency of chronic illnesses is predicted to grow, advancements in medical care have led to enhanced treatment options, enabling individuals to enjoy extended lifespans (WHO). For example, back in 1970, a child who was born with sickle cell disease had an anticipated life expectancy of around 14 years. However, if a child is born with sickle cell disease today, it's probable that they'll have a life expectancy exceeding 40 years [35].

2.2. Rare Disease

Rare diseases are those that impact a small portion of the population. The majority of these conditions have genetic roots, and a striking statistic is that 50% of individuals with rare diseases do not survive beyond the age of 5. It has been approximated that there are around 7,000 rare diseases affecting 300 million individuals worldwide. The specific definition of what constitutes a "rare" disease can differ depending on the geographical region or country in question. Prominent organizations in Western nations, like the National Organization for Rare Disorders (NORD) in the US (United States) and the (EURORDIS) European Organization for Rare Diseases in Europe, have played a substantial role in increasing awareness about rare diseases [27]. Parents of children diagnosed with rare diseases are recognized for their frequent use of the internet to search for information [36]. They also utilize social media platforms like Facebook to connect and communicate with others [37]. This indicates that the majority of these parents are already familiar with Facebook and probably possess the required skills for social networking. As a result, these parents could easily derive benefits from expanding their use of Facebook to include participation in online patient support groups [38].

2.3. Life-Threatening Disease

Despite the progress in medical care, numerous patients still grapple with substantial difficulties when dealing with life-threatening diseases. Offering social support can significantly improve the well-being of individuals facing life-threatening illnesses and contribute to better overall results for them [39]. Online patient support groups can play a significant role in offering social support and enhancing the psychosocial well-being of individuals dealing with an illness. Virtual connections can be especially beneficial for patients facing obstacles in attending in-person groups, like those who are geographically isolated or socially isolated. In the case of severe, life-threatening diseases like cancer, patients often turn to the internet to find both emotional and informational support [40,41]. Online support groups for patients provide mutual aid and self-help for individuals coping with chronic diseases, life-threatening conditions, and addiction problems [42].

2.4. Homophily

One of the exciting aspects that current online social network (OSN) services study is the concept of "homophily" among users. Homophily refers to the tendency of similar individuals to connect with each other more frequently than with those who are dissimilar. This characteristic is present in all online social networks because it is a natural aspect of users' lives [43]. A prominent advantage of online support groups is their ability to foster a sense of shared experiences and commonalities among the participants, known as

homophily. Recognizing similarities is a known factor that can evoke feelings of attraction and make a person more likely to be influenced in various types of communication. In numerous situations, the simple realization that there are others who share similar physical and emotional experiences can be highly therapeutic. It's quite common to come across messages expressing gratitude for the existence of online platforms that introduce newcomers to a community of hundreds of individuals who are "just like me" [44]. Positively, the researcher identified a notable empirical connection between a homophily measure and the level of satisfaction with support in a survey conducted among users of online patient support groups [45].

2.5. Perceived Social Support

For individuals dealing with chronic illness, their condition can lead to a loss of social connections, diminished support networks, and a sense of isolation from their social circles. According to the study, significant sources of social support for patients undergoing chronic conditions include family members, healthcare providers, friends, and neighbors [46]. Social support is a reciprocal interaction involving at least two individuals, with the goal of improving the recipient's well-being [47]. With the growing trend of people spending more time online and using digital communication tools, various types of online patient support groups have emerged to connect individuals facing similar health challenges [48]. In these online communities, individuals look for guidance and counsel, express their feelings [49], locate others in comparable circumstances who they can relate to emotionally, and encourage one another to acquire new perspectives and behaviors . In online health communities, social support often results in a sense of perceived empathy because members typically have either firsthand experience or indirect experience (through their loved ones) with the disease. Empathy arises when patients perceive that others within the community have encountered comparable situations and can truly comprehend what the patient is going through [50].

3. Methodology

This study is empirical in nature and based on survey-based evidence. The study design is associative, and where disease type (Life threatening, Chronic or Orphan) is the dependent variable and which is categorical in nature. Perceived social support, perceived empathy and homophily are the independent variables. The aim of the study is to classify disease-type on the basis of independent variables using discriminant analysis. The data used are primary in nature. All scales are based on a 7-point Likert scale. The sample size is 700. Respondents are identified from the OPSG website and contacted online. There are respondents from various countries around the world. The information covers the period from July 2020 to November 2022.

4. Results and Discussion

Result and discussion has been discussed under following subheadings:
   a. ANOVA for testing hypothesis that significant differences in independent variable exists across disease types
   b. Eigenvalues
   c. Wilk's Lambda
   d. Classification Table

ANOVA: Table-1 provides the necessary details. We find that there are six variables (Perceived social support -2; perceived empathy - 2 and homophily - 2) that differ significantly (but weakly) across disease-type. Homophily, Perceived empathy and perceived social support are significantly higher for rare disease. This study is first of its kind and hence comparisons in

literature review are not available. Since the difference is weak, the study needs to be repeated with a different set of patients visiting OPSGs. But why is homophily, Perceived empathy and perceived social support scores are higher in case of rare diseases? For life threatening diseases and chronic diseases a patient may be finding sufficient support from family as well as healthcare providers as these are better known and hence there is a greater understanding amongst others. Rare diseases, on the other hand, being rare are not fully understood. Very few people may understand the predicament of a patient suffering from rare diseases and hence a perceived lack of homophily, social support and empathy. Such patients of rare diseases may find other patients suffering from same disease and having deeper understanding of disease, symptoms, diagnosis, prevention, cure, precautions and hence the patient visiting patient to these sites may feel a strong homophily and corresponding empathy and social support. This hypothesis needs to be explored through a more robust research study.

Table-1: ANOVA: Disease type						
		N	Mean	Std. Deviation	F	p-Value
HP2	Life Threatening	185	3.6432	1.86276		
	Rare	386	3.9119	1.59138		
	Chronic	107	3.4486	1.92909		
	Total	678	3.7655	1.73150	3.66	0.026
HP4	Life Threatening	185	3.5725	1.80519		
	Rare	386	4.2	1.61363		
	Chronic	107	3.5794	1.94275		
	Total	678	3.7448	1.74219	8.8	0
PSS2	Life Threatening	185	3.8432	2.02760		
	Rare	386	4.1192	2.00423		
	Chronic	107	3.6168	1.92130		
	Total	678	3.9646	2.00411	3.12	0.045
PSS4	Life Threatening	185	4.2595	1.98575		
	Rare	386	4.6632	1.97005		
	Chronic	107	3.8037	1.87052		
	Total	678	4.4174	1.98178	8.9	0
PE3	Life Threatening	185	3.8324	2.04542		
	Rare	386	4.1710	1.93311		
	Chronic	107	4.3084	1.83473		
	Total	678	4.1003	1.95412	2.6	0.074
PE5	Life Threatening	185	3.4054	1.91191		
	Rare	386	3.3938	1.90020		
	Chronic	107	3.8972	1.85785		
	Total	678	3.4764	1.90278	3.129	0.044

Having established that significant differences (even if weak) in homophily, Perceived empathy and perceived social support values exist for patients suffering from rare, chronic and life-threatening diseases. The next step would be to explore whether patients of these diseases can be correctly classified on the basis of these differences. To achieve this discriminant analysis has been applied

Eigen value: To assess the suitability of data for a discriminant analysis, the first step comprises of measuring the eigen values (Table-2). We find two eigen values for three variables having a value of 0.377 and 0.318. High Eigen values reflect a greater possibility of correct classification. Values we have arrived at are not very high and which is understandable as the ANOVA results also reflect week significant differences. But these are sufficiently high to go ahead with discriminant analysis.

Table-2: Eigen values

Function	Eigen value	% of Variance	Cumulative %	Canonical Correlation
1	0.377	54.3	54.3	.523
2	0.318	45.7	100.0	.491

a. First 2 canonical discriminant functions were used in the analysis.

Wilk's Lambda: A corresponding indicator for the good ness of data for discriminant analysis is Wilk's Lambda. Its values range between 0 and 1 with lower values indicating a better possibility of correct classification. Table-3 provides us with Willk's Lambda (Table-3: values of 0.551 and 0.759, suggesting a moderate goodness of the data.

Table-3: Wilks' Lambda

Test of Function(s)	Wilks' Lambda	Chi-square	df	Sig.
1 through 2	0.551	393.979	58	0
2	0.759	182.311	28	0

Classification Results: Classification results have been shown in Table-4. From the table we find that out of 185 patients of life-threatening diseases, as many as, 137 have been classified correctly. This is 74.1% correct classification. Then out of 386 patients having rare disease, 227 (57.8%) have been identified correctly. For chronic disease out of 107 patients enduring chronic diseases 77 (72%) have been identified correctly. Overall correct classification stands at 64.5%. For a three level classification, 50% or more correct classification is considered significant and hence it may be interpreted that that values of homophily, Perceived empathy and perceived social support can be useful to identify patients in terms of their disease-type. This establishes that Homophily, Perceived empathy and perceived social support are important functions served by OPSGs.

Table-4: Classification Results

		Diseasetype	Predicted Group Membership			Total
			Life Threatening	Rare	Chronic	
Original	Count	Life Threatening	137	24	24	185
		Rare	106	223	57	386
		Chronic	21	9	77	107
		Ungrouped cases	10	12	0	22
	%	Life Threatening	74.1	13.0	13.0	100.0
		Rare	27.5	57.8	14.8	100.0
		Chronic	19.6	8.4	72.0	100.0
		Ungrouped cases	45.5	54.5	.0	100.0

a. 64.5% of original grouped cases correctly classified.

Why is classification merely 64.5%? In this study the assumption is that three types of diseases are homogeneous in terms of severity, pain, occurrence, diagnosis and outcomes. But this assumption is practically incorrect. Diseases withing these groups are markedly heterogenous. Perhaps dividing diseases in that manner may result in a better identification of diseases.

5. Conclusions

This study explores the possibility of correctly identifying patients visiting OPSGs, ailing from rare, chronic or life-threatening disease on the basis of their scores on Homophily, Perceived empathy and perceived social support they derive from OPSGs. Our findings indicate that weakly significant differences occur for the scores on Homophily, Perceived empathy and perceived social support by these patients. Discriminant analysis reveals that classification is fairly accurate.

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Author contributions

Vivek Pandey: Introduction, Literature Review, Methodology
Samrat Kumar Mukherjee: Results and Discussions, Literature Review, **Prof. Ajeya Jha:** Analysis, Interpretation, Conclusion, Reviewing and Editing.

Conflicts of interest

The authors declare no conflicts of interest.

References

[1] S. Fox and K. Purcell, "Chronic Disease and the Internet".
[2] Levy, M. (2007). Online health: assessing the risk and opportunity of social and one-to-one media. *Jupiter Research*, 2.
[3] Sarasohn-Kahn, J. (2008). The wisdom of patients: Health care meets online social media.
[4] Sarasohn-Kahn, J. (2009). *Participatory health: Online and mobile tools help chronically ill manage their care*. California HealthCare Foundation.
[5] L. An *et al.*, "Utilization of Smoking Cessation Informational, Interactive, and Online Community Resources as Predictors of Abstinence: Cohort Study," *Journal of Medical Internet Research*, vol. 10, no. 5, p. e1018, Dec. 2008, doi: 10.2196/jmir.1018.
[6] J. N. Cummings, L. Sproull, and S. B. Kiesler, "Beyond hearing: Where the real-world and online support meet," *Group Dynamics: Theory, Research, and Practice*, vol. 6, no. 1, pp. 78–88, 2002, doi: 10.1037/1089-2699.6.1.78.
[7] E. G. Feil, J. Noell, E. Lichtenstein, S. M. Boles, and H. G. McKay, "Evaluation of an Internet-based smoking cessation program: Lessons learned from a pilot study," *Nicotine & Tobacco Research*, vol. 5, no. 2, pp. 189–194, Jan. 2003, doi: 10.1080/1462220031000073694.
[8] H.-Y. Lu, B. R. Shaw, and D. H. Gustafson, "Online health consultation: Examining uses of an interactive cancer communication tool by low-income women with breast cancer," *International Journal of Medical Informatics*, vol. 80, no. 7, pp. 518–528, Jul. 2011, doi: 10.1016/j.ijmedinf.2011.03.011.
[9] Bender, J. L., O'Grady, L., & Jadad, A. R. (2008). Supporting cancer patients through the continuum of care: a view from the age of social networks and computer-mediated communication. *Current Oncology*, 15(s2), 107.
[10] M. N. Kamel Boulos and S. Wheeler, "The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education1," *Health Information & Libraries Journal*, vol. 24, no. 1, pp. 2–23, 2007, doi: 10.1111/j.1471-1842.2007.00701.x.
[11] D. M. Boyd and N. B. Ellison, "Social Network Sites: Definition, History, and Scholarship," *Journal of Computer-Mediated Communication*, vol. 13, no. 1, pp. 210–230, Oct. 2007, doi: 10.1111/j.1083-6101.2007.00393.x.
[12] J. E. Chung, "Social Networking in Online Support Groups for Health: How Online Social Networking Benefits Patients," *Journal of Health Communication*, vol. 19, no. 6, pp. 639–659, Jun. 2014, doi: 10.1080/10810730.2012.757396.
[13] E. A. Adama *et al.*, "The psychosocial impact of rare diseases among children and adolescents attending mainstream schools in Western Australia," *International Journal of Inclusive Education*, vol. 27, no. 12, pp. 1273–1286, Oct. 2023, doi: 10.1080/13603116.2021.1888323.
[14] V. C. Delisle *et al.*, "Perceived Benefits and Factors that Influence the Ability to Establish and Maintain Patient Support Groups in Rare Diseases: A Scoping Review," *Patient*, vol. 10, no. 3, pp. 283–293, Jun. 2017, doi: 10.1007/s40271-016-0213-9.

[15] Kralik, D. (2002). The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of advanced nursing*, 39(2), 146-154.

[16] A. Karasz, S. C. Ouellette, and H. C. Features Submission, "Role Strain and Psychological Well-Being in Women with Systemic Lupus Erythematosus," *Women & Health*, vol. 23, no. 3, pp. 41–57, Dec. 1995, doi: 10.1300/J013v23n03_03.

[17] K. E. Luck, S. Doucet, and A. Luke, "Occupational disruption during a pandemic: Exploring the experiences of individuals living with chronic disease," *Journal of Occupational Science*, vol. 29, no. 3, pp. 352–367, Jul. 2022, doi: 10.1080/14427591.2020.1871401.

[18] Anderson, G. F. (2010). *Chronic care: making the case for ongoing care*. Robert Wood Johnson Foundation.

[19] L. M. Lix *et al.*, "The Canadian Chronic Disease Surveillance System: A model for collaborative surveillance," *Int J Popul Data Sci*, vol. 3, no. 3, p. 433, doi: 10.23889/ijpds.v3i3.433.

[20] C. Hajat and E. Stein, "The global burden of multiple chronic conditions: A narrative review," *Preventive Medicine Reports*, vol. 12, pp. 284–293, Dec. 2018, doi: 10.1016/j.pmedr.2018.10.008.

[21] S. M. McPhail, "Multimorbidity in chronic disease: impact on health care resources and costs," *Risk Management and Healthcare Policy*, vol. 9, pp. 143–156, Jul. 2016, doi: 10.2147/RMHP.S97248.

[22] Y. Jin, M. Bhattarai, W. Kuo, and L. C. Bratzke, "Relationship between resilience and self-care in people with chronic conditions: A systematic review and meta-analysis," *Journal of Clinical Nursing*, vol. 32, no. 9–10, pp. 2041–2055, 2023, doi: 10.1111/jocn.16258.

[23] B. Riegel *et al.*, "Self-care research: Where are we now? Where are we going?," *International Journal of Nursing Studies*, vol. 116, p. 103402, Apr. 2021, doi: 10.1016/j.ijnurstu.2019.103402.

[24] K. LeMay and K. G. Wilson, "Treatment of existential distress in life threatening illness: A review of manualized interventions," *Clinical Psychology Review*, vol. 28, no. 3, pp. 472–493, Mar. 2008, doi: 10.1016/j.cpr.2007.07.013.

[25] C. W. Ellison, "Spiritual Well-Being: Conceptualization and Measurement," *Journal of Psychology and Theology*, vol. 11, no. 4, pp. 330–338, Dec. 1983, doi: 10.1177/009164718301100406.

[26] H. K. Rajasimha *et al.*, "Organization for rare diseases India (ORDI) – addressing the challenges and opportunities for the Indian rare diseases' community," *Genetics Research*, vol. 96, p. e009, Jan. 2014, doi: 10.1017/S0016672314000111.

[27] X. Li *et al.*, "The urgent need to empower rare disease organizations in China: an interview-based study," *Orphanet J Rare Dis*, vol. 15, no. 1, p. 282, Oct. 2020, doi: 10.1186/s13023-020-01568-5.

[28] L. Edwards *et al.*, "Are People With Chronic Diseases Interested in Using Telehealth? A Cross-Sectional Postal Survey," *Journal of Medical Internet Research*, vol. 16, no. 5, p. e3257, May 2014, doi: 10.2196/jmir.3257.

[29] L. Madrigal and C. Escoffery, "Electronic Health Behaviors Among US Adults With Chronic Disease: Cross-Sectional Survey," *Journal of Medical Internet Research*, vol. 21, no. 3, p. e11240, Mar. 2019, doi: 10.2196/11240.

[30] A. Barak, M. Boniel-Nissim, and J. Suler, "Fostering empowerment in online support groups," *Computers in Human Behavior*, vol. 24, no. 5, pp. 1867–1883, Sep. 2008, doi: 10.1016/j.chb.2008.02.004.

[31] E. J. Madara, "The mutual-aid self-help online revolution," *Social Policy*, vol. 27, no. 3, pp. 20–27, Mar. 1997, Accessed: May 11, 2024. [Online]. Available: https://go.gale.com/ps/i.do?p=AONE&sw=w&issn=00377783&v=2.1&it=r&id=GALE%7CA20220442&sid=googleScholar&link access=abs

[32] M. Barrera Jr., R. E. Glasgow, H. G. McKay, S. M. Boles, and E. G. Feil, "Do Internet-Based Support Interventions Change Perceptions of Social Support?: An Experimental Trial of Approaches for Supporting Diabetes Self-Management,"

American Journal of Community Psychology, vol. 30, no. 5, pp. 637–654, 2002, doi: 10.1023/A:1016369114780.

[33] S. C. Titgemeyer and C. P. Schaaf, "Facebook Support Groups for Pediatric Rare Diseases: Cross-Sectional Study to Investigate Opportunities, Limitations, and Privacy Concerns," *JMIR Pediatrics and Parenting*, vol. 5, no. 1, p. e31411, Jan. 2022, doi: 10.2196/31411.

[34] M. G. Checton, K. Greene, K. Magsamen-Conrad, and M. K. Venetis, "Patients' and partners' perspectives of chronic illness and its management," *Families, Systems, & Health*, vol. 30, no. 2, pp. 114–129, 2012, doi: 10.1037/a0028598.

[35] G. R. Maslow, A. Haydon, A.-L. McRee, C. A. Ford, and C. T. Halpern, "Growing Up With a Chronic Illness: Social Success, Educational/Vocational Distress," *Journal of Adolescent Health*, vol. 49, no. 2, pp. 206–212, Aug. 2011, doi: 10.1016/j.jadohealth.2010.12.001.

[36] A. E. Tozzi *et al.*, "The internet user profile of Italian families of patients with rare diseases: a web survey," *Orphanet J Rare Dis*, vol. 8, no. 1, p. 76, May 2013, doi: 10.1186/1750-1172-8-76.

[37] H. Nicholl, C. Tracey, T. Begley, C. King, and A. M. Lynch, "Internet Use by Parents of Children With Rare Conditions: Findings From a Study on Parents' Web Information Needs," *Journal of Medical Internet Research*, vol. 19, no. 2, p. e5834, Feb. 2017, doi: 10.2196/jmir.5834.

[38] S. C. Titgemeyer and C. P. Schaaf, "Facebook Support Groups for Rare Pediatric Diseases: Quantitative Analysis," *JMIR Pediatrics and Parenting*, vol. 3, no. 2, p. e21694, Nov. 2020, doi: 10.2196/21694.

[39] T. E. Flickinger *et al.*, "Social Support in a Virtual Community: Analysis of a Clinic-Affiliated Online Support Group for Persons Living with HIV/AIDS," *AIDS Behav*, vol. 21, no. 11, pp. 3087–3099, Nov. 2017, doi: 10.1007/s10461-016-1587-3.

[40] Y.-C. Wang, R. E. Kraut, and J. M. Levine, "Eliciting and Receiving Online Support: Using Computer-Aided Content Analysis to Examine the Dynamics of Online Social Support," *Journal of Medical Internet Research*, vol. 17, no. 4, p. e3558, Apr. 2015, doi: 10.2196/jmir.3558.

[41] V. S. Helgeson and S. Cohen, *Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research*. in Cancer patients and their families: Readings on disease course, coping, and psychological interventions. Washington, DC, US: American Psychological Association, 1999, p. 79. doi: 10.1037/10338-003.

[42] M. White and S. M. Dorman, "Receiving social support online: implications for health education," *Health Education Research*, vol. 16, no. 6, pp. 693–707, Dec. 2001, doi: 10.1093/her/16.6.693.

[43] A. De Salve, B. Guidi, L. Ricci, and P. Mori, "Discovering Homophily in Online Social Networks," *Mobile Netw Appl*, vol. 23, no. 6, pp. 1715–1726, Dec. 2018, doi: 10.1007/s11036-018-1067-2.

"Current Oncology | Free Full-Text | Supporting Cancer Patients through the Continuum of Care: A View from the Age of Social Networks and Computer-Mediated Communication." Accessed: May 11, 2024. [Online]. Available: https://www.mdpi.com/1718-7729/15/12/270

[44] J. B. Walther, S. Pingree, R. P. Hawkins, and D. B. Buller, "Attributes of Interactive Online Health Information Systems," *Journal of Medical Internet Research*, vol. 7, no. 3, p. e382, Jul. 2005, doi: 10.2196/jmir.7.3.e33.

[45] K. Wright, "Perceptions of on-line support providers: An examination of perceived homophily, source credibility, communication and social support within on-line support groups," *Communication Quarterly*, vol. 48, no. 1, pp. 44–59, Jan. 2000, doi: 10.1080/01463370009385579.

[46] M. Mollaoglu, "Perceived social support, anxiety, and self-care among patients receiving hemodialysis," *Dialysis & Transplantation*, vol. 35, no. 3, pp. 144–155, 2006, doi: 10.1002/dat.20002.

[47] B. Ploderer, W. Reitberger, H. Oinas-Kukkonen, and J. van Gemert-Pijnen, "Social interaction and reflection for behaviour change," *Pers Ubiquit Comput*, vol. 18, no. 7, pp. 1667–1676, Oct. 2014, doi: 10.1007/s00779-014-0779-y.

[48] H. Taiminen and K. Taiminen, "Usage of Facebook-and Anonymous Forum – Based Peer Support Groups Online and Their Influence on Perceived Social Support Types in Weight Loss," in *2016 49th Hawaii International Conference on System Sciences (HICSS)*, Jan. 2016, pp. 3094–3103. doi: 10.1109/HICSS.2016.389.

[49] M. Tanis, "Health-Related On-Line Forums: What's the Big Attraction?," *Journal of Health Communication*, vol. 13, no. 7, pp. 698–714, Oct. 2008, doi: 10.1080/10810730802415316.

[50] B. N. Uchino, J. T. Cacioppo, and J. K. Kiecolt-Glaser, "The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health," *Psychological Bulletin*, vol. 119, no. 3, pp. 488–531, 1996, doi: 10.1037/0033-2909.119.3.488.