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Direktorin: Universitätsprofessorin Dr. rer. nat. B. Wirth

Facebook Support Groups for Rare Pediatric Diseases: Quantitative Analysis and Cross- Sectional Study to Investigate Opportunities, Limitations, and Privacy Concerns

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Sarah Catrin Titgemeyer
aus Gütersloh

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Dekanin/Dekan: Universitätsprofessor Dr. Gereon R. Fink

1. Gutachter: Universitätsprofessor Dr. med. C. Schaaf
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
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Für Oma und Opa.

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Abkürzungsverzeichnis/Abbreviations

IQR: interquartile range

KI: Konfidenzintervall

OMIM: Online Mendelian Inheritance in Man

OR: Odds Ratio

SD: standard deviation, Standardabweichung

1. Zusammenfassung/German Summary

Seltene Erkrankungen mit Manifestation im Kindesalter stellen für die Familien häufig eine erhebliche Belastung dar. Viele Eltern empfinden Einsamkeit und soziale Isolation. Die oft weite geographische Verteilung der Betroffenen erschwert jedoch die Bildung von traditionellen Selbsthilfegruppen. Eine mögliche Alternative stellt die Teilnahme an einer online-Selbsthilfegruppe dar. Soziale Netzwerke wie Facebook werden zunehmend für Gesundheitskommunikation, Informationsaustausch und Selbsthilfegruppen genutzt. Einige Studien haben bereits gezeigt, dass Betroffene von Online-Selbsthilfegruppen profitieren können. Daher ist es von großem Interesse, genauer zu analysieren, in welchem Ausmaß Selbsthilfegruppen auf sozialen Medien wie Facebook existieren und genutzt werden, sowie welche Vor- und Nachteile dies mit sich bringt.

Zu diesem Zweck führten wir zwei Studien durch: (1) eine quantitative Analyse der Anzahl und Struktur von Facebook Selbsthilfegruppen für seltene Erkrankungen im Kindesalter und (2) eine Mitgliederbefragung mittels online-Fragebogen bezüglich Nutzungsverhalten und empfundenen Vor- und Nachteilen der Nutzung des Mediums Facebook für diese Selbsthilfegruppen. Anhand der Datenbank des Portals für seltene Krankheiten und Orphan Drugs Orphanet erstellten wir eine Übersicht der seltenen Erkrankungen mit Erstmanifestation im Kindesalter und krankheitsbeschreibender Parameter wie Prävalenz, Art der Erkrankung und Vererbungsmodus. Danach erstellten wir durch Eingabe von bis zu 5 synonymen Krankheitsbeschreibungen in die Suchleiste für Facebookgruppen eine Übersicht der Facebookgruppen und gruppenbeschreibenden Parameter, wie Mitgliederzahl, Anzahl neuer Mitglieder, Anzahl neuer Beiträge, Sprache und Gruppenuntertypen. Krankheits- und gruppenbeschreibende Parameter wurden mit Standardmethoden deskriptiv statistisch ausgewertet. Für den Fragebogen kontaktierten wir die Administratoren und Administratorinnen von 12 Facebook-Selbsthilfegruppen für 12 verschiedene seltene Erkrankungen mit Erstmanifestation im Kindesalter und verschickten einen Link zu einer Online-Umfrage auf der Plattform SurveyMonkey. Die Umfrage wurde zwischen dem 19.07.2019 und 10.10.2019 durchgeführt.

Die Studien zeigten insgesamt, dass die Nutzung von Facebook als Medium für Selbsthilfegruppen für seltene Erkrankungen im Kindesalter bereits weit verbreitet ist und insbesondere durch eine hohe Erreichbarkeit und hohen praktischen Nutzen ein geeignetes Medium sein kann.

Die quantitative Analyse zeigte, dass die Anzahl der Facebook-Selbsthilfegruppen für seltene Erkrankungen im Kindesalter seit 2008 stetig ansteigt. Im Jahr 2019 wurden insgesamt 6398 Gruppen für 826 von 4246 (19,5%) der im Register Orphanet gelisteten Erkrankungen mit Erstmanifestation im Kindesalter gefunden. Gruppenart, -größe, -aktivität, Anzahl neuer Mitglieder und Sprache variierten stark (Mitgliederzahl: Minimum 1, Maximum 23414; Aktivität

in den letzten 30 Tagen: Minimum 0, Maximum 3606). 69% der identifizierten Gruppen waren private Gruppen. Die Wahrscheinlichkeit, eine Facebook-Gruppe zu einer Erkrankung zu finden, stieg mit dem Grad der verfügbaren Informationen: bekannte Prävalenz (Odds Ratio [OR] 3,98, 95% KI 3,39-4,66, $P < 0,001$), bekannte Art der Erkrankung (OR 3,15, 95% KI 2,70-3,68, $P < 0,001$) und bekannter Vererbungsmodus (OR 2,06, 95% KI 1,68-2,52, $P < 0,001$) waren alle mit einer höheren Wahrscheinlichkeit verbunden, eine Facebook-Gruppe zu finden. Die Anzahl der Gruppen pro Erkrankung stieg mit zunehmender Prävalenz.

Von den 231 in die Studie eingeschlossenen Befragten waren 87,0% ($n=201$) weiblich, 12,6% ($n=29$) männlich und 0,4% ($n=1$) gaben ein anderes Geschlecht an. Das Durchschnittsalter der Befragten betrug 41,56 Jahre (SD 9,375), 91,3% ($n=211$) waren Eltern (183 Mütter, 27 Väter, 1 anderes Geschlecht). 59,7% ($n=138$) gaben an, die Facebook-Gruppe selbst gesucht zu haben, und 24,2% ($n=56$) erhielten die Empfehlung, auf Facebook nach einer Gruppe zu suchen, von betreuendem medizinischen Fachpersonal und 12,6% ($n=29$) von einer anderen betroffenen Person. Die Befragten nutzen die Gruppen, um sich über die Krankheit zu informieren, für emotionale Unterstützung und um sich mit anderen zu vernetzen. Dafür teilen und lesen sie private Erfahrungen und Fotos und erhalten Ratschläge zum Umgang mit ihren Kindern und der Erkrankung. Mitglieder gaben durchschnittlich eine allgemeine Facebook-Nutzung mindestens einmal täglich, eine passive Gruppenteilnahme mehrmals wöchentlich und eine aktive Teilnahme einmal im Monat an. Die Privatsphäre-Einstellung der Gruppe kann für die Teilnahme entscheidend sein, da nur 41,1% ($n=95$) der befragten Mitglieder ihre privaten Erfahrungen in einer öffentlichen Gruppe teilen würden. Deutlich mehr Mitglieder gaben Bedenken bezüglich Datenschutzes und Privatsphäre auf Facebook allgemein (61,5%, $n=142$) als in ihrer Selbsthilfegruppe (29,9%, $n=69$) an. Ein großer Teil der Befragten (79,2%, $n=183$) war positiv gegenüber der Gruppenteilnahme von medizinischem Fachpersonal eingestellt. 74,5% ($n=172$) zeigten Interesse daran, über die Gruppe für die Teilnahme an medizinische Studien kontaktiert zu werden und 38,5% ($n=89$) wären daran interessiert, auf diesem Wege von Pharmaunternehmen kontaktiert zu werden.

Diese Ergebnisse können dazu genutzt werden, medizinisches Fachpersonal, Eltern und Bezugspersonen betroffener Kinder über die möglichen Vor- und Nachteile der Nutzung von Facebook als Medium für Selbsthilfegruppen für seltene Erkrankungen im Kindesalter zu informieren. Eltern könnten von Beratung hinsichtlich der möglichen Risiken des Teilens sensibler Daten profitieren, um die Privatsphäre der Kinder zu schützen. Die unterschiedlichen Meinungen zur Teilnahme von medizinischem Fachpersonal und der Kontaktierung zum Zwecke einer Studienrekrutierung oder von Pharmaunternehmen sollten genauer untersucht werden, um sicherzustellen, dass Facebook auf eine Art für Selbsthilfegruppen genutzt wird, die die Bedürfnisse und Erwartungen aller Mitglieder respektiert.

2. Introduction

2.1 Rare diseases

To date, about seven thousand rare diseases have been described, and still new diseases are frequently discovered.^{1,2} While each individual rare disease affects only a small number of individuals, rare diseases collectively affect approximately 6-10% of the population.³ Many rare diseases are genetic in etiology, but rare diseases can also have different origins, such as rare forms of infectious diseases, autoimmune diseases, rare cancers, or rare variants of common diseases.^{1,2} Often, first signs of rare diseases can be observed at birth or in childhood, which we describe as pediatric rare diseases.

Due to such a low prevalence, many health professionals are unaware of these diseases and those affected subsequently encounter difficulties in the process of finding the diagnosis, relevant information and access to medical support.¹ At the same time, rare disease are often chronic, progressive, severe, disabling or life threatening and most have no cure.^{1,4}

2.2 Parents of children affected by rare diseases

Parents or caregivers of a child with a rare disease often face multidimensional challenges.³ Though affected children's health problems may vary, parents were shown to have similar supportive care needs.³ Those affected by rare diseases are often more psychologically, socially, economically and culturally vulnerable and commonly lack access to quality health care, overall social and medical support as well as social and professional integration and independence.¹

Psychological stress can be due to social isolation, unemployment, diagnostic delays, uncertainties, lack of information and difficulty accessing appropriate health care.⁴ Caregivers often experience a certain powerlessness⁴, lack of control,⁵ incompetence,⁶ and low perceived controllability. Commonly expressed feelings among parents of a child with a rare disease are fear, worry, frustration, uncertainty, helplessness and vulnerability.⁷⁻⁹ Parenting a child with a rare disease has also been shown to negatively impact parents' relationship with each other.³ Economically, parents can face high expenses for specialized medical, allied health and educational services, specialized equipment, travel, and partial or total loss of income for the primary caregiver.⁴

Culturally, parents often suffer from social isolation, loneliness and feeling disconnected from others because of having a child with a rare disease.³ After the diagnosis of a chronic illness, parents have to adapt to a new way of life they never could have envisioned, which often includes substantial lifestyle changes.⁵ Parents have been shown to feel excluded from mainstream society for various reasons, e.g. due to the associated caring routine or sometimes due to the nature of their child's disease demanding isolation.³ Parents also feel disconnected

from families with chronically sick children who have common diseases due to the inequity in the care that their child receives.³

Furthermore, parents caring for a child with a rare disease have a high need for information.^{3,8} They need to acquire health literacy and care-giving skills beyond usual requirements as part of their parenting.³ Parents often express a desire to be regarded as partners in the care of their child,⁵ and treated as such by health professionals.

EURORDIS, a non-governmental patient-driven alliance of patient organizations representing rare diseases, co-funded by the Health Programme of the European Union, describes living with a rare disease as an “ongoing learning experience for patients and families”.¹⁰ This underlines the importance of gaining access to informational and emotional resources. Social support has been described as a protective factor for parents of a child with a rare disease.³

2.3 Support groups

A support group is defined as “a group of people, who provide each other moral support, information and advice on problems relating to some shared characteristic or experience”.¹¹ Suffering from a disorder in general can cause intense emotions and a desire to talk to others and interpersonal exchange helps understanding the illness.¹² People who face similar challenges can help each other by coming together and creating a collective wisdom based on their experiences.¹²

There are different forms of support groups with different focus points. The American Genetic and Rare Diseases Information Center categorizes groups into the following three categories: condition-specific groups, umbrella groups or alliances and general support groups.¹³ Groups offer medical information, lists of helpful resources, registries, research information and enrolment and advocacy by educating others and improving legislation and support by connecting people.^{13,14} Groups can also be involved in creating guidelines for care, organize social events, workshops and fundraisers.¹⁴

2.4 Online support groups

The Internet in general is increasingly used for health communication, for example via health-related informational websites and social media.

There are many health-related informational websites, for example the bilingual website gesundheitsinformation.de (informedhealth.org) by the German Institute for Quality and Efficiency in Health Care as part of their legal responsibility to provide the general public with easy-to-understand health information. Other examples are databases such as Orphanet, the portal for rare diseases and orphan drugs, or rarediseases.info.nih.gov by the American Genetic and Rare Diseases Information Center. There are also many websites which are not provided by health care professionals but display lay information.

Social networking platforms are increasingly used for communicating health-related topics, exchanging information and support.^{8,9} In a 2013 systematic review, Moorhead et al. identified the following ways that social media is being used by patients and health professionals: (1) provide health information on a range of conditions, (2) provide answers to medical questions, (3) facilitate dialogue between patients to patients, and patients and health professionals, (4) collect data on patient experiences and opinions, (5) use for health intervention, health promotion and education, (6) reduce stigma, (7) provide online consultation.¹⁵ In their systematic review, Moorhead et al. also identified six overarching benefits of using social media for health communication: (1) increased interactions with others, (2) more available, shared, and tailored information, (3) increased accessibility and widening access to health information, (4) peer/social/emotional support, (5) public health surveillance, and (6) potential to influence health policy.¹⁵ Other studies have shown that using social media for health-related online communication offers increased connectedness and community support.^{9,16} Online support groups offer several advantages, such as an international scope, unlimited number of participants, cost-effectiveness,¹⁷ 24-hour availability,¹⁸ and asynchronous communication.^{8,9,17}

A meta-analysis showed that between 2011 and 2016 Facebook and Twitter were the most preferred social networking platforms for health, used mainly to meet others and exchange information about health concerns, but also to access information and expertise.¹⁶

Facebook is one of the longest existing and largest social networking platforms.^{8,9} In the third quarter of 2021, Facebook reported 1,930 million daily active and 2,910 million monthly active users.¹⁹ Individuals can connect via Facebook through individual and group communication. Facebook users create an account with a personal profile to which they can upload personal information and pictures and send contact requests to other users. As communication tools, users can direct-message using Facebook messenger, post on their own or other's profile or on pages and participate in public or private groups. Facebook users can to some degree adapt their Facebook privacy settings according to their preference, ranging from displaying only their username to all personal information and pictures publicly. To create a Facebook account, an Internet device and connection is necessary. Users must be at least 13 years old and confirm an email or mobile phone number.²⁰

2.5 Rare diseases in the context of online health information and online support groups

Pelentsov et al. showed that many parents of children with rare diseases when asked whether they would seek support from a parent of a child with another disorder answered that they would not because they expect their experiences to be different to their own.³ Nevertheless, due to the diseases being rare and affected individuals often geographically dispersed,⁸ many

parents have never come into contact with other parents who take care of a child with a similar condition.⁷⁻⁹ Finding a condition- or disorder-specific support group can be difficult for rare diseases, since the disease prevalence is so low and affected individuals may be widely geographically dispersed. Online support groups for rare diseases offer the distinct advantage of connecting people with a large geographical distance.^{8,9}

Several studies have shown that parents of children with rare diseases are usually active Internet²¹ and social media²² users, and therefore fulfill the prerequisites of engaging in a Facebook support group.⁹ A few studies have shown that social media such as Facebook are utilized by and beneficial for persons affected by rare pediatric diseases.^{9,22-26}

2.5.1. Support group benefits

Support groups offer distinct benefits. When comparing studies performed on support group benefits, three common main themes emerge: informational support, connecting with others and emotional support. These common themes appear in studies on traditional, online, and rare disease-specific parental support groups.

A study on mothers' participation in support groups on Facebook regardless of their child's health status showed a reduction in stress and improvement in overall health and quality of life.²⁷ One of the early studies examining the benefits of parent-to-parent support groups for parents of children with disabilities found the following key benefits: (1) belonging to a community, being understood and accepted, and having friendships and social networks; (2) gaining a sense of control and agency; (3) feelings of increased self-esteem and confidence, less guilt and self-blame and greater acceptance of their child's disability.²⁸ Furthermore, they showed that the groups provided parents with a range of coping resources, acquired through the shared knowledge by others who had gone through similar experiences.²⁸ A study on resilience in families raising children with disabilities and behavior problems discussed how family life congruence can be substantially enhanced through more opportunities for support between families raising children with disabilities.²⁹ Cantwell et al. showed that social support acts as a moderating factor regarding the association between stress and physical health, influencing how stress impacts the physical health of parents of children with developmental disabilities.³⁰

A 2013 systematic review of peer support for parents of children with chronic disabling conditions identified four common themes: (1) shared social identity, (2) learning from the experience of others, (3) personal growth, and (4) support others.³¹ A study of the influence of a parent-to-parent peer support scheme on the wellbeing of parents of disabled children or children with additional needs, showed that an improved sense of hope and a feeling of belonging were key benefits that resulted from forming social connections.³² An analysis of messages exchanged in two parental Facebook support groups for autism found that the

highest percentage of messages offered dealt with Informational (30.7%) and emotional support (27.8%).²⁴

There have been some studies on rare disease support groups in general and condition-specific online support groups or communities, that showed similar benefits.^{18,25,33} In a scoping review from 2017, Delisle et al. identified seven different perceived benefits of participating in rare disease support groups: (1) meeting and befriending other people with the same rare disease and similar experiences, (2) learning about the disease and related treatments, (3) giving and receiving emotional support, (4) having a place to speak openly about the disease and one's feelings, (5) learning coping skills, (6) feeling empowered and hopeful, and (7) advocating to improve healthcare for other rare disease patients.¹⁸

Oprescu et al., who analyzed messages posted to an online community by caregivers (parents) of children with clubfoot, found that online communities can be an effective channel for caregivers, especially women, to seek and offer information required for managing clubfoot-related uncertainty.³³ Wittmeier et al., who conducted a descriptive and quantitative analysis of the use of a Facebook page for Hirschsprung's Disease, found that social networks are well suited for discussion, support and advocacy for health-related conditions and can be especially important in connecting families affected by rare conditions.²⁵

Increased social support can thus positively impact parents caring for children with chronic diseases, disabilities, additional needs, behavioral problems, and rare diseases.^{9,17,23-26,33,34}

2.5.2. Challenges of online support groups

While online support groups offer these distinct advantages, there are also several challenges. Communication difficulties can arise due to the limitation to written interaction.¹⁷ The accuracy, quality and reliability of information obtained online can be questioned, as well as the possible misinterpretation and questionable application to a personal situation.^{15,17,22} This can be especially problematic when parents turn to the internet to obtain a "second opinion", which often does not take into consideration all individual aspects.

Another topic to be discussed in the context of online support groups is confidentiality and privacy. Anonymity can facilitate discussing topics that are perceived as embarrassing or taboo.¹⁷ Postings can be a permanent record and be viewed by an increasing audience, of which users might be unaware.¹⁵ Several studies have found that individuals are often unaware of the risks to disclosing personal information online.^{15,35,36} Many individuals appear to be unaware that this data might potentially be used against them by organizations or individuals.^{35,36}

Parental usage of Facebook for online support groups can involve sharing a child's personal and health information online.⁸ At the same time, children have interests in protecting personal information and may not agree with a parent's decision to share information online, but do not

necessarily have control over their own digital footprint.³⁶ Negative consequences can for example be embarrassment, humiliation and bullying.³⁶ The United Nations' Convention on the Rights of the Child protects children's privacy, honor and reputation in Article 16: *"No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honor and reputation."*^{36,37} Hence, there is a potential conflict between parent's right of free expression and parental rights and the child's privacy interest, leading to a controversial discussion of children's digital identities and children's rights online.³⁶

To understand the complex concept of privacy, there are several approaches to privacy theories.³⁸ These theories address the moral questions of how information about humans should be processed, who can access the data, and how to regulate this access.³⁹ Integrative approaches, which combine control and limitation theories of privacy define privacy as a right that should be protected and as individual control of personal information in form of restricted access.^{8,38} Facebook's privacy concept combines self-regulation and an individualistic understanding of privacy, and according to some authors, Facebook's privacy policy puts capital interest first in the interest of sharing information with advertisers to create profit.³⁹

A systematic literature review from 2017 that investigated discrepancies between expressed privacy concerns and actual behavior online found three categories of decision-making on online information disclosure: a rational risk-benefit calculation, an irrational risk-benefit calculation based on biased assessment, and processes with negligible or no risk assessment, e.g. due to information deficit or low privacy valuation.⁴⁰ This discrepancy between privacy concerns and actual information disclosure is described as the privacy paradox.^{8,40} As participation in online support groups presumably involves sharing private information online, it is of interest to explore if the privacy paradox is applicable to parental behavior in online support groups for rare diseases.⁸

2.5.3. Role of health care professionals

A high frequency of participation by clinical geneticists in advocacy groups suggests an extension of their activities with patients and families beyond the traditional setting and context.⁴¹ Their involvement was shown to include education, examination, and organization.⁴¹ Even though this activity is voluntary, health care professionals can also benefit from group participation by having the opportunity of meeting many individuals with a rare disease, profit from their shared knowledge and recruit for research projects.⁴¹ Facebook has been successfully used for study recruitment for rare disease research,^{41,42} and a high number of study participants can be recruited with low associated costs.^{8,42} In a survey by Lin and Terry that involved 67 medical geneticist who partake in support groups, most acknowledged that patient confidentiality (78%), potential conflicts of interest (66%), and medico-legal liability (72%) were relevant issues.⁴¹ Yet, the role of health care professionals in the context of support

groups and especially online support groups has not yet been clearly defined and can vary between groups.⁸

2.6 Research rationale

Parents caring for children with rare conditions have special supportive care needs and participation in support groups can be an important resource of social support.^{8,9} As rare diseases have such a low prevalence, finding and taking part in a support group is often difficult due to large geographical distances between affected individuals.^{8,9} Parents may therefore turn to the Internet and especially social networking platforms such as Facebook. Some studies have shown that Facebook is utilized by and beneficial for persons affected by rare pediatric diseases.^{8,9} However, since most of these studies focused on specific conditions or groups, the extent of support group usage and overall representation of rare pediatric diseases on Facebook remains unknown.^{8,9} With our two studies we therefore aimed to (1) provide a comprehensive quantitative analysis of the extent of Facebook usage as a tool for rare pediatric disease support groups and analyze disease- and group-describing parameters to explore factors that influence a disease's representation on Facebook,⁹ and (2) put into perspective the chances and challenges of Facebook as a tool for online support groups for rare pediatric diseases by analyzing group accessibility and usage, perceived privacy and views on using Facebook for communication between health professionals and parents, pharmaceutical companies and for study recruitment (see figure 1).⁸

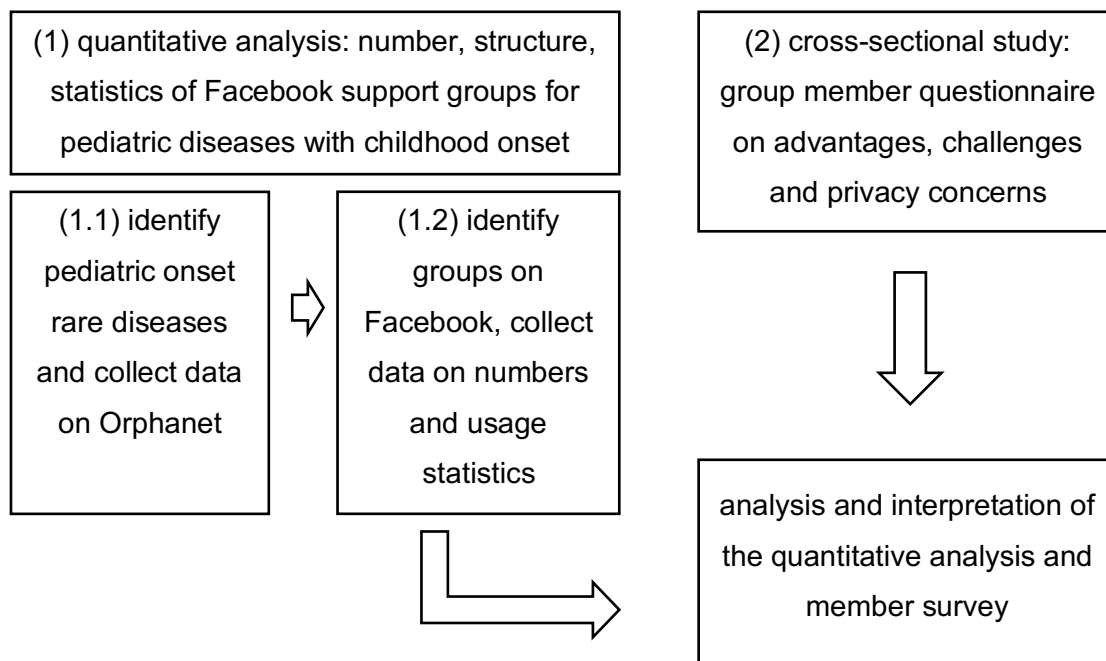


Figure 1: overview of research methods

3. Paper 1 – Facebook Support Groups for Rare Pediatric Diseases: Quantitative Analysis

Original Paper

Facebook Support Groups for Rare Pediatric Diseases: Quantitative Analysis

Sarah Catrin Titgemeyer¹; Christian Patrick Schaaf^{2,3}, MD, PhD

¹University of Cologne, Cologne, Germany

²Institute of Human Genetics, Heidelberg University, Heidelberg, Germany

³Institute of Human Genetics, University Hospital Cologne, Cologne, Germany

Corresponding Author:

Christian Patrick Schaaf, MD, PhD

Institute of Human Genetics

Heidelberg University

Im Neuenheimer Feld 366

Heidelberg, 69120

Germany

Phone: 49 6221 565151

Email: christian.schaaf@med.uni-heidelberg.de

Abstract

Background: Loneliness, social isolation, and feeling disconnected from society are commonly experienced by parents of children with rare diseases and are, among others, important reasons for special supportive care needs. Social networking platforms are increasingly used for health communication, information exchange, and support. In the field of rare pediatric diseases, qualitative studies have shown that Facebook online support groups are utilized by and beneficial for persons affected by rare pediatric diseases. Nonetheless, the extent of this usage has not been investigated.

Objective: This study aims to provide a comprehensive quantitative analysis of the extent of Facebook usage as a tool for rare pediatric disease support groups and to explore factors that influence a disease's representation on Facebook. These results potentially offer important insights for future public health initiatives and give direction to further research that can give much needed support to parents of children with rare diseases.

Methods: We determined rare pediatric diseases using the inventory of the online portal Orphanet. Facebook support groups were identified by searching 5 synonymous disease descriptions using the group category search bar. Disease- and group-describing parameters were statistically analyzed using standard descriptive statistical methods.

Results: 6398 Facebook support groups, representing 826 diseases (19.5% of all searched diseases), were found. 69% are private groups. Group type, size, activity (sum of posts, comments, and reactions calculated by Facebook), new memberships, and language varied largely between groups (member count: minimum 1, maximum 23,414; activity last 30 days: minimum 0, maximum 3606). The highest percentage of awareness and information groups was found for teratogenic diseases (18/68, 26%). The odds of finding a Facebook group increased according to the level of information available about the disease: known prevalence (odds ratio [OR] 3.98, 95% CI 3.39-4.66, $P < .001$), known disease type (OR 3.15, 95% CI 2.70-3.68, $P < .001$), and known inheritance mode (OR 2.06, 95% CI 1.68-2.52, $P < .001$) were all associated with higher odds of finding a Facebook group, as was dominant compared to nondominant inheritance (OR 2.05, 95% CI 1.74-3.42, $P < .001$). The number of groups per disease increased with higher prevalence.

Conclusions: Facebook is widely used as a tool for support groups for rare pediatric diseases and continues to be relevant. Two-thirds of the groups are private groups, indicating group participants' need for privacy, which should be further explored. The advantages and limitations of Facebook as a tool for support groups in the field of rare diseases should be further investigated as it will allow health professionals to use Facebook more meaningfully in their counseling and guidance of affected individuals and their family members.

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KEYWORDS

pediatric rare diseases; rare diseases; support group; online support; Facebook support group; social media; parent support; support group privacy; counseling

Introduction

Background

Many parents of children affected by rare diseases described caring for a child with a rare disease to be highly isolating—with loneliness, social isolation and feeling disconnected from society being mentioned as common problems [1]. Most parents had never come into contact with other parents of a child with a similar condition to that of their own child, and many were dissatisfied with the overall support that they had received for their child with a rare disease from any source [1]. Since rare diseases have per definition a very low prevalence (European definition of rare diseases: <1 per 2000) [2], affected individuals are often geographically dispersed. For many rare diseases there is a deficit of medical and scientific knowledge [2]. Rare diseases are often serious, chronic, and progressive, and persons affected by rare diseases are more psychologically, socially, economically, and culturally vulnerable [2]. Hence, parents of children with rare diseases have special supportive care needs [1].

Parent-to-parent peer support has been shown to have beneficial effects on parents of children with disabilities and children with additional needs [3]. Parents benefit from support groups most importantly by building social connections, gaining a sense of belonging [4,5], and developing a sense of control [5]. Support groups provide an environment for parent-to-parent support, which offers several benefits through improved social support. Participating parents can experience improved social connections [4], a heightened sense of control [5], higher family life congruence [6], and lower consequences of perceived stress [7].

Social networking platforms are increasingly used for health communication, information exchange, and support. Benefits of using social media for health-related online communication and community include connectedness, increased community support, and online support groups [8]. Several advantages of social media for online support have been identified, including international scope, unlimited number of participants, cost-effectiveness [9], and 24-hour availability [10]. However, there are limitations, such as questionable reliability [11], accuracy [9], quality [12], application to personal situations [11], and the possible misinterpretation [9] of information found online and on social media.

Founded in 2004, Facebook is one of the longest existing social networking platforms [13]. In the second quarter of 2019, Facebook reported 2.41 billion monthly active users [14]. Thus, chances are presumably high that another person affected by the same disorder also uses Facebook and would be eligible to form a support group. Facebook allows persons to connect independent of geographic location and offers options for both individual and group communication [13].

Prior Work

Parents of children with rare diseases are active internet users, search for information online [15], and use social media such as Facebook to communicate and link with others [12], showing that most parents are already familiar with Facebook and are, therefore, likely have the required social networking skills. Therefore, they could benefit by extending their Facebook usage to participation in support groups quite effortlessly.

To our knowledge, only little research exploring the specific topic of online support groups for rare pediatric diseases has been conducted so far. Content analyses of specific online and Facebook support groups have been performed (eg, on groups for cleft lip and palate, clubfoot, Hirschsprung disease, autism spectrum disorders, Dravet syndrome, and related epilepsy disorders [16-21]). Group members benefit from giving and receiving informational and emotional support and from connecting with others since meeting others with similar experiences has been shown to decrease isolation [10,16-19].

Research Rationale

Social support can provide several benefits for parents caring for children with chronic diseases, disabilities, additional needs, behavioral problems, and rare diseases [3-10,12,13,15,16,18,20]. Qualitative studies have shown that Facebook is utilized by and beneficial for persons affected by rare pediatric diseases. However, since these studies focused on specific conditions or groups, they failed to reflect the extent of support group usage and the overall representation of rare pediatric diseases on Facebook.

Our study therefore aimed to provide a comprehensive quantitative analysis of the extent of Facebook usage as a tool for rare pediatric disease support groups and at analyzing disease- and group-describing parameters to explore factors that influence a disease's representation on Facebook.

These results may offer important insights for future public health initiatives and give direction to further research which can improve much needed support of parents of children with rare diseases. The analysis of Facebook groups dedicated to rare pediatric diseases and their development over time, for example, shows how many groups and individuals could benefit from an optimization of support groups conditions on Facebook. Initiatives that aim to promote communication among affected families can use this analysis to learn about support group structures such as group sizes and privacy settings. Having built the foundation of a quantitative analysis, future research can, for example, focus on a more in-depth qualitative analysis of Facebook group. Furthermore, this study points to the need for health professionals who treat individuals with rare pediatric disorders or affected parents or caregivers or provide genetic counseling to get better acquainted with the topic of social media support groups in order to understand and promote the communication among parents or caregivers of children with rare disorders.

Methods

Data Collection

Rare diseases with childhood manifestation were identified using the inventory of the online portal for rare diseases and orphan drugs Orphanet). Orphanet uses the European definition of rare disease [22]. A rare pediatric disease is defined as a disease with onset before adulthood; thus, age of onset had to be defined as antenatal, conatal/neonatal, infancy, childhood or adolescent but not adult, older adult, or all ages. Data collected included disease name, 4 synonyms, ORPHAcode, Online Mendelian Inheritance in Man number, International Statistical Classification of Diseases Tenth Revision, disease prevalence, inheritance mode (autosomal or sex-linked, recessive or dominant, etc), age of onset and disease type (monogenic, deletion or alteration of a single gene; chromosomal, alteration in the number or structure of a chromosome; microdeletion, deletion of a small chromosomal segment; teratogenic disorder, result of exposure to teratogenic agent; mitochondrial; infectious disease; multigenic or multifactorial). Age of onset and disease type information was extracted from disease name or Orphanet disease description. Data were collected between January 1, 2019 and March 13, 2019.

Facebook support groups were identified by searching 5 synonymous disease names or descriptions using the Facebook group category search bar. The researcher used a Facebook account, newly created for this purpose, that contained only the researcher's name, picture, gender (female) and location (Cologne, Germany); but no activity (likes, shares, etc) expect for searching for aforementioned disease names. Groups were subcategorized according to their specific focus using the information available from the group title, the group category provided by Facebook's group categorization or the publicly available group description. Groups had to be clearly recognizable as support groups, groups to raise awareness and information, or support groups for individual patients. Groups that explicitly focused on research, fundraising and charity, medication sales, and disease-related pages were excluded from analysis (examples for categorization using group title *Disorder A fundraiser* was categorized as focus on fundraising and excluded from analysis, *Child B's journey with disorder C* was categorized as personal support group, *Disorder D: spread awareness* was categorized as awareness and information group). Data collected on Facebook included group type, name, language, privacy setting (public or private), foundation date, member count, and group insights. Group insights are provided by Facebook and displayed on each group information page, regardless of privacy status. They report activity (sum of posts,

comments, and reactions calculated by Facebook) and new members during the past 30 days. Only groups with at least 1 member qualified. Foundation dates for groups on Facebook can be entered automatically or manually; manually entered foundation dates before Facebook launch in 2004 were excluded from analysis due to a lack of reliability of information. Data were collected between March 13, 2019 and March 31, 2019.

Data Analysis

Data were analyzed using standard descriptive statistical methods using SPSS statistics (version 26; IBM Corp). Normally distributed data are presented using mean and standard deviation, skewed distributions are presented using median and interquartile range, binary and categorical variables are presented using counts and percentages. Odds ratios (ORs) were calculated. The 1-sample Kolmogorov-Smirnov test was applied to test for normal distribution. Nonparametric tests (Spearman ρ correlation, independent sample Mann-Whitney U test) were applied. Binomial and chi-square tests were used to investigate binary and categorical variables.

This study has been reviewed by the Ethics Commission of the Medical Faculty of the University of Cologne (protocol 19-1027), and all research has been carried out within the scope of the approval.

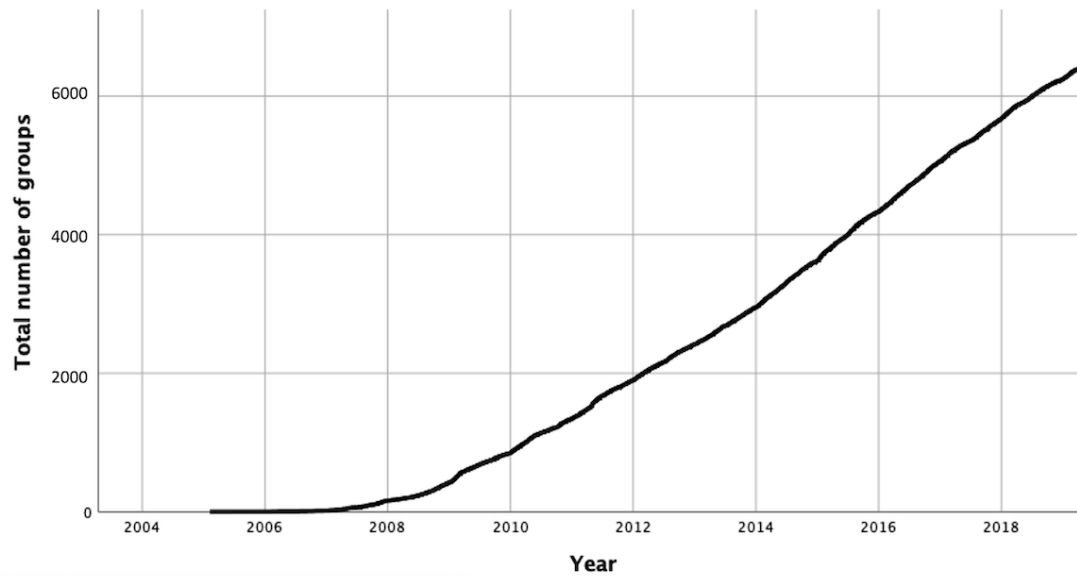
Results

General

A total of 4246 rare disorders with onset before adulthood were identified using the Orphanet inventory, and 6398 support groups were found on Facebook. These groups represent 826 diseases, which amounts to 19.5% of all searched diseases.

The 10 diseases for which the most Facebook support groups were found are Down syndrome (145/6398, 2.3%), 22q11.2 deletion syndrome (117/6398, 1.8%), hypoplastic left heart syndrome (117/6398, 1.8%), Turner syndrome (97/6398, 1.5%), gastroschisis (95/6398, 1.5%), cleft lip and palate (93/6398, 1.5%), Ehlers-Danlos syndrome (93/6398, 1.5%), craniosynostosis (92/6398, 1.4%), microtia (90/6398, 1.4%), and retinoblastoma (89/6398, 1.4%). An alphabetic list of diseases on Facebook, including Online Mendelian Inheritance in Man number and the respective number of groups, is presented in [Multimedia Appendix 1](#).

The total number of Facebook groups has continuously increased since 2008 ([Figure 1](#)). The number of newly created Facebook support groups shows fluctuation with an overall increase ([Multimedia Appendix 2](#)).

Figure 1. Development of the total number of Facebook support groups for pediatric rare diseases over time.

Disease-Describing Parameters

Of the 4246 diseases listed on Orphanet, 529 (12.9%) diseases show antenatal and 2815 (68.9%) show conatal/neonatal onset, 2167 (53.0%) start during infancy, 1074 (26.3%) during childhood, and 165 (4.0%) show adolescent onset. More than one age of onset may apply.

Table 1 depicts the distribution of disease type and prevalence among all identified diseases and diseases with at least 1 support group and the number and percentage of Facebook support groups per disease type and prevalence. 274/934 (29.3%) of the monogenic diseases, 51/145 (35.2%) of the chromosomal, 85/158 (53.8%) of the multigenic or multifactorial, and 4/22 (18.2%) of the teratogenic diseases found on Orphanet are represented on Facebook, and 376/2830 (13.3%) of the diseases with unknown disease type. The mean number of groups per disease increases with increasing prevalence (mean 2 for

prevalence <1 per 1,000,000; mean 5 for prevalence 1-9 per 1,000,000; mean 14 for prevalence 1-9 per 100,000; mean 28 for prevalence 1-9 per 10,000).

Table 2 displays the number and percentage of diseases on Orphanet and diseases with at least one group following the different inheritance modes. More than one inheritance mode may apply.

ORs were calculated to compare the probability of a disease with known or unknown disease-describing parameters to be represented by at least one Facebook group: known prevalence (OR 3.98, 95% CI 3.39-4.66, $P<.001$), known disease type (OR 3.15, 95% CI 2.70-3.68, $P<.001$), and known inheritance mode (OR 2.06, 95% CI 1.68-2.52, $P<.001$) are all associated with higher odds of finding a Facebook group; as is dominant compared to nondominant inheritance (OR 2.05, 95% CI 1.74-3.42, $P<.001$).

Table 1. Diseases and Facebook support groups by prevalence and type of disease.

	Diseases found on Orphanet (n=4246), n (%)	Facebook support groups (n=6398), n (%)	Diseases with ≥1 group (n=826), n (%)
Prevalence			
<1 per 1,000,000	2516 (59.3)	620 (9.7)	253 (30.6)
1-9 per 1,000,000	150 (3.5)	452 (7.1)	85 (10.3)
1-9 per 100,000	188 (4.4)	1825 (28.5)	132 (16.0)
1-9 per 10,000	77 (1.8)	1251 (19.6)	44 (5.3)
1-9 per 1000	1 (<0.1)	0 (0.0)	0 (0.0)
Unknown	1314 (30.9)	2250 (35.2)	312 (37.8)
Disease type			
Monogenic	934 (22.0)	1623 (25.4)	274 (33.2)
Chromosomal	145 (3.4)	655 (10.2)	51 (6.2)
Mitochondrial	25 (0.6)	11 (0.2)	2 (0.4)
Infectious disease	2 (<0.1)	1 (<0.1)	1 (0.1)
Multigenic or multifactorial	158 (3.7)	988 (15.4)	85 (10.3)
Teratogenic disorder or infectious fetopathy	22 (0.5)	68 (1.1)	4 (0.5)
Micro-/contiguous gene deletion/duplication/triplication	130 (3.0)	290 (4.5)	33 (4.0)
Unclassified	2830 (66.7)	2762 (43.2)	376 (45.5)

Table 2. Pediatric rare diseases on Orphanet and diseases with at least one group that follow the different inheritance modes (more than one may apply).

Type ^a	Pediatric rare diseases on Orphanet that follow this inheritance mode, n (%)	Pediatric rare diseases with ≤1 group that follow this inheritance mode, n (%)
Autosomal recessive	1765 (55.6)	314 (38.0)
Autosomal dominant	971 (30.6)	279 (33.8)
X-linked recessive	306 (9.6)	75 (9.1)
X-linked dominant	70 (2.2)	25 (3.0)
Multigenic or multifactorial	74 (2.3)	31 (3.8)
Mitochondrial	15 (0.5)	1 (0.1)
Y-linked	1 (<0.01)	0 (0.0)
Inheritance not applicable	513 (16.2)	197 (23.8)

^aMore than one may apply.

Group-Describing Parameters

Group Type

The support groups are further divided into the following subcategories: general support groups (4385/6398, 68.5%), personal support groups (828/6398, 12.9%), support groups with focus on awareness and information (450/6398, 7.0%), not further specified groups (649/6398, 10.1%), groups for several diseases (86/6398, 1.3%). The following were not included: main focus on research (n=147), fundraising and charity (n=338), and medication sales (n=4). The highest percentage of awareness and information groups was found for teratogenic diseases (18/68, 26%).

Group Language

Disease names or synonyms were entered into the Facebook search bar in English. Groups were mostly English speaking (5721/6398, 89.4%), with a smaller number listing French (227/6398, 3.5%), Spanish (99/6398, 1.5%), German, Dutch, Portuguese, Swedish, Turkish, Polish, or Danish as the group language. In total, 38 different group languages were found (Multimedia Appendix 3).

Group Statistics

Group-describing parameters were not normally distributed. The sum of group members in all groups amounted to 1,784,435. Membership in more than one group was possible. The median number of members was 33 (IQR 183, Q1 5, Q3 188; for comparison: mean 278.91, SD 989.46). This varied between

personal support groups (mean 87.50, IQR 238.75), general support groups (mean 44, IQR 217), and awareness and information groups (mean 15, IQR 105.25). The maximum group member count was 23,414 in a group for pediatric multiple sclerosis, the minimum was 1 member in 496 groups. Of these, 326 groups were the only Facebook support group for the respective disease. Of these groups, 268 (82.2%) were general support groups, 12 (3.7%) were personal support groups, 11 (3.4%) were awareness and information groups, 5 (1.5%) were groups for several diseases, and 30 (9.2%) were not further specified groups.

Throughout all groups, 84,966 new posts, comments and reactions were found (range 3606, minimum 0, maximum 3606; mean 0, IQR 3, Q1 0, Q3 3). In total, 4021 groups showed no group activity. 35,119 persons joined the identified Facebook support groups (range 1357, minimum 0, maximum 1357; mean 0, IQR 1, Q1 0, Q3 1).

Privacy Settings

When set to private, content, such as posts and pictures, is only accessible to members whose membership must be approved by a group administrator. Group title, group description, and group statistics including member count, new members last 30 days and activity last 30 days are always publicly available. Of the identified groups, 69% (4414/6398) are private, and 31%

(1984/6398) are public. The sum of group members was 1,468,102 in private and 316,333 in public groups, with a maximum of 23,414 members in a private and 17,000 members in a public group. The median member count was higher in private (mean 46) than in public groups (mean 14). The median activity and new members in the 30 days prior to analysis was 0 for both private and public groups, with a sum of 78,023 activities in private and 6943 activities in public groups and a sum of 29,566 new members in private and 5553 new members in public groups. Performing an independent-sample Mann-Whitney *U* test showed that the distribution of the group-describing parameters differed slightly between the 2 privacy settings with higher member count, activities last 30 days, and new members last 30 days in private groups (member count: $U=5,296,374$, $z=13.44$, $P<.001$, effect size $r=0.17$; activities last 30 days: $U=5,602,193$, $z=20.65$, $P<.001$, effect size $r=0.29$; new members last 30 days: $U=5,104,178$, $z=13.04$, $P<.001$, effect size $r=0.16$).

Correlation Analyses of Group- and Disease-Describing Parameter

Correlation analyses showing relations between group- and disease-describing parameters are displayed in Table 3. The minimal age of onset correlates neither with the number of groups per disease nor with the group member count.

Table 3. Spearman correlations between disease- and group-describing parameters.

Interpretation, variables	ρ	<i>P</i> value
Significant strong positive correlation		
Recent group activity and number of new members	0.769	<.001
Significant moderate positive correlation		
Prevalence and number of groups per disease	0.530	<.001
Group member count and recent group activity	0.691	<.001
Group member count and new group members	0.628	<.001
Significant weak positive correlation		
Prevalence and group member count	0.101	<.001
Time that a group exists and member count	0.111	<.001
No significant correlation		
Time that a group exists and recent group activity	0.011	.39
Time that a group exists and number of new members	-0.002	.85
Disease's minimal age of onset and number of groups per disease	-0.021	.55
Disease's minimal age of onset and group member count	0.006	.62

Discussion

Principal Findings

Facebook is widely used as a tool for support groups for individuals affected by rare pediatric diseases. This study has shown that, for approximately every fifth rare pediatric disease, one can find an existing Facebook support group. Group type, size, activity, new memberships, privacy settings, and language vary largely between groups.

Within the first years after the launch of Facebook in 2004, only a few Facebook support groups for rare pediatric diseases were created. Starting 2008 and onward, the total number of Facebook groups has been following almost linear growth. Consequently, we expect the number of groups and the number of diseases represented on Facebook to further increase in the coming years.

Facebook Support Group Subtypes

Support group subcategories allow different group focus and benefits. Analyses of some general support groups have shown that group members give and receive informational and

emotional support [19], exchange knowledge and advice [18], and benefit from the ability to connect with others via Facebook [16].

Personal support groups (about every eighth identified group) are dedicated to one specific child with a certain disorder. Information about this child's health is shared and discussed. This group format has similarities with a blog but offers more personal two-way communication and thereby opportunities for emotional support. These groups' creator and members may especially benefit from having a place to speak openly about the disease and feelings as well as from receiving emotional support, which are 2 main benefit categories identified by White and Dorman [9]. A possible explanation for why these groups show the highest median member count could be a different target group. While other support groups are usually joined by parents and other immediate family members [12,16-18,20], these groups are probably also joined by family friends, who receive health updates and offer comfort, but who do not have a child with a similar condition. It could be of interest to evaluate the impact of this method of receiving social support in the context of rare diseases, since such groups do not depend on disease prevalence and finding others with the same condition.

Almost every tenth identified support group also focuses specifically on creating awareness and providing information. This is in agreement with previous studies' findings: families of patients with rare disease often become involved in raising public awareness [10], and social media can increase rare disease awareness [23]. The highest percentage of awareness and information groups was found for teratogenic diseases. Many teratogenic diseases are preventable disorders and parents, caregiver, or patients might therefore utilize Facebook groups to spread awareness to prevent future cases of the same disease.

Insights Gained From Group Statistics

Facebook Group Accessibility

Even though we used English search terms, we found support groups in 38 different languages, indicating that Facebook support groups are a worldwide development. This supports that Facebook is a fitting tool for support groups since it is a globally accessible platform [13]. Facebook offers the possibility to easily and inexpensively share information 24 hours a day and time-zone independent [10,21]. Parents of children with rare diseases are active internet users and use social media such as Facebook [12,15]. Together with the aspect of internationality, Facebook is therefore accessible as a tool for support groups for many, if not most, caregivers for a child with a rare disease.

Group Members and Activity

Group sizes vary greatly. Group member count can be influenced by multiple factors, as we have shown for disease prevalence. Other factors may include group promotion among affected families and by health professionals.

Correlation analyses showed that groups with more group members also had slightly more recent group activity and new members. Support group participants could therefore benefit from joining a larger Facebook group, since it offers more active

discussions and more individuals to connect with. Group activity and new member count showed a strong positive correlation, which indicates that new members start new conversations.

Many groups did not show any group activity. This could be either coincidental or indicate that these groups are inactive. Even if groups are formally inactive, there might still be private conversations between group members using Facebook Messenger or other personal messaging services, which we were not able to evaluate.

Looking for Others to Start a Support Group

Our analysis showed that 326 persons created a group for a specific disease, but at the time of study no one had joined their group, which means that they were unsuccessfully looking for someone to start a support group with. Possible reasons are that no one directly or indirectly affected by the same condition has turned to Facebook in order to look for a support group, or that no one is available for a support group on Facebook. Regarding the first explanation, it could be helpful to raise awareness of Facebook as a tool for rare pediatric disease support groups among parents and caregivers. A survey of caregivers of children with Autism Spectrum Disorders found that caregivers whose diagnosing clinician had referred them to a support group were more likely support group participants [20]. Therefore, health professionals ought to get better acquainted with the topic of social media support groups if they aim to promote the communication among parents and caregivers of children with rare disorders.

Facebook Support Group Privacy

A group's privacy setting limits access to the group. When set to private, membership must be validated by a group administrator before content such as posts and pictures can be accessed or created. Group description and group statistics are publicly available. Our analysis showed that two thirds of the groups were private, which is in agreement with a survey conducted among patients with newly described or rare genetic findings, of whom 60% were uncomfortable with sharing information in a public group [13].

Because of the need of a validation before joining a private group, we expected public groups to have higher member counts, but private groups' median member count resulted to be three times higher. More individuals appear to prefer joining private support groups, which indicates members' preference of a more private environment when sharing experiences related to their children's health.

Nevertheless, sharing information in a private Facebook group still means sharing information about a child online and oftentimes with (relative) strangers. Confidentiality and privacy issues are an important topic, since group participants are often unaware of risks of disclosing personal information [11]. Studies on mothers' habits of sharing private details on their children on Facebook regardless their children's health status have shown that mothers become increasingly aware of privacy issues on Facebook and try to find a balance between the need for privacy and the benefits of openness; some felt that some information was not appropriate to share [24,25]. This topic is particularly challenging since children cannot object to sharing information

and pictures online, but might experience negative consequences later in life. Privacy issues therefore need to be investigated in the context of Facebook as a tool for rare pediatric disease support groups.

Factors That Influence a Disease's Representation on Facebook

The more individuals are affected by a disease, the more individuals potentially turn to Facebook to look for or create a support group. Many diseases with higher prevalence have several support groups, and these groups' descriptions often include geographic locations, eg different countries or states. Facebook group members have been shown to organize meetings for particular events [19], and Facebook groups organized according to members' locations could facilitate this.

The analysis of variables collected in this research showed that the odds of finding a Facebook group for a disease with known prevalence are almost four times higher compared to with unknown prevalence, for a disease with known inheritance two times higher than with unknown inheritance, and for a disease with known disease type more than three times higher than with unknown disease type. These findings suggest that the chances of finding a Facebook group increase with a higher level of understanding about the disease. New diseases are described regularly, but it takes time and resources to investigate newly described diseases, and for many rare diseases there is a subsequent deficit of medical and scientific knowledge [2]. It also takes time until more affected children have been diagnosed. This limited information and the factor of time influence the chance of finding a group on Facebook. Other factors may play a role as well. The impact of disease-specific mortality, for example, could be of great importance and might therefore be of interest for further investigation.

The odds of finding a Facebook support group for a disease with possible dominant inheritance are twice as high as for a disease without dominant inheritance. The risk of transmission in dominant diseases is 50%. Individuals affected by dominant diseases therefore encounter several challenges, such as reproductive decision making, feelings of guilt, and the need to communicate genetic risk with their children and family members [26]. These challenges can influence an individual's need for peer support, which may, in part, explain the higher probability of finding groups for dominant diseases.

Consequences for Treating Physicians and Other Health Care Professionals

This study indicates a need for health care professionals to become acquainted with social media as a tool for support groups, since it is already widely used. To allow informed decision making on whether to refer parents and caregivers of children with a rare disease to Facebook, more research about the strengths and limitations of Facebook as a tool for support groups is needed. If treating physicians decide to promote Facebook support groups, they can inform patients about the

chances of finding a group, which is 1 in 5 overall but higher for monogenic, chromosomal, and multigenic or multifactorial diseases. Physicians with a focus on certain diseases can use our research to explore the extent of Facebook usage for groups for the respective disease. Furthermore, this study strengthens the importance of further research about rare diseases, since knowledge about a rare disease also influences the availability of support groups.

Study Strengths and Limitations

This study is a broad-scope analysis. All Orphanet-listed diseases which conform to the inclusion criteria were searched on Facebook using 5 synonymous disease descriptions. Nevertheless, it is impossible to know whether all existing support groups have been identified. Even though the Facebook search was conducted in English, groups in 38 different languages were identified. It is possible that not all existing non-English groups have been found, especially when disease names differ largely from the English disease name. Other groups regardless of group language may not at all use a disease description in their group title. Facebook search engine optimization may have influenced our search results using the researcher's information regarding location and gender. To minimize this effect, no other activities such as viewing, liking or sharing have been performed. Group activity and the number of new memberships could vary and since this was a cross-sectional study our data may not be representative. This could be investigated by repeating the study at another point in time. The limited information on Orphanet also limited our analysis. Disease type was evident for only a third of the diseases and information on prevalence was provided for only two-thirds of the diseases.

Conclusion

There has been a continuous rise in the number of support groups and diseases represented on Facebook since 2008. We expect that the relevance of Facebook as a tool for rare pediatric disease support groups will continue to increase. Group type, size, activity, new memberships, privacy settings, and language vary largely between groups. Support group subcategories allow different group focus. The odds of finding a Facebook group have been shown to increase according to the level of information available about the disease, and the number of groups increases with higher prevalence. Two-thirds of the groups are private groups, indicating the group participants' need for privacy, which should be further explored. More research is necessary to investigate the strengths and limitations of Facebook as a tool for support groups in the field of rare disease. This will allow health professionals to use Facebook more meaningfully in their counseling and guidance of affected individuals and their family members. It may also allow Facebook and other similar social media platforms to improve their toolkits and offerings for individuals affected by rare diseases.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Alphabetic list of diseases.

[\[DOC File , 711 KB-Multimedia Appendix 1\]](#)

Multimedia Appendix 2

The number of newly created Facebook support groups shows fluctuation with an overall increase.

[\[PNG File , 60 KB-Multimedia Appendix 2\]](#)

Multimedia Appendix 3

Full list of Facebook support groups by language.

[\[DOC File , 51 KB-Multimedia Appendix 3\]](#)

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4. Paper 2 – Facebook Support Groups for Pediatric Rare Diseases: Cross-Sectional Study to Investigate Opportunities, Limitations, and Privacy Concerns

Original Paper

Facebook Support Groups for Pediatric Rare Diseases: Cross-Sectional Study to Investigate Opportunities, Limitations, and Privacy Concerns

Sarah Catrin Titgemeyer¹; Christian P Schaaf², MD, PhD, FACMG

¹University of Cologne, Cologne, Germany

²Institute of Human Genetics, Heidelberg University, Heidelberg, Germany

Corresponding Author:

Christian P Schaaf, MD, PhD, FACMG

Institute of Human Genetics

Heidelberg University

Im Neuenheimer Feld 366

Heidelberg, 69120

Germany

Phone: 49 6221 56 5151

Email: christian.schaaf@med.uni-heidelberg.de

Abstract

Background: Because of the nature of rare diseases with affected individuals being widely geographically dispersed, finding an in-person/offline support group itself can be a challenge. Affected individuals therefore turn to social networking platforms such as Facebook for online support groups.

Objective: We aim to put into perspective the opportunities Facebook offers as a tool for pediatric rare disease support groups by investigating its use, advantages, and limitations including privacy concerns. We analyze group accessibility and usage, advantages specific to rare diseases, perceived privacy, and views on using Facebook for communication between health professionals and parents, pharmaceutical companies, and study recruitment.

Methods: We contacted 12 Facebook support groups for 12 respective rare diseases with pediatric onset and invited group members to participate in a cross-sectional online survey.

Results: Of 231 respondents, 87.0% (n=201) of respondents were female, 12.6% (n=29) were male, and 0.4% reported another sex (n=1). Respondents' mean age was 41.56 years (SD 9.375); 91.3% (n=211) of respondents were parents (183 mothers, 27 fathers, 1 other sex); 59.7% (n=138) reported a self-initiated search for the Facebook group, 24.2% (n=56) received recommendations from their health professionals, and 12.6% (n=29) recommendations from someone else affected by the disease. On average, support group members visited Facebook at least once a day, visited and passively participated (read/liked posts) several times a week, and participated actively (commented/posted) once a month. As much as 79.2% (183/231) agreed that they would like to have health professionals as members of the respective Facebook group. Group members expressed more concern about privacy issues on Facebook in general than in their respective Facebook support groups, with concerns mostly related to Facebook itself and nongroup members.

Conclusions: Our study confirmed that Facebook enhances support group accessibility for parents of children with rare diseases. Group participants perceive a reduction and elimination of distance, a common challenge in rare disease, and Facebook support groups create an environment of perceived privacy. The group's privacy setting can be a critical factor for active support group participation. Sharing personal information and pictures on Facebook is very common among group participants, which shows the importance of discussing and protecting children's privacy rights in this context.

Trial Registration: German Clinical Trials Register DRKS00016067; https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00016067

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KEYWORDS

Facebook; support group; parental support; pediatric rare diseases; privacy paradox; children's privacy

Introduction

The types of emotions most frequently expressed by parents of children with a rare disease include fear, worry, frustration, uncertainty, helplessness, and vulnerability [1]. Parents often feel dissatisfied with the overall level of support for their child with a rare disease [1]. Affected individuals are often geographically dispersed, because rare diseases by definition have a very low prevalence. According to the European definition, a disease is considered rare when its prevalence is below 1 in 2000 [2]. Therefore, many parents have never come into contact with another parent taking care of a child with a similar condition [1]. Social isolation and the feeling of being disconnected from society are common experiences [3]. For many rare diseases, medical and scientific knowledge remains scarce [2]. At the same time, these diseases are often serious and chronic, thereby increasing psychological, social, economic, and cultural vulnerability [2]. Consequently, parents of children with rare diseases encounter substantial challenges and have special supportive care needs [1,3].

Support groups offer improved social support [1,4,5] through befriending other people with similar experiences; learning about the disease, treatments, and coping skills; emotional support; and feeling empowered [4]. However, due to the nature of rare diseases with affected individuals being widely geographically dispersed, finding an in-person/offline support group itself can be a challenge. Affected individuals therefore turn to social networking platforms such as Facebook for online support groups. The use of social media for health communication offers increased interactions; more available, shared, and tailored information; and peer, emotional, and social support [6].

Facebook is one of the longest existing social networking platforms [7], and with more than 2.4 billion monthly active users also one of the largest [8]. In March 2019, Facebook support groups were available for more than 4000 pediatric rare diseases with approximately 1.8 million group members in more than 6000 groups [9]. Facebook has an international scope, provides options for individual and group communication [7], offers an unlimited number of participants, and is very cost-effective [10]. Nevertheless, Facebook support group accessibility is limited by access to a computer and the internet [10], related handling skills, and age restrictions. Concerning informational exchanges on social media, the reliability [6], accuracy [10], quality [11], application to personal situations [6], and the possible misinterpretation [10] of information found online and on social media have been questioned. Especially considering how frequently Facebook is being used for support groups, an investigation into whether Facebook represents a suitable tool for pediatric rare disease support groups is needed to improve the much needed support for parents of children with rare diseases.

The usage of Facebook for parent support groups can involve sharing a child's personal health information online. Sharing information online can be potentially harmful due to the ability to identify individuals and the potential misuse of this information by organizations and individuals [12]. Known

negative consequences of sharing information about a child on social media include embarrassment, humiliation, and bullying [13]. The involvement of sharing private information about children online thus encloses a controversial discussion on a child's digital identity and protecting children's rights online [13].

Integrative privacy theories define privacy as a right that should be protected and as individual control of personal information in the form of restricted access [14,15]. Information and communication have been identified as the most relevant dimension of privacy when discussing internet privacy [16]. While the United Nations' Convention on the Rights of the Child protects children's privacy, honor, and reputation [17], only little guidance is provided by specific privacy laws regarding children's need for protection from their parents' online disclosure [13]. When considering how to protect a child's privacy online, different approaches to decision making on online information disclosure can play a role, such as decision making based on risk-benefit calculations or decision making based on benefits with little to no risk assessment [18]. A discrepancy between expressed privacy concerns and actual information disclosure, which often becomes evident in online communication, is described as the privacy paradox [18].

It is important to analyze how privacy dimensions, approaches to decision making on online information disclosure, and the privacy paradox play a role in the use of Facebook as a tool for pediatric rare disease support groups to improve the protection of children's privacy rights and awareness of the risks related to sharing information online.

The role of health professionals in Facebook support groups has not yet been defined. To date, only few studies have examined the opportunities Facebook offers for a communication between parents and health professionals, pharmaceutical companies, and study recruitment [19-24]. Social media can improve patient-to-patient and patient-to-health professional dialogue and can be used for data collection, intervention, promotion, and education [6]. A study on support groups for autism spectrum disorder showed that parents whose diagnosing clinician had referred them to a support group were more likely support group participants [25]. Furthermore, Facebook has been successfully used for study recruitment in rare diseases, resulting in high numbers of study participants with low associated costs, thus improving recruitment for rare disease research [21]. Social media can be used for recruitment of geographically dispersed [20] and socially and culturally diverse [19] individuals. Given all these opportunities, it is of interest to gain insights into group participants' perspective toward involvement of health professionals and the instrumentalization of Facebook for study recruitment and by pharmaceutical companies.

Only little research exploring the topic of online support groups for pediatric rare diseases has been conducted so far. A few analyses of specific online and Facebook support groups have been performed, for example, on groups for cleft lip and palate [22], clubfoot [5], Hirschsprung disease [23], and autism spectrum disorders [24,25]. These analyses have shown support group benefits which can be classified into the following 3 main

categories: informational support, emotional support, and connecting with others. Our prior large quantitative analysis regarding the extent of Facebook support groups for pediatric rare diseases has shown that both the total number of support groups and the number of diseases for which a support group can be found have increased [9]. With two-thirds of these groups being private Facebook groups, we found that the need for privacy should be further explored [9]. Also, given the already widespread use of Facebook as a tool for support groups for pediatric rare diseases, an analysis of its strengths and limitations could allow health professionals to improve their understanding of this tool and, consequently, use Facebook more meaningfully in their counseling and guidance of affected individuals and their family members [9].

With this study, we therefore aim to put into perspective the opportunities Facebook offers as a tool for pediatric rare disease support groups by investigating its use, advantages, and limitations including privacy concerns. We analyze group accessibility and usage, advantages specific to rare diseases, perceived privacy, and views on using Facebook for communication between health professionals and parents, pharmaceutical companies, and study recruitment.

Our results can offer improved knowledge about the opportunities of Facebook support groups as well as their disadvantages. These findings may allow Facebook and similar

social media platforms to discover starting points for improving their toolkits and offerings. Parents and caretakers of children with rare diseases can directly or indirectly benefit from this increase in information directly or indirectly through receiving guidance on important points to be considered prior to joining a group from their treating physicians when searching for ways to receive much-needed social support. By informing medical professionals and, subsequently, parents about potential privacy concerns, active decision making on online information disclosure considering children's privacy rights can be initiated.

Methods

We contacted 12 Facebook support groups for 12 respective rare diseases with pediatric onset and invited group members to participate in a cross-sectional online survey. For each of these diseases a Facebook group was contacted (Table 1). Group administrators were contacted by either email or Facebook messenger. The members of the respective groups were subsequently invited through a wall post within the actual closed Facebook groups.

The date of first enrolment was July 19, 2019, while the survey was closed on October 10, 2019. Respondents had to be group members of Facebook support groups for rare diseases with childhood onset; this inclusion criterion had to be confirmed in the questionnaire.

Table 1. List of each disease for which a Facebook group was contacted.

Orphanet disease description	Orphanet disease synonym	ORPHAcode	OMIM ^a number
15q13.3 Microdeletion syndrome	Del(15)(q13.3)	199318	612001
Lamb–Shaffer syndrome	SOX5 haploinsufficiency syndrome	530983	616803
Alacrimia–choreoathetosis–liver dysfunction syndrome	NGLY1 deficiency	404454	615273
Optic atrophy–intellectual disability syndrome	BBSOAS	401777	615722
17p11.2 microduplication syndrome	Potocki–Lupski syndrome	1713	610883
Prader–Willi syndrome	Prader–Labhart–Willi syndrome	739	610883
Rare nonsyndromic intellectual disability	CHAMP1 variant	101685	616579
Rett syndrome	—	778	312750
MAGEL2-related Prader–Willi-like syndrome	Schaaf–Yang syndrome	398069	615547
Smith–Magenis syndrome	17p11.2 microdeletion syndrome	819	182290
16p13.2 Microdeletion syndrome	Del(16)(p13.2)	500055	602519
White–Sutton syndrome	Intellectual disability–microcephaly–strabismus–behavioral abnormalities syndrome	468678	616364

^aOMIM: Online Mendelian Inheritance in Man.

We developed the survey according to the information needed from participants to evaluate usage, advantages, and limitations with a focus on privacy concerns. It included 3 demographic questions, 11 questions about frequency and details of group usage, 9 statements on positive/negative aspects and privacy concerns, and 3 statements on involvement of medical professionals. Opinions on attitudinal/opinion-based questions were elicited using a 5-point Likert scale or binary (yes/no) scale (Multimedia Appendix 1). The online survey was provided using SurveyMonkey [26]. Prior to participation, respondents

were informed about the research project's purpose and the voluntary and anonymous nature of their participation. Respondents were informed that withdrawal was possible at any given time and without consequences. No further incentive or reimbursement was given. Starting the questionnaire constituted informed consent to study participation.

By contacting 12 groups we expected to reach the target sample size of 100 respondents. This sample size was thought to provide a sufficient overview of usage data trends and the range of

opinions about positive and negative aspects of Facebook usage for childhood rare disease support groups. Being a purely descriptive study, power calculations were not needed. Effectively, exceeding these expectations, a sample size of 238 respondents was reached, of whom 7 were excluded as the inclusion criterion question had not been answered.

The study and recruitment method have been reviewed by the Ethics Commission of Cologne University's Faculty of Medicine (19-1027) and all research had been carried out within the scope of the approved study.

Survey answers were statistically analyzed by standard descriptive statistical methods using IBM SPSS statistics version 26. Metric data (age) were presented using mean and SD, ordinal data by the median and IQR, and binary and categorical variables using counts and percentages. Kendall τ was used to calculate rank correlations.

Results

Overview

In total, 231 respondents affirmed participation in a Facebook support group for a rare disorder; 7 did not respond to this question and were thus removed from the sample. Of the total respondents, 87.0% (n=201) were female, 12.6% (n=29) were male, and 0.4% reported another sex (n=1). Respondents' mean age was 41.56 years (SD 9.375), with a median of 39 years (range 21-80 years) and an IQR of 10 years (Q1=35, median=39, Q3=45).

Of the 231 study respondents, 91.3% (n=211) were parents (183 mothers, 27 fathers, and 1 other sex), 5.6% (n=13) other relatives (eg, grandmothers, child), 1.7% (n=4) patients, 1 friend, 1 health professional, and 1 with no specified connection (0.4% each).

As much as 59.7% (138/231) reported a self-initiated search for the Facebook group, 24.2% (56/231) received recommendations from their health professionals, and 12.6% (29/231) recommendations from someone else affected by the disease. A total of 5/231 respondents created the group (2.2%), 1/231 respondent found the group via disease-related website (0.4%), and 1/231 via Facebook post (0.4%).

Accessibility and Group Usage

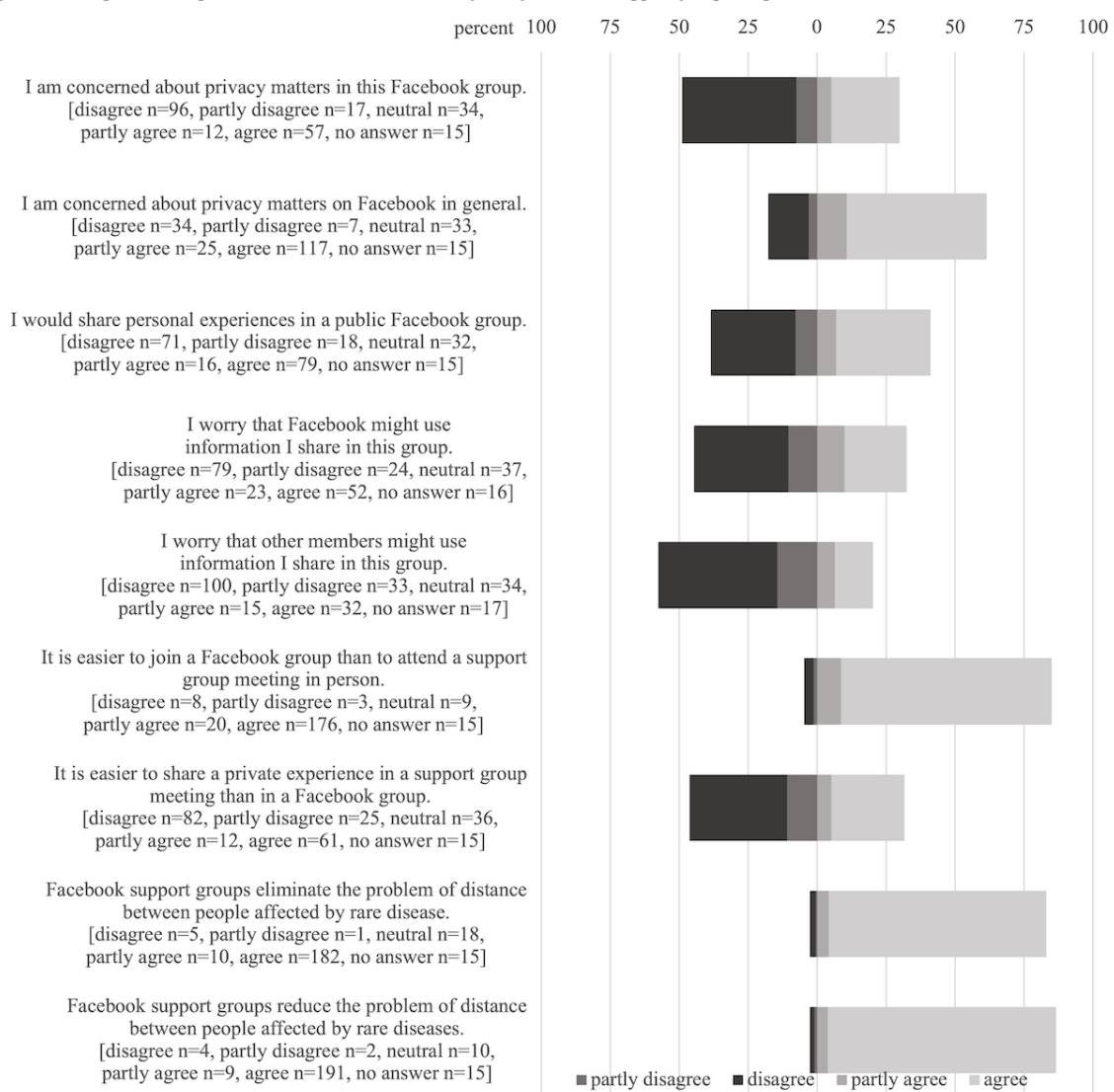
On average, support group members visited Facebook at least once a day, visited and passively participated (read/liked posts) several times a week, and participated actively (commented/posted) once a month. Answers ranged from less than every 3 months to at least once a day for all questions (Table 2). Kendall τ showed a weak positive correlation between overall Facebook usage and support group usage ($r=0.334$, $P<0.0001$).

Most members used the Facebook group to find medical information about the disease, to read about personal experiences concerning the disease, to get advice on caring for someone with this disease, and to share their personal experiences concerning the disease. They agreed that Facebook reduces and eliminates the problem of distance between people affected by rare diseases (Figure 1).

Table 2. Facebook overall and Facebook support group usage frequencies (N=231).

Frequency	Overall Facebook usage, n (%)	Facebook support group usage, n (%)	Passive participation, n (%)	Active participation, n (%)
At least once a day	175 (75.8)	89 (38.5)	71 (30.7)	20 (8.7)
Several times per week	38 (16.5)	88 (38.1)	100 (43.3)	38 (16.5)
Once a week	7 (3.0)	31 (13.4)	34 (14.7)	41 (17.7)
Once a month	2 (0.9)	9 (3.9)	9 (3.9)	62 (26.8)
Once every 3 months	0 (0.0)	3 (1.3)	3 (1.3)	27 (11.7)
Less than once every 3 months	2 (0.9)	5 (2.2)	5 (2.2)	34 (14.7)
No answer	7 (3.0)	6 (2.6)	9 (3.9)	9 (3.9)
Total	231 (100.0)	231 (100.0)	231 (100.0)	231 (100.0)
Median	At least once a day	Several times per week	Several times per week	Once a month
IQR	0	Several times per week to at least once a day	Several times per week to at least once a day	Once every 3 months to several times per week

Figure 1. Group member's perceived benefits and concerns regarding Facebook support groups for pediatric rare diseases.

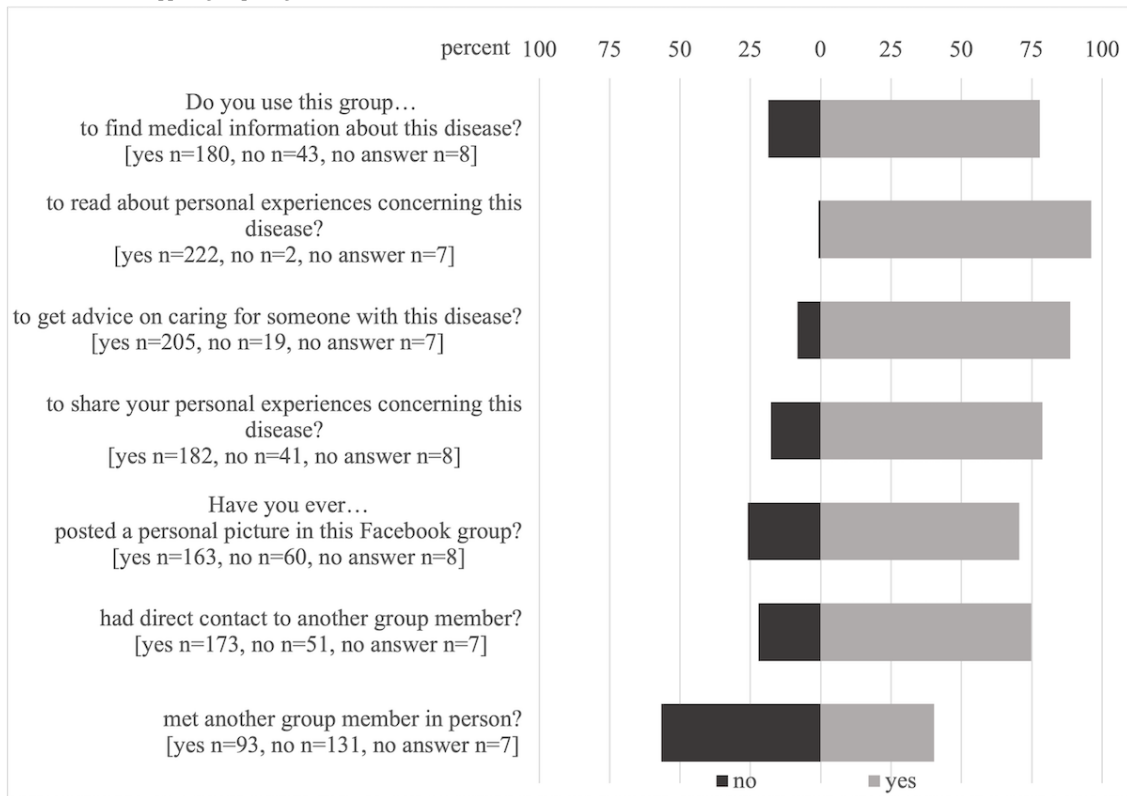


Support Group Benefits

In our survey, we investigated 3 main categories of perceived benefits: informational support (finding medical information,

getting advice on caring for someone with this disease), emotional support (reading or sharing personal experiences), and connecting with others (Figure 2).

Figure 2. Facebook support group usage.



Privacy Perception and Concerns

Information shared in a public Facebook group is accessible to every Facebook user worldwide; however, a private group offers a more selected audience. Group members expressed more concern about privacy issues on Facebook in general than in their respective Facebook support groups, with concerns mostly related to Facebook itself and nongroup members. Twice as many respondents agreed to being concerned about privacy matters on Facebook in general than to being concerned about privacy matters in their Facebook group (Figure 1).

Using Facebook for Communication With Health Professionals, Pharmaceutical Companies, and Study Recruitment

Concerning group member’s perspectives on being contacted through their respective group, 67.1% (155/231) and 7.4% (17/231) fully and partly agreed, respectively, that they would be interested in being contacted through this group for the purpose of recruitment for medical studies and 34.2% (79/231) and 4.8% (11/231) fully and partly agreed, respectively, that they would be interested in being contacted by pharmaceutical companies. As much as 74.5% (172/231) and 4.8% (11/231) fully and partly agreed, respectively, that they would like to have health professionals as members of the respective Facebook group (Figure 3).

Figure 3. Group member’s perspective on involvement of health professionals, pharmaceutical companies and study recruitment in Facebook support groups for pediatric rare diseases.



Discussion

Accessibility and Group Usage

Our study confirmed that Facebook enhances support group accessibility for parents of children with rare diseases. For most participants (196/231, 84.8%) it was easier to join a Facebook group than to attend a support group meeting in person. Reasons may include lack of in-person support group due to large geographic distances, limited time, and means of transportation. This increased accessibility is an important advantage specifically for the field of rare diseases with often large geographic distances between affected individuals.

Group members’ regular participation rates (Table 2) likely indicate high accessibility and practicality. Only 31.6% (73/231) of respondents agreed to finding it easier to share a private experience in a support group meeting than in a Facebook group, suggesting that Facebook support groups could possibly be considered an equally adequate setting for support groups. By providing options for both passive (read/like) and active (comment/post) participation, Facebook allows different degrees of involvement, which can facilitate group participation.

Support Group Benefits

These 3 main categories of perceived benefit (informational support, emotional support, and connecting with others) are common benefit categories previously investigated in studies on pediatric rare diseases or online support [1,4-6,11,22-24].

Informational Support

As 77.9% (180/231) of respondents used their Facebook group to find medical information about the respective disease, our study strengthens previous studies’ findings that social media, including Facebook, is being used to search for medical information [5,6,11,22,23]. Increased knowledge can reduce stress related to parental incompetence and may result in better use of resources in the family [27]. Disease-specific Facebook support groups also facilitate the exchange of personal experiences in caring for someone affected; 88.7% (205/231) of respondents to our survey used their Facebook group to obtain advice on caretaking. This can ultimately improve parental management and care of rare conditions and have an empowering effect on parents who can become experts in their child’s care [11].

Emotional Support

Reading and sharing personal experiences is a starting point for emotional support in patient-to-patient communication. Seeing others’ similar experiences can install a sense of belonging [25], seeing same struggles can make one feel less alone, and seeing others’ positive developments can give hope. Almost all group members (222/231, 96.1%) used the Facebook group to read personal experiences and 78.8% (182/231) also shared personal experiences. About 70.6% (163/231) had already posted a personal picture in their group (Figures 1 and 2). Group participants’ frequent reading and sharing of personal experiences confirm that emotional support is a fundamental element of support groups, including support groups for rare diseases [4,6,22,24].

Connecting With Others

Facebook support groups and social media in general enable parents to connect with others [1,4,6,11,22,28]. This is especially important for those affected by rare diseases, because distance between affected individuals is a challenge in rare diseases which highly contributes to social isolation. Most respondents to our study agreed that Facebook reduces (200/231, 86.6%) and even eliminates (192/231, 83.1%) the problem of distance between people affected by rare diseases (Figure 2).

Facebook provides multiple communication functions including group and individual communication [7]. Usage of these functions is evident in our study: all respondents participated in group communication and 74.9% (173/231) reported direct contact to another group member via personal messaging services. Connections are also reported outside the virtual world: about 40.3% (9/231) had already met another group member in person (Figure 2). A study on online support groups for autism spectrum disorders indicated that a connection via Facebook could also be the starting point of organizing meetings for particular events [24].

These findings underline that parents and caregivers of children with rare diseases use Facebook support groups to connect and build relationships, and that Facebook is particularly useful for connecting with others affected by rare diseases by addressing the problem of distance between affected individuals.

Privacy

Two-thirds of support groups for pediatric rare diseases on Facebook are private groups [9], reflecting on members' need for privacy when sharing personal information and experiences online. In our survey, participants were divided about whether or not they would share personal experiences in a public group. About 41.1% (95/231) would share personal experiences in a public Facebook group, whereas 38.5% (89/231) would not, while 13.9% (32/231) remained neutral (Figure 1). These negative answers showed that privacy setting can be decisive for active support group participation. Privacy concerns generally appear to be mostly directed at Facebook itself and users who are not involved in the group: while only 29.9% (69/231) were concerned about privacy matters in their Facebook group, 61.5% (142/231) were concerned about privacy matters on Facebook in general and 32.5% (75/231) worried that Facebook might use information they shared in their group compared with 20.3% (47/231) who worried that other members might use this information (Figure 1). This suggests that their Facebook groups achieve a certain environment of perceived privacy.

As we have shown, most respondents of this study shared private information on Facebook, even though they had privacy concerns. This shows that the privacy paradox, which describes the discrepancy between expressed privacy concerns and actual information disclosure [18], is also applicable to pediatric rare disease support group members. More discussions on actual privacy, perceived privacy, and responsible decision making on online information disclosure with regard to protecting children's privacy rights are needed. With an increasing number of Facebook support groups and increasing relevance for

affected families, ultimately, guidelines on sharing children's personal information online will be needed.

Using Facebook for Communication With Health Professionals, Pharmaceutical Companies, and Study Recruitment

Giving recommendations to look for a Facebook group appears to be common practice, with 24.2% (56/231) of the participants having been referred to the Facebook group by a health professional (Figure 3). Having investigated the opportunities and limitations of Facebook support groups, our study can improve health professional's knowledge on this type of support groups. When giving the recommendation to look for a support group on Facebook, health professionals can use this knowledge to inform individuals about the points that should be considered prior to joining a group, which include benefits that are to be expected, which prerequisites and limitations could possibly be encountered, and that sharing personal (health) information online requires careful consideration.

Study Strengths and Limitations

Our study had a larger than expected sample size, with various diseases and support groups being represented. There were only few ethical implications because data were collected anonymously and respondents were given the option to omit questions if they did not feel comfortable answering. This may result in a low social desirability bias and central coherence bias. Nevertheless, representability and external validity can be questioned. Only groups addressing 12 pediatric rare diseases were invited, and our demographic analysis shows that males were under-represented. The study results might be influenced by a response/selection bias, because anyone completing the survey self-selected to do so, especially regarding the question on study recruitment. Future research should involve a more in-depth analysis of participant's privacy concerns and behavior, including participant's decision-making process on online information disclosure with regard to children's privacy rights.

Conclusion

We have shown that Facebook is a suitable tool for pediatric rare disease support groups, offering the distinct advantages of high accessibility and practicality. Group participants perceive a reduction and elimination of distance between affected individuals, a common challenge in rare disease, and Facebook support groups create an environment of perceived privacy allowing participants to share personal experiences and pictures.

We confirmed that participants of Facebook support groups for pediatric rare diseases benefit from informative support, emotional support, and the opportunity to connect with others. Our study has confirmed that most support group members use their Facebook group to find medical information, and further research is needed regarding how parents process and apply information found in online support groups to evaluate the risk of information inaccuracy and misinterpretation. Through our recruitment methods we provide an example of how Facebook support groups can be used for study recruitment and our survey showed that many group participants are in favor of study recruitment through their Facebook support groups.

We found that a group's privacy setting can be a critical factor for active support group participation. Furthermore, we have shown the importance of discussing children's privacy rights: sharing personal information and pictures on Facebook is very common among group participants. Group member's privacy concerns appear to be mostly directed at Facebook itself and to users not involved in the group, which offers potential starting points for improving privacy in Facebook support groups. Our study showed that the privacy paradox is applicable to group

members' online information disclosure habits: parents share private information even though they are concerned about privacy matters on Facebook. Parents could benefit from guidance on responsible decision making about online information disclosure with regard to protecting children's privacy rights. Ultimately, guidelines on sharing children's personal information online could be a useful tool for finding the right balance between the risks of information disclosure and the benefits of participating in a support group on Facebook.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire: Pediatric rare disease support groups on Facebook.

[\[DOCX File , 19 KB-Multimedia Appendix 1\]](#)

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5. Discussion

5.1 Rare disease representation on Facebook

Our research has shown that in 2019, a Facebook support group could be found for approximately one in five rare pediatric disease.⁹ Since 2008, the number of groups has shown almost linear growth.⁹ Group type, size, activity, new memberships, privacy settings, and language vary greatly between groups.⁹

For many rare diseases, information about the disease is scarce: often the exact cause and prevalence are still unknown and most diseases have no treatments.^{1,2} Our Orphanet search has confirmed this, since the prevalence of 30.9% of the pediatric rare diseases listed was unknown and of 66.7% the disease type (genetic, teratogenic etc.) has not yet been specified.⁹ Our research has further shown that the level of understanding about a disease influences the disease's representation on Facebook: the odds of finding a group are higher when prevalence is known than unknown, when inheritance is known than unknown and when disease type is known than unknown.⁹ This indicates that further research can not only improve knowledge on diseases but probably also access to support. The number of groups for diseases with known possible dominant inheritance was found to be twice as high as without dominant inheritance mode.⁹ In diseases with dominant inheritance the risk of transmission is 50%, which can add more challenges such as reproductive decision making, feelings of guilt and the need to communicate genetic risk with children and other family members, which may add to the need for informational and emotional support.⁹

When investigating correlations between disease-describing parameters, a moderate positive correlation between prevalence and number of groups per disease and a weak positive correlation between prevalence and group member count were found.⁹ A higher number of individuals affected by a disease means a higher number of potential support group members. In the Facebook group search, 496 groups with only one group member were found.⁹ Of these, 326 groups were the only Facebook support group for the respective disease.⁹ This indicates that someone founded the group and is looking for others to join to build a support group.

5.2 Support group subgroups

Our Facebook group search showed groups that can be further classified into the following subgroups: general support groups, personal support groups, advocacy and awareness groups and not further specified condition-specific groups.⁹ Other group types that were identified but excluded from our analysis because of different focus points were groups with focus on research, fundraising and charity, and medication sales.⁹ Comparing our findings with The American Genetic and Rare Diseases Information Center categorization of condition-specific groups, umbrella groups and general support groups,¹³ our search shows further subdivisions in the groups of condition-specific and general support groups.

Several more common and/or more known rare diseases have several support groups, which then often include geographic locations such as countries or states.⁹ A study on two online support groups for Autism Spectrum Disorders has shown that these groups were also the starting point of organizing in-person meetings.²⁴ The aforementioned groups who bring affected individuals who live geographically close together could also help organize such in-person meetings.

Personal support groups are dedicated to one specific child and information about this child's health and everyday life is shared and discussed.⁹ This shows similarity to a traditional blog format with added interactions such as liking and sharing and more interactive communication. Compared to the other subgroups, these personal support groups showed the highest median member count.⁹ A possible explanation is that these groups are probably joined not only by individuals who are directly affected or direct caregivers, but also by family friends or persons who are interested in the child's story and development, but who themselves do not have a child with a similar condition.⁹

Every tenth identified group focusses on creating awareness and providing information.⁹ These groups reflect the high need for informational support. *"The highest percentage of awareness and information groups was found for teratogenic diseases."*⁹ A possible explanation for this finding is that teratogenic diseases are often preventable and affected patients, parents or caregivers utilize Facebook groups to spread awareness to prevent future cases.⁹

5.3 Chances and challenges: using Facebook for rare pediatric disease support groups

5.3.1. Support group accessibility

To access a Facebook support group, access to a computer with Internet connection and the knowledge of computer and Facebook use are necessary.⁸ A national survey of the general American population showed that 79% of Americans that used the Internet also used Facebook in 2016, which amounted to 68% of all Americans regardless of Internet use, and increased to 72% in 2019.^{43,44} A study on internet use by parents of children with rare conditions found that of 128 parents, all were frequent Internet users and most had a Facebook account.²² A study of 516 Italian parents of patients with rare diseases from 2013 showed that they were active Internet users, and looked online for information on diagnosis, the disease, nutrition, alternate therapy, and frequently used Facebook.²¹ It has to be kept in mind though that these studies focused on Western European and American individuals and are therefore not representative of the world population.

Facebook is a globally accessible platform, though Internet and Facebook access varies largely across different regions. The Facebook earnings presentation of the third quarter in 2021 (2019) showed that the 2,910 million monthly active Facebook users are spread as

follows: 261 (247) million US & Canada, 423 (387) million Europe, 1,278 (1,013) Asia-Pacific, 949 (802) million Rest of the World.¹⁹ We could not find more detailed information on the regions that Facebook labels as “Rest of the World” and it is likely that though these absolute numbers appear large, the relative numbers of regular Facebook access vary largely between developed and developing countries.

Even though our research did not involve searching for Facebook groups in various languages, our Facebook group search using up to four English disease descriptions found groups in 38 different languages, including languages such as Hebrew, Malaysian, Bosnian and Serbian.⁹ This indicates that Facebook groups are created all around the world. Individuals who speak English either as first or second language probably have access to a larger number of groups, since English is the language with most total speakers and often serves as common language. In the Facebook Help Center, information on features and technologies that enhance accessibility for people with disabilities include navigating Facebook using keyboard shortcuts, screen readers and assistive technology such as VoiceOver, adding captions to videos, and using the computer’s options for adjusting text size and contrast.²⁰ Still, difficulties might arise and limit individuals’ with disabilities or older persons’ Facebook support group accessibility. Our study showed that group members not only perceive a reduction but often even an elimination of distance between affected individuals.⁸ This is especially important in rare diseases, as due the low prevalence affected individuals and families are widely spread.⁸ Advantages of joining a Facebook support group can be that the group is accessible to individuals who have no means of transportation or limited time.

5.3.2. Insight gained from usage analysis

Most respondents to our questionnaire were female (87.0%, n=201), and 91% (n=183) of these were parents. These findings are in line with studies on online support groups where the majority were mothers or female caregivers.^{23,33,45} In a longitudinal study on mothers’ of children with genetic disorders use of the Internet regarding genetic knowledge it was shown that it is mostly women who manage health information and join online communities.⁴⁶

Our study showed that on average, support group members visited Facebook at least once a day, visited and passively participated (read/liked posts) several times a week and participated actively (commented/posted) once a month.⁸ While 75.8% reported daily overall Facebook usage, 38.5% reported daily Facebook support group usage with 8.7% of the respondents actively participating at least once a day.⁸ These regular participation rates could indicate the high accessibility and practicality of Facebook as a platform for rare disease support groups.⁸ These findings can also support that participation in very active forums or groups can cost substantial amounts of time, as White and Dorman pointed out in their review of health-related online support.¹⁷

5.3.3. Support group chances and challenges

The three main categories of perceived benefit (informational support, emotional support, connecting with others) we explored have been previously investigated in other studies on pediatric rare diseases and/or online support to some extent.^{7,8,15,18}

Respondents to our questionnaire affirmed that they use the respective Facebook group to find medical information, to read about personal experiences, to get advice on caring for someone with this disease, to share their personal experiences concerning the disease and were shown to personally connect with others.⁸ Our survey thus confirms that Facebook support groups for rare pediatric diseases offer these benefits similarly to other support groups.⁸

5.3.4. Informational support

In our study, 77.9% (n=180) responded positive to using the Facebook group to find medical information,⁸ which strengthens previous studies' findings that showed that social media, including Facebook, is being used to search for medical information.^{8,15,22,25,26,33}

88.7% (n=205) responded positive to using the Facebook group to get advice on caring for someone with the disease.⁸ Nicholl et al. have shown that getting advice can improve parental management and care and can have an empowering effect so that parents can become experts in their child's care.^{8,22} Facebook support groups offer the opportunity of having direct conversations about health information, which can help discuss information and receive simplified explanations.

Nevertheless, the suitability of social media as a source for health information is to be questioned. Social media communities lack access to consistent evidence-based guidance.²⁵ The accuracy, quality and reliability of information obtained online can be doubted, as well as the possible misinterpretation and questionable application to a personal situation.^{15,17,22} It is therefore of interest to analyze how group members process and apply information found in online support groups.⁸

5.3.5. Emotional support

Our survey showed that 96.1% (n=222) of participants use the Facebook group to read about personal experiences and 78.8% (n=182) share their own personal experiences, which are starting points of emotional support.⁸ Seeing others' similar experiences can install a sense of belonging.^{8,23} Web-sourced information was shown to have an empowering effect on parents and social media provided access to other parents with children with similar conditions.^{8,22}

5.3.6. Connecting with others

We confirmed that parents of children with rare diseases use Facebook to connect and build relationships.⁸ Our survey showed that many group members perceive a reduction up to elimination of the problem of distance between affected individuals.⁸

Facebook offers different options for communication: members can engage in group communication or direct contact via personal messaging services such as Facebook messenger. 74.9% (n=173) of respondents to our questionnaire reported having had direct contact to another group member via personal messaging services and 40.3% (n=93) had met another Facebook group member in person.⁸ This shows that Facebook support group members closely connect on Facebook and outside the virtual world.

Belonging to a community²⁸ and an improved sense of belonging as a result from forming social connections³² have been identified as key benefits from support groups and as we have shown, members of Facebook support groups for rare diseases closely connect with others and can thus benefit from these aspects.⁸

5.3.7. Privacy issues in Facebook support groups

As several studies have pointed out, individuals are often unaware of the risks to sharing personal information online, and especially health information.^{15,35,36} As mentioned, there are several approaches to privacy theories which address how information about humans should be processed, who can access the data and how to regulate this access.³⁹ The approach we discuss in the context of Facebook support group privacy is an integrative approach. This approach combines control and limitation theories of privacy and defines privacy as a right that should be protected and as individual control of personal information in form of restricted access.^{8,38}

Facebook offers two options for sharing information: public or private. Public information can be seen by anyone, including off of Facebook and other sites on the Internet.²⁰ Name, gender, username, profile picture and cover photo are always public.²⁰ Users can restrict access to their profile and content they post.

Facebook help center displays the following information on names on Facebook: *“To make sure people know who they’re connecting with, we ask everyone to use the same name on Facebook that they use in everyday life. We may ask you to confirm that the name on your Facebook account is the name you’re known by. [...] You may be asked to upload an ID.”*²⁰ Facebook therefore does not offer the possibility to anonymously take part in a Facebook support group.

There are two different privacy settings for Facebook groups: public or private. Facebook describes public groups as “public spaces” and anyone who can see the group can see posts or comments.²⁰ Group description and group statistics are always publicly available.⁹ This includes information on when the group was founded, the member count, group members’ names, when they joined the group, number of new posts and new members in the last 30 days. When set to private, only group members can see more information after being approved as members by an administrator. Two thirds of the support groups for rare pediatric diseases we identified on Facebook were private groups.⁹

78.8% (n=182) of members in our study had shared personal experiences concerning the disease and 70.6% (n=163) posted a personal picture.⁸ This regular sharing of private experiences and pictures shows the relevance of discussing support group privacy concerns. Our questionnaire explored group members' privacy perceptions: *"Group members expressed more concern about privacy issues on Facebook in general than in their respective Facebook support groups, with concerns mostly related to Facebook itself and non-group-members. Twice as many respondents agreed to being concerned about privacy matters on Facebook in general than to being concerned about privacy matters in their Facebook group."*⁸ This shows that the Facebook groups create a certain environment of perceived privacy.⁸ The aspect of knowing who one is connecting with because they must display their real name may, among other factors, play a role in creating this perception.

The answers to our questionnaire showed that the privacy paradox applies to Facebook support groups for rare pediatric diseases.⁸ The privacy paradox describes the discrepancy between privacy concerns and actual information disclosure, which is evident in our study as 78.8% (n=182) of members shared personal experiences and 70.6% (n=163) posted a personal picture even though 61.5% (n=142) answered positively to being concerned about privacy matters on Facebook in general and 32.5% (n=75) worried that Facebook might use information they shared in the group.⁸

Setting a Facebook profile and/or group privacy setting to private serves as a form of restricted access for information control in the integrative privacy approach. Nevertheless, some information like username and the information of being a member in the group are always publicly available so that anyone can gain the information that someone takes part in a certain support group. In our study, 41.1% (n=95) answered positively and 38.5% (n=89) negatively when asked if they would share personal experiences in a public Facebook group.⁸ This shows that the group privacy setting can be decisive for active group participation.⁸

Since most group members were shown to be parents of someone affected by a rare disease (91.3%, n=211),⁸ it is important to discuss sharing information about children online. When asking for advice caring for their children and when sharing personal experiences and photos, parents potentially reveal personal information about their child on Facebook. Children usually cannot regulate what is shared about them online, even though they may have an interest in protecting personal information.³⁶

An example of how parents could decide on online information disclosure that is necessary to fully participate in a Facebook support group is a rational risk-benefit calculation which evaluates not only their personal benefit from sharing information online but also the possible positive or negative effect on their child. Examples for positive effects on their child could be improved knowledge on the disease and improved parental caregiving skills. Negative effects may include embarrassment, humiliation and bullying.³⁶

To our knowledge, only vague guidelines on disclosing a child's health information online exist so far. Subsequently, health care professionals should inform parents about potential conflicts and privacy issues when referring them to online support groups. Parents should carefully evaluate what information about themselves and their children they share online.

5.4 Involvement of health professionals and study recruitment via Facebook

5.4.1. Referral to Facebook

In our study, 24.2% (n=56) responded that they were referred to the group by a health professional, which supports that giving recommendations to look for a Facebook group is already common practice.⁸ A survey among caregivers of children with Autism Spectrum Disorders showed that those whose diagnosing clinician had referred them to a support group were more likely support group participants.^{9,23}

As our Facebook group analysis has shown, 326 groups were the only condition-specific group, but had only one member.⁹ Raising awareness of Facebook as a tool for pediatric rare disease support groups among affected families could help these individuals who are apparently unsuccessfully looking for someone to connect with.⁹

The aforementioned website rarediseases.info.nih.gov by the Genetic and Rare Diseases Information Center for example informs patients and parents about the option of looking online for a group: *"Social media sites can be a great way to connect with others, especially if a medical condition is very rare. You can try searching the condition name on Facebook to find a group. Other social media tools such as Twitter may also be options for rare and genetic conditions. Medical information that is suggested by others on social media is usually not reviewed by medical professionals, so we suggest that you discuss any medical recommendations with your doctor or another trusted medical care professional."*¹³ While this example of raising awareness for Facebook as a tool for rare disease support groups includes advice on critical reflection of social media-sourced information, it should also include information on sharing health information online.

5.4.2. Health professionals as group members

The involvement of health professionals in support groups can include education, examination and organization.⁴¹ In a survey by Lin and Terry that involved 67 medical geneticist who partake in support groups, most acknowledged that patient confidentiality (78%), potential conflicts of interest (66%), and medico-legal liability (72%) were relevant issues.⁴¹ This highlights the importance of exploring group members' views on health professionals as group members. In our study, 74.5% (n=172) agreed and 4.8% (n=11) partly agreed that they would like to have health professionals as members of the respective Facebook group.⁸

5.4.3. Study recruitment

A systematic review that identified studies published in English between 2004 and 2020 showed that despite its potential benefits in rare disease research, the use of social media is still methodologically limited and participants reached may not be representative.⁴⁵ They showed that between 2004 and 2020, 79 studies used social media for study recruitment, e.g. for online surveys, in-person studies, clinical trials or interviews.⁴⁵ As we have shown, only one in five rare diseases is represented on Facebook with a support group.⁹ That means that a lot of rare disease communities may not be reachable.

In a first study design, we sent invitations to our questionnaire to group administrators of 100 randomly selected Facebook support groups for pediatric rare diseases. From the little feedback we got, it was evident that due to a Facebook algorithm that identified our Facebook profile as strangers to the contacted individuals, our messages were received in a kind of spam or contact request folder without being openly displayed. We therefore received only very few answers and this method proved to be ineffective for our research. We then contacted the aforementioned twelve groups for twelve different pediatric rare diseases via email and received 231 responses to our questionnaire.⁸ This experience showed that while Facebook may offer opportunities for research in rare diseases, application may be difficult.

As social media is increasingly used for research in rare diseases, the question whether support group members are in favor of social media recruitment methods arises. In our study, 67.1% (n=155) agreed and 7.4% (n=17) partly agreed that they would be interested in being contacted through this group for the purpose of recruitment for medical studies.⁸ These numbers may not be representative because respondents were recruited due to their membership in Facebook groups. This bias further stresses the importance of discussing the meaning of negative answers to this question, since 8.2% (n=19) disagreed and 3.0% (n=7) partly disagreed,⁸ even though they took part in our questionnaire. Further research into the reasons for these negative answers is necessary to ensure that group members do not for example feel an intrusion in their perceived safe environment of the support group due to study recruitment on social networking platforms.

5.5 Study strengths and limitations

Combining the two studies, we offer an extensive overview of the usage of Facebook as a tool for online support groups for rare pediatric diseases.^{8,9} The quantitative analysis⁹ is a broad-scope analysis and to our knowledge the first to explore how many rare disease support groups exist, which diseases are represented and what factors influence this. We cannot be sure that all existing support groups have been identified, especially non-English groups when the disease name differs largely from the English disease description and maybe not all groups use the disease name in their group name. To minimize the risk of overlooking groups, we

searched for up to four synonymous disease descriptions or names found on Orphanet.⁹ Even though we used a Facebook profile created only for this search and only the researcher's name, gender and location were entered, Facebook search engine optimization may have influenced our search results by using the researcher's information.⁹ No other activities such as viewing, liking or sharing have been performed to minimize this effect.⁹ Since our study was a cross-sectional study, especially the data on group activity and number of new memberships could vary largely.⁹ This could be investigated by repeating the study at a later time point.⁹ Orphanet offers only limited information on diseases: for 1314 diseases (30.9%) prevalence was unknown, and 2830 diseases (66.7%) had an unclassified disease type (genetic, infectious, teratogenic etc.).⁹ Our analysis of disease-describing parameters and their influence on Facebook search results was therefore limited.

Our cross-sectional study using a questionnaire explored group members' perceptions and opinions regarding various aspects of advantages and challenges to Facebook as a tool for these support groups.⁸ Since data was collected anonymously and respondents did not have to answer questions if they did not feel comfortable, there were only few ethical implications and probably low social desirability and central coherence bias.⁸ The study had a larger than expected sample size.⁸ Still, the representativeness and external validity must be questioned because with rare diseases, each disease has specific challenges and individuals affected by only twelve different rare diseases were contacted.⁸ Our demographic analysis showed that males were severely under-represented, which, though common in studies on support groups, should be further explored.⁸ Especially regarding the question on study recruitment through the Facebook group, our result may be influenced by a response/selection bias, as respondents freely chose to participate in the study.⁸

5.6 Future research

Our studies have shown the importance and influence of several factors that should be further explored. As our analysis has shown, there is a lack of information on many rare pediatric diseases but the chances of finding a Facebook support group appear to increase with a higher level of understanding about the disease.⁹

Regarding the subgroup of personal support groups, an evaluation of the impact of this group style as a method of receiving social support in the context of rare diseases could be interesting.⁹ These groups are not dependent on disease prevalence and finding others with a similar condition, which can facilitate founding the group, but could also be a limitation due to the probable lack of exchange of personal experiences.⁹

Regarding informational support, it is of interest to analyze how information gained from support groups is processed and to evaluate the risk of information inaccuracy and misinterpretation.⁸

Concerning support group privacy, a more in-depth analysis of group members' privacy concerns and behavior including decision-making processes on online information disclosure could be helpful.⁸ In-depth studies on how online (health) information disclosure affects children with rare diseases could help evaluate the risks and benefits and provide further insight into the suitability of Facebook for parental support groups.

As our questionnaire has shown, members have varying opinions on participation of health care professionals, being contacted for recruitment for medical studies and being contacted by pharmaceutical companies through the Facebook group.⁸ It could be helpful to explore reasons for participants' views to improve usage of Facebook support groups in a way that is sensitive to group members' needs and expectations.

It can be of interest to explore and compare the representation of rare diseases and online support groups on other social media platforms.

5.7 Conclusion

These two studies show to what extent Facebook is currently used for Facebook support groups for rare pediatric diseases, what chances it offers and which challenges can arise.

There has been a continuously rising number of groups since 2008, amounting to a total number of 6398 support groups representing 826 of 4246 (19.5%) rare pediatric disorders listed in the Orphanet inventory.⁹ *“Group type, size, activity, new memberships, privacy settings and language vary largely between groups”*.⁹ Two thirds of the support groups are private groups.⁹ Support groups can be subdivided according to different group focus into general, personal, advocacy and not further specified condition-specific groups.⁹ Other groups focused on research, fundraising and charity and medication sales.⁹ Factors that influence rare disease representation on Facebook are the level of understanding about the disease with higher odds of finding groups for known vs. unknown prevalence, inheritance and disease type.⁹

Facebook can be a suitable tool for pediatric rare disease support groups, offering high accessibility and practicality and allowing members to receive a reduction and even elimination of the important challenge of distance between affected individuals.⁸ Members were shown to use the group for informational support, emotional support and connecting with others.⁸ Our questionnaire showed that on average, respondents use Facebook at least once a day, passively participate (reading or liking posts) in the support group several times per week and actively participate (commenting or posting) once a month.⁸ We found that the group privacy setting can be a critical factor for active support group participation, as only 41.1% (n=95) would share personal experiences in a public group.⁸ 59.7% (n=138) reported a self-initiated search for the Facebook group, 24.2% (n=56) received recommendations from their health professionals and 12.6% (n=29) recommendations from someone else affected by the disease.⁸ Group members were shown to share private experiences and pictures, use the

group to read about others' experiences and receive advice on caretaking.⁸ More members expressed concern about privacy issues on Facebook in general (61.5%, n=142) than in their respective support groups (29.9%, n=69), with concerns mostly directed at Facebook itself and non-group members.⁸ This shows that the privacy paradox applies to Facebook support groups, as members share private information despite being concerned about privacy matters.⁸ 79.2% (n=183) would like to have health professionals as group members, 74.5% (n=172) would be interested in being contacted through their group for the purpose of recruitment for medical studies, and 38.5% (n=89) agreed that they would be interested in being contacted by pharmaceutical companies through the group.⁸

These results can be used to inform health professionals and parents or caregivers about the chances and challenges of using Facebook for rare pediatric disease support groups. Parents could benefit from guidance on responsible decision-making online information disclosure and protecting children's privacy rights.⁸ The reasons for participants' differing views on being contacted for medical study recruitment of pharmaceutical companies through the groups should be further explored to ensure usage of Facebook in a way that is sensitive to group members' needs and expectations.

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7. Appendix

7.1 Figures

Figure 1: overview of research methods

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8. Vorabveröffentlichungen von Ergebnissen/Publications

Titgemeyer SC, Schaaf CP. Facebook Support Groups for Rare Pediatric Diseases: Quantitative Analysis. *JMIR Pediatr Parent* 2020; **3**(2): e21694.

Titgemeyer SC, Schaaf CP. Facebook Support Groups for Pediatric Rare Diseases: Cross-Sectional Study to Investigate Opportunities, Limitations, and Privacy Concerns. *JMIR Pediatr Parent* 2022; **5**(1): e31411.