FINAL REPORT

RISE

Raising awareness for mental health in people affected by neuropediatric diagnosis leading to severe disability

Project co-lead
Oliver Gruebner, oliver.gruebner@uzh.ch, UZH
Emiliano Albanese, emiliano.albanese@usi.ch, USI

Project team
Suzanne Elayan, S.Elayan2@lboro.ac.uk, Loughborough University, UK
Marta Fadda, marta.fadda@usi.ch, USI
Afua van Haasteren, afua.van.haasteren@usi.ch, USI
Anna Hug, anna.hug@uzh.ch, UZH Psychology
Michael von Rhein, Michael.vonRhein@kispi.uzh.ch, University Children's Hospital Zurich
Martin Sykora, M.D.Sykora@lboro.ac.uk, Loughborough University, UK
Markus Wolf, markus.wolf@psychologie.uzh.ch, UZH Psychology

Project Achievements

Two persons joined the project team. Dr Afua van Haasteren was appointed as a postdoctoral student at USI and BSc Anna Hug was appointed as a student assistant at UZH to work on the project goals. All other team members contributed in kind. The team had weekly online meetings to plan, prepare, discuss, work, and evaluate on the work packages to fulfil the project goals.

We have applied three work packages (WP). In **WP-1**, we successfully conducted an online workshop on Zoom, September 9 2021 in which we have established relationships with several stakeholders. The workshop program and the introductory slides can be found in the supplementary material below. Workshop participants included representatives of the Swiss Muscular Society (Sandra Messmer), physicians (Georg Stettner, USZ, Cornelia Enzmann, University of Basel), Swiss Multiple Sclerosis registry (Viktor von Wyl), Swiss Neuromuscular Disease registry (Anne Tscherter, Dominique Baumann), CARE NMD CH (Veronika Waldboth) and all project team members listed above.

In **WP-2**, we reviewed mental health challenges and digital place use of families and patients affected by paediatric neuromuscular diseases. Specifically, this was done through intensive discussions with stakeholder groups during the workshop introduced in WP-1 and a scoping literature review of digital place use in the context of paediatric neuromuscular diseases. The manuscript is currently being peer-reviewed in the Journal of Medical Internet Research (JMIR) and can be also found in the supplementary material below.

In **WP-3**, we have designed a multi-lingual poster with information on mental health challenges and digital place use in the context of paediatric neuromuscular diseases. This poster is also attached in its current form (in English) in the supplementary material. We were further invited to present this poster at the Swiss Duchenne Conference September 9/10 2022[1]. The poster is linked with an online survey that will further contribute to the ongoing discussion on mental health challenges and digital place use in the context of paediatric neuromuscular diseases to **rise awareness about mental health in this population group.**

---

[1] https://progena.ch/en/duchenne-konferenz-2022/

Finally, this project has significantly contributed to the development of a new consolidator grant proposal to the SNSF on Smarter Urban Health: Smart cities and smart citizens for inclusive cities and improved urban population health.

We thank the Swiss School of Public Health for funding the RISE project.

Best regards

Oliver Gruebner

On behalf of all project members

Supplementary material

- Poster
- Workshop program
- Introductory slides of the workshop
- Manuscript (JMIR)

Università
della
Svizzera
italiana

**Institute
of
Public
Health**

Mental health challenges and digital place use in the context of pediatric neuromuscular disease

Raising awareness for mental health in patients and families affected by pediatric neuromuscular diagnoses leading to severe disability.

The project received funding from the Swiss School of Public Health (SSPH+)

In collaboration with

Universität Zürich UZH

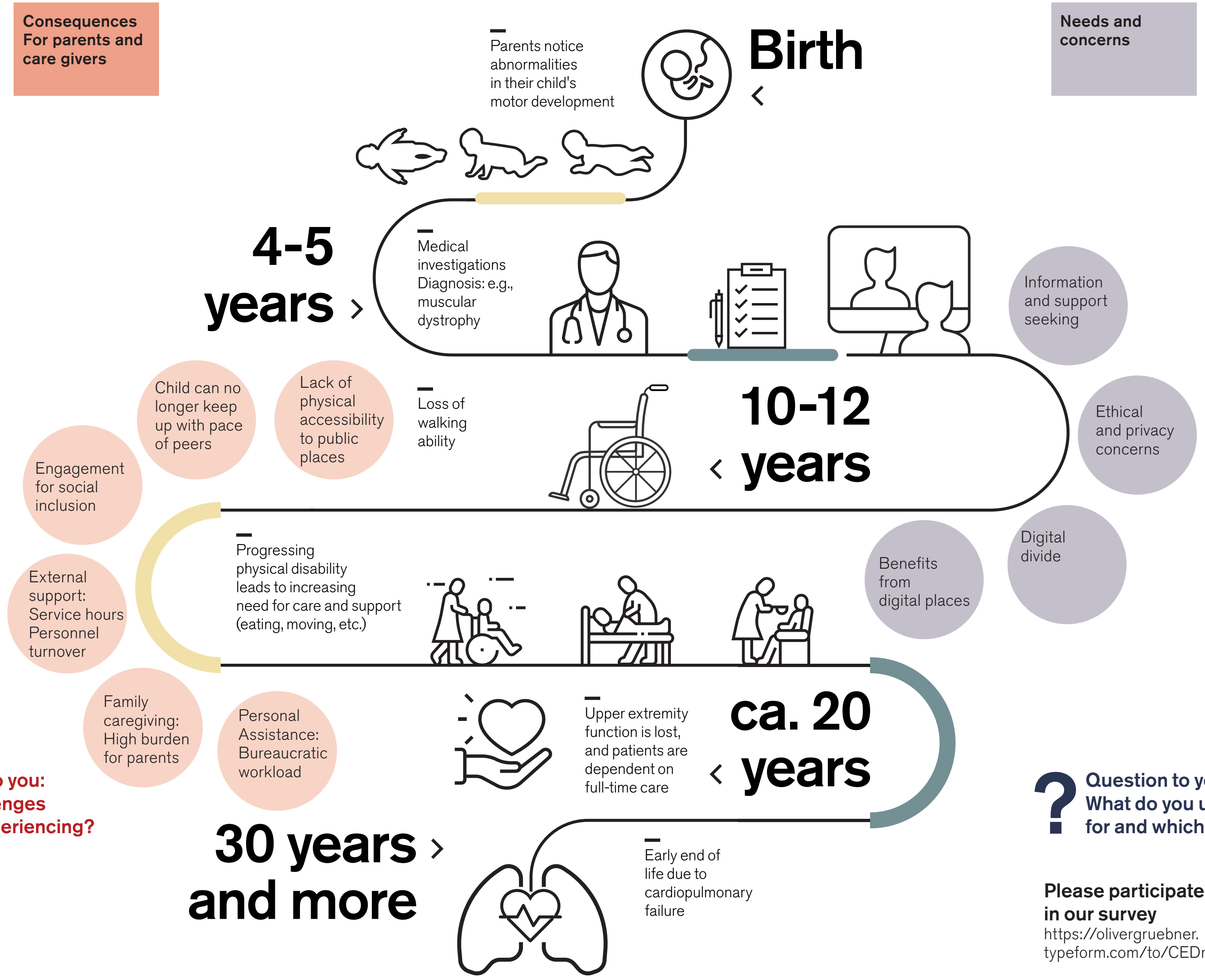
Loughborough University

University Children's Hospital Zurich
The hospital of the Eleonore Foundation

Mental health challenges for parents and care givers

- Diagnosis as a potential traumatic experience
- Information overload often difficult to classify
- Decreasing social inclusion
- Difficult to lead a self-determined life
- High organisational and care burden
- Demanding end of life questions

Consequences For parents and care givers



Birth

Parents notice abnormalities in their child's motor development

4-5 years

Medical investigations Diagnosis: e.g., muscular dystrophy

10-12 years

Loss of walking ability

Progressing physical disability leads to increasing need for care and support (eating, moving, etc.)

ca. 20 years

Upper extremity function is lost, and patients are dependent on full-time care

30 years and more

Early end of life due to cardiopulmonary failure

Child can no longer keep up with pace of peers

Lack of physical accessibility to public places

Engagement for social inclusion

External support: Service hours Personnel turnover

Family caregiving: High burden for parents

Personal Assistance: Bureaucratic workload

Information and support seeking

Ethical and privacy concerns

Digital divide

Benefits from digital places

Needs and concerns

Digital Place Use

- Social inclusion
- Organization and management of care
- **Social support:**
  - Informational
  - Emotional
  - Instrumental
  - Appraisal

? Question to you: What challenges are you experiencing?

? Question to you: What do you use digital media for and which platforms?

Please participate in our survey
https://olivergruebner.typeform.com/to/CEDr0a0D

Università
della
Svizzera
italiana

September 9, 2021
14.00–17.00

Online
https://uzh.zoom
us/j/67943091821?
pwd=aEpPck9raHo4N2
xxcGN4T1h1aDVyQT09

Contact
Dr. Oliver Gruebner
oliver.gruebner@uzh.ch

The project received funding from the Swiss School of Public Health (SSPH+)

In
collaboration
with

Universität
Zürich UZH

Loughborough
University

UNIVERSITY
CHILDREN'S HOSPITAL
ZURICH

The hospital of the Eleonore Foundation

Raising awareness for mental health in patients and families affected by pediatric neuromuscular diagnoses leading to severe disability.

14.00–14.10	Opening remarks **Presentation of the project and workshop goals**
14.10–14.15	Review study **Social media use for self-help**
	Lightning talks
14.15–14.30	**Patient association perspective**
14.30–14.45	**Health care perspective**
14.45–15.00	**Questions / comments**
15.00–15.30	**Speed dating format** **Clinicians / researchers' perspective**
15.30–15.45	**Questions / comments**
15.45–16.00	Break
16.00–16.30	**Break out groups:** **2 moderated group sessions on mobility/access and information/ support seeking** (Moderator Michael von Rhein) 1. What are potential influencing factors from physical environments, digital places, and health care? (Moderator Markus Wolf) 2. What digital interventions may be most appropriate and effective? (Moderator Martin Sykora)
16.30–16.50	**General assemby** (Moderator Michael von Rhein) **Groups' verbal report**
16.50–17.00	Closing remarks

RISE

Raising awareness for mental health in patients and families affected by pediatric neuromuscular diagnoses leading to severe disability

September 9, 2021 – 14:00 - 17:00

UZH Geography Department
UZH Epidemiology, Biostatistics and Prevention Institute (EBPI)
USI Institute of Public Health (IPH)
University Children`s Hospital Zurich, Child Development Centre
Loughborough University Centre for Information Management

Agenda

14.00 – 14.10	Opening remarks (Oliver Gruebner) **Presentation of the project and workshop goals**
14.10 – 14.15	Review Study **Social media use for self-help** (Afua van Haasteren)
	Lightning talks
14.15 – 14.30	**Patient association perspective** (Sandra Messmer, Swiss Muscular Society)
14.30 – 14.45	**Health care perspective** (Veronika Waldboth, ZHAW School of Health Professions)
14.45 – 15.00	**Questions / Comments**
	Speed dating format
15.00 – 15.30	**Clinicians / researchers' perspective**
15.30 – 15.45	**Questions / Comments**
15.45 – 16.00	Break
16.00 – 16.30	Break out groups **Two group sessions on mobility/access and information/support seeking** (Moderator Michael von Rhein) 1. What are potential influencing factors from physical environments, digital places, and health care? (Moderator Markus Wolf) 2. What digital interventions may be most appropriate and effective? (Moderator Martin Sykora)
16.30 – 16.50	General assembly (Moderator Michael von Rhein) **Groups' verbal report**
16.50 – 17.00	Closing remarks (Oliver Gruebner)

About the project

- We are funded by the Swiss School of Public Health (SSPH+)
- Funding period: June 2021 - May 2022, 12 months
- **Project team:**

Suzanne Elayan
Loughborough University

Martin Sykora
Loughborough University

Markus Wolf
UZH Psychology

Oliver Gruebner
UZH Geography

Anna Hug
UZH Psychology

Emiliano Albanese
USI Public Health

Marta Fadda
USI Public Health

Afua van Haasteren
USI Public Health

Michael von Rhein
University Children's Hospital Zurich

About the project part #2

Overall goal: to prepare for a larger SNSF funded research project.
We specifically aim to:

1. Establish relationship and trust with patient groups and relevant stakeholders → This workshop to inform about the project and to get to know each other

2. Increase literacy about data security, ethics, and privacy concerns when using digital devices in affected populations → Scoping review of the literature

3. Raise awareness about mental health in individuals and their families affected by neuropediatric diagnosis leading to severe disability
→ knowledge dissemination

Goals of the Workshop

We aim to submit a SNSF research proposal (3 years, 2 PhD cand.)

Proposed title:

Mental health resilience in patients and families affected by pediatric neuromuscular diagnoses leading to severe disability

- What is the role of mobility and health seeking behavior in the digital sphere? -

With focus on mobility and digital health care needs**,**
we want to discuss with you today:

- The most common challenges for mental health resilience in patients and family members
- The most practical and effective approaches for digital interventions to help improve mental health resilience in this group

Mental health resilience in patients and families affected by pediatric neuromuscular diagnoses leading to severe disability

- RISE
  - Mental health resilience (survey response, social media timeline, interviews)
    - Assess hope, well-being
    - Investigate Stress
  - Mobility
    - Assess personal activity spaces
      - Physical activity and transport mode
      - Green space and street layout
    - Explore access to social and health care facilities
      - Schools, family doctor, neurological center
  - Digital help seeking
    - Assess need and service use for unprofessional support /exchange
      - WhatsApp / Facebook use, etc
    - Assess need and service use for professional support /exchange
      - Professional digital tools

Questions?

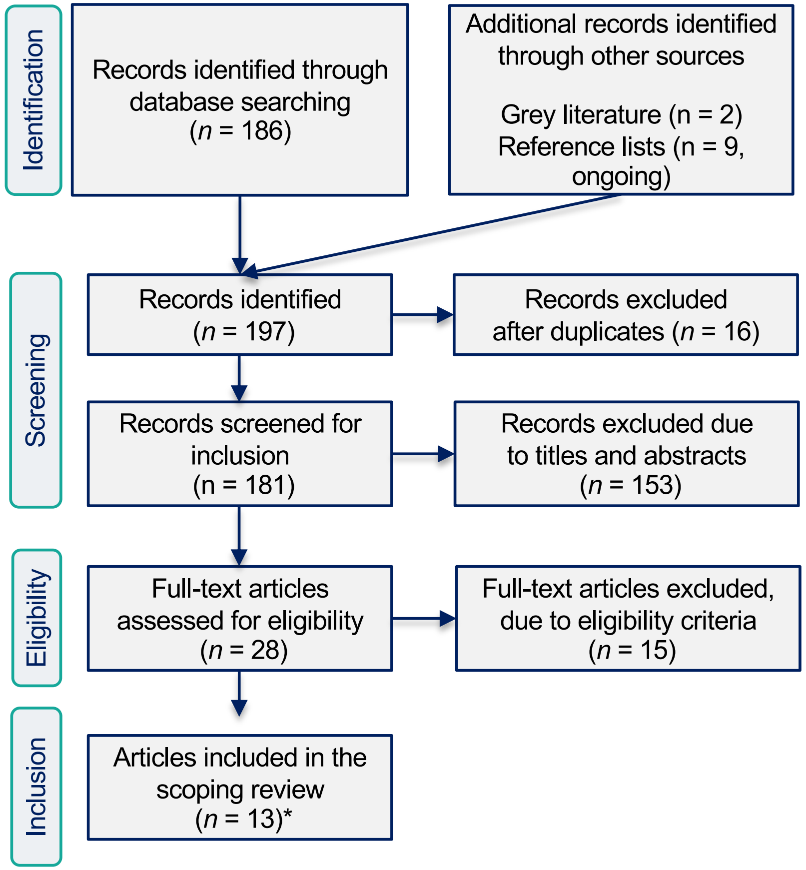
Scoping review: Social media use for self-help

Inclusion criteria:

- English language
- Published between 2011 to date
- Study types: reviews, quantitative, qualitative
- Focused childhood onset conditions

Databases

- CINAHL
- Communication & Mass Media Complete
- PubMed
- PsycINFO
- Psychology & Behavioral Sciences Collection



Identification

Records identified through database searching (*n* = 186)

Additional records identified through other sources

Grey literature (n = 2)
Reference lists (n = 9, ongoing)

Screening

Records identified (*n* = 197)

Records excluded after duplicates (*n* = 16)

Records screened for inclusion (n = 181)

Records excluded due to titles and abstracts (*n* = 153)

Eligibility

Full-text articles assessed for eligibility (*n* = 28)

Full-text articles excluded, due to eligibility criteria (*n* = 15)

Inclusion

Articles included in the scoping review (*n* = 13)*

Scoping Review – Preliminary findings

Overview on Social media use:
- Posts are tailored to platform e.g., Facebook for personal posts and Twitter for advocacy
- Women more likely to use than men
- Information most needed after diagnosis/before or after doctor visits
- Parents left out due to low education, language barriers, low tech skills due to age

Reasons for use:
- Information more readily available
- To find resources: health professionals, education, diagnosis, childcare
- Empowerment/emotional support
- Reduce isolation (rural/geographically isolated parents)
- Advocacy (help other parents)
- Group resources tailored to needs/diagnosis

Concerns:
- Difficult to distinguish between good and bad information
- Privacy concerns: preference for closed groups
- Lack of language accommodations
- Content difficult to understand
- Websites difficult to navigate/not visually appealing
- Too negative outlook on diagnosis
- Little to no access to professionals (for some)

Recommendations:
- Encourage reader ratings to help identify credible information
- Link information to official institutions/ researchers to boost credibility
- Encourage empathy in posts

Questions?

Lightning talks (Moderator Oliver Gruebner)

Patient association perspective
(Sandra Messmer, Swiss Muscular Society)

Health care perspective
(Veronika Waldboth, ZHAW School of Health Professions)

Questions?

Speed dating (Moderator Marta Fadda)

Clinicians / researchers' perspective

Please introduce yourself (Name, affiliation)

Please reflect (2-3 sentences) on what you just heard from Sandra and Veronica: How does this apply to your own professional work experiences?

Questions?

Break: 15.45-16.00

Break out groups (Moderator Michael von Rhein)

When thinking of mobility (incl. availability and accessibility of health and social services) and digital social / health care needs (incl. unprofessional tools and professional tools):

1. What are potential influencing factors from physical environments, digital places, and health care? (Moderator Markus Wolf)
2. What digital interventions may be most appropriate and effective (Moderator Martin Sykora)

Break out group #1 (Moderator Markus Wolf) - 30min -

When thinking of mobility (incl. availability and accessibility of health and social services) and digital social / health care needs

What are potential influencing factors from the:

physical environments

::: e.g. physical availability and accessibility of health and social services etc. :::

digital places

::: e.g., seeking for information and support etc. :::

Break out group # 2 (Moderator Martin Sykora) **- 30min -**

When thinking of mobility (incl. availability and accessibility of health and social services) and digital social / health care needs:

What digital interventions may be most appropriate and effective?

1) Think of social media etc., such as Facebook, WhatsApp, Google for self help and social support

2) Think of professional digital health tools

Findings (Moderator Michael von Rhein)

When thinking of mobility (incl. availability and accessibility of health and social services) and digital social / health care needs (incl. unprofessional tools and professional tools):

1. What are potential influencing factors from physical environments, digital places, and health care? (Moderator Markus Wolf)

2. What digital interventions may be most appropriate and effective (Moderator Martin Sykora)

Closing remarks

Please join the team!

- Scientific Advisory / Sounding Board Member
- Project collaborator
- Co-applicant
- Keep informed

- We will send an invitation to a quick post WS survey
  - Feedback on the WS
  - Knowledge dissemination

Thank you for participating at this workshop!

We acknowledge funding from the
Swiss School of Public Health

Dr. sc. nat. Oliver Gruebner
Group leader health geography
oliver.gruebner@uzh.ch

University of Zurich
Department of Geography
Winterthurerstrasse 190
CH-8057 Zurich

University of Zurich
Epidemiology, Biostatistics and Prevention
Institute (EBPI)

Review

Digital platform uses for help and support seeking of parents with children affected by disabilities: A scoping review

Oliver Gruebner[1,2], Afua van Haasteren[3], Anna Hug[1], Suzanne Elayan[4], Martin Sykora[4], Emiliano Albanese[3], John A. Naslund[5], Markus Wolf[6†], Marta Fadda[3†], Michael von Rhein[7†]

Affiliations

[1]University of Zurich, Department of Geography, Switzerland
[2]University of Zurich, Epidemiology, Biostatistics, and Prevention Institute, Switzerland
[3]Università della Svizzera italiana, Institute of Public Health, Switzerland
[4]Loughborough University, Centre for Information Management, United Kingdom
[5]Department of Global Health and Social Medicine, Harvard Medical School, Boston, MA, USA
[5]University of Zurich, Department of Psychology, Switzerland
[6]University Children's Hospital Zurich, Switzerland

†shared last authorship

Correspondence: oliver.gruebner@uzh.ch

Abstract

Background: Receiving a diagnosis that leads to severe disability in childhood can cause a traumatic experience with long-lasting emotional stress for patients and family members. In recent decades, emerging digital technologies have transformed how patients or caregivers of persons with disabilities manage their health conditions, and as a result, information (e.g., on treatment and resources) has become widely available to patients and their families. Parents and other caregivers can use digital platforms such as websites or social media to derive social support usually from other patients and caregivers who share their lived experiences, challenges, and successes on these platforms. However, gaps remain in our understanding about the platforms that are most frequently used or preferred among parents and caregivers of children living with disabilities. In particular, it is not clear what factors primarily drive or discourage engagement with these digital tools and what the main ethical considerations are in relation with these tools.

Objective: We aimed to 1) identify prominent digital platforms used by parents or caregivers of children with disabilities; 2) explore the theoretical contexts and reasons for digital platform use, and experiences made with using these platforms reported in the included studies; and 3) identify any ethical concerns emerged in the available literature in relation to use of these platforms.

Methods: We conducted a scoping review of five academic databases of English language articles published within the last 10 years for diseases with childhood onset disability and self-help or parent/caregiver-led digital platforms.

Results: We identified 17 papers in which digital platforms used by parents of affected children predominantly included social media elements but also search engines, health-related apps, and medical websites. Information retrieval and social support were the main reasons for their utilization. Nearly all studies were exploratory, and applied either quantitative, qualitative, or mixed methods. Main ethical concerns for digital platform users included hampered access due to language barriers, privacy issues, and perceived suboptimal advice (e.g., due to missing empathy of medical professionals). Older and non-college educated individuals, as well as ethnic minorities appeared less likely to access information online.

Conclusions: This review showed that limited scientifically sound knowledge exists on digital platform use and needs in the context of disabling conditions in children as the evidence consists mostly of exploratory studies. We could highlight that affected families seek information and support from digital platforms, as the health care systems seem to be insufficient in satisfying the knowledge and support needs through traditional channels.

Keywords: digital place; pediatric diagnoses; conditions; disability; neuromuscular; information and support seeking; online; social media; peer support; lived experience

Introduction

Receiving the diagnosis of a disease leading to disability in childhood can cause long-lasting emotional stress for patients and family members. There is considerable evidence illustrating the adverse mental health consequences and higher levels of psychological distress experienced among children with disabilities[1,2]. Similarly, parents and caregivers (hereafter referred to as "parents" for simplification) of children with disabilities also experience elevated stress and can face challenges adapting to the care needs of their child[3]. Importantly, efforts are needed to support parents in adapting and meeting the needs of their child, as this can directly impact the child's development and well-being and development over the life course[4,5]. Therefore, it is critically important to determine effective approaches for supporting parents of children with disabilities, so that they can adopt necessary and desired coping strategies and feel confident in meeting the day-to-day needs of their children.

In recent decades, emerging digital technologies have transformed how patients or parents of persons with disabilities manage their health conditions[6], and information (e.g., on treatment and resources) has become more widely available to them. Furthermore, social and emotional support (e.g., by online self-help and peer support groups) is now more readily accessible through various online platforms. For instance, Oldenburg et al.[7] present a helpful rundown of the role new media have played (e.g., PatientsLikeMe) in supporting patients suffering with chronic diseases, while in the work of Sykora[8] some early health related social platforms are mentioned (e.g., PatientOpinion, CarePages, CureTogether, PatientsLikeMe) and a walkthrough of the social platform CureTogether (now defunct after being bought by 23andMe) is provided. Parents of children with debilitating diseases can potentially use digital platforms such as search websites or social media (e.g., Reddit; WhatsApp groups) to derive social support usually from other patients and parents who share their lived experiences, challenges, and successes on these platforms.

However, gaps remain in our understanding about the platforms that are most frequently used or preferred among parents of children living with disabling conditions. For example, it is not clear what factors drive or discourage engagement with these digital tools. In addition, there is little evidence available about the ethical concerns over services provided by digital platforms that are used by parents for information and support seeking in the context of a disabling and/or lethal disease of their child.

In this scoping literature review, we aimed to 1) identify prominent digital platforms used by parents or caregivers of children with disabilities; 2) explore the theoretical contexts and reasons for digital platform use, and experiences made with using these platforms reported in the included studies; and 3) identify any ethical concerns emerged in the available literature in relation to use of these platforms.

Methods

Study Design

We conducted a scoping review following the framework of Arksey & O'Malley [9]. The search was performed using five scientific databases: *PubMed, CINHAL, PsycINFO, Communication & Mass Media Complete and Psychology & Behavioral Sciences Collection*. EBSCO Host was used to concurrently search through all of the databases with the exception of PubMed. In line with Arksey & O'Malley[9], the reference lists of the articles included were screened for additional studies. Grey literature searches were also conducted on the websites of various major organizations tackling NMDs (Appendix 1) in addition to using Google search engine to retrieve further studies. All of the searches were conducted between July-September 2021.

Identifying relevant studies - Search strategy

Based on the severity of the disease, and the high psycho-emotional distress it can cause to parents of affected children, initial searches began with a primary focus on retrieving studies relating to Neuromuscular Diseases (NMD) with a pediatric onset such as Duchenne Muscular Dystrophy (DMD). However, these searches resulted in few studies relevant to the subject of interest. Therefore, a search strategy was adopted to include *disabilities* as a broader keyword. Table 1 details the keywords and search terms used to identify relevant studies. The inclusion criteria to identify relevant papers were: Scientific English articles published in the last 10 years (2011- 2021), papers on diseases with childhood-onset disability, all study types (e.g., reviews, original studies), use of self-help or parent/caregiver-led digital platforms (e.g., internet, websites, social media or online support groups), and that papers describe either reasons, expectations, concerns, suggestions, or experience on digital platforms. The exclusion criteria were Non-English articles or articles published prior to 2011, adult-onset diseases, and papers reporting on digital platforms maintained by medical institutions or those designed for research, and papers with a main focus on health professionals' experiences with digital platforms.

Two researchers (AH and AvH) independently screened the titles, abstracts, and full-texts while a third author (MF) was consulted to establish consensus. Detailed inclusion and exclusion criteria used to select studies is highlighted in Textbox 1 below and in Table 1.

Charting the data

The descriptive attributes of each article such as the authors, year of publication, country, and objective of the study were extracted from each article. To facilitate the process of identifying the most prolific digital platforms, the scope of study and its objectives (capturing the parents and caregivers' experiences, reasons for digital platform use, the type and name of digital platforms examined in each article) along with the outcome measured were also extracted from each full-text article included in the review.

Collating, summarizing and reporting the results

In line with the aim of deriving an overview of the informational needs of parents and/or other caregivers of children living with disabilities, the preferred online platforms, as well as specific experiences, expectations, concerns, and suggestions for improvement highlighted by each study were identified. These were later labelled under broader concepts and organized around more general, coherent themes. In the last stage of the analysis process, common and divergent themes and topics in findings among and across all of the included articles were identified.

Results

Our search yielded a total of 184 scientific articles. Additionally, 18 articles were identified by reference list screenings and two articles [14,15] were obtained from grey literature, bringing the total number of retrieved articles to 204. Of these, 16 records were identified as duplicates and excluded. Of the resulting 188 articles, 153 were excluded according to the inclusion and exclusion criteria based on titles and abstracts. Subsequently, we screened the full texts of the remaining 35 articles, with 17 final articles included in the review. The PRISMA flow diagram in Figure 1 displays the entire process involved in selecting the included papers.

Detailed information about the year of publication, study design and population size, location, study objective, main digital platform, and outcome measured can be found in Table 2. The earliest study included in our review was conducted in 2011, while the most recent study was from 2020[14,16]. Most studies (14) were original and observational, applying either qualitative (5)[14,17–20], quantitative (5)[16,21–24], or mixed method approaches (4)[25–28]. The remaining articles consisted of two reviews[29,30] and a case study[15]. Mothers made the bulk of the study participants in all of the included studies aside from Ammari and Schoenebeck[19], where efforts were made to over-recruit fathers. In one study (Rocha and colleagues[23]), the gender of parents was not identified likely due to the study's recruitment of participants through two online registries (Simons Variation in Individuals Project and GenomeConnect). Most studies were conducted in the United States (5)[14–16,18,28], while participants for six studies were derived from multiple countries due to online recruitment[19,22,23,26,29,30]. The remaining studies were from Australia[25,27], Italy[24], Kuwait[21], Norway[20], and The Netherlands[17].

Digital platforms utilized

We classified the types of digital platforms identified in the reviewed articles into two categories: I) Digital platforms with social interaction options, such as social media and II) other platforms, such as search engines, medical websites, and health-related apps. Due to the overall aim of this review and the search strategy applied, health-related apps were not prominently found. As listed in Textbox 1, social media were the most prolific digital platforms used by caregivers and parents and were mentioned in three of 17 papers[16,20,21]. Furthermore, one study[18] focused entirely on online support groups by comparing the differences in online and offline interactions, whereas all other studies examined online support within the context of other digital platforms[20–25]. Some studies reported on the use of internet search engines[17,24,26,27] or other online information sources [16,25]. Medical websites that were frequented by caregivers were also identified in some studies [20,21,24,28]. Differences in digital platform preference were evident among different age groups as noted by Tozzi and colleagues[24]. They found that compared to younger age groups, respondents 55 years or older appeared to be less familiar with Twitter or smartphones per se, preferring to use e-mails and Facebook instead[24].

Textbox 1: Digital platforms mentioned in the reviewed literature

I. **Platforms with social interaction options**: Facebook, Twitter, Instagram, YouTube, Pinterest, LinkedIn, Skype, Viber, MSN messenger, Yahoo! Answers (operating between June 2005 to May 2021), Yahoo Groups, Quora, Google groups, CaringBridge, CarePages (shut down in 12/2017), and other online forums, blogs, discussion boards, and e-mails.

II. **Other platforms:** search engines, medical websites (BabyCenter website, Better Start website, helping children with autism website), and health-related apps.

Theoretical contexts and reasons for digital platform use and experiences made

Overall, five studies[14,15,18–20] adopted various theoretical frameworks for guiding the understanding of how social interactions and support work. First, the *Ecological Model of Human Development* as used in Fostervold Wells[15], is a theory that helps us to understand the interconnectedness of family and the larger society, and the resulting socialization of a child. The *Symbolic Interaction Framework*[31] employed in the study of Sharaievska and Burk[18] suggests that individuals' perception of reality is constructed through their interaction with people and objects around them. The thesis of Terra [14] applied two theories, the theory of *Sense of Community and the Empowerment Theory*. Based upon the theory of sense of community developed in 1976 and published in 1986 by McMillan and Chavis[32 p. 6], which 'sought to explain the dynamics of the sense-of-community force'[14]. The identified components of sense of community were membership, influence, fulfillment of needs and a shared emotional connection[14]. The empowerment theory describes a process in which people gain understanding and control over personal, social, economic, or political forces in order to take action to better their lives and was utilized in the study of Terra[14] to focus on the impact of the community membership upon education, awareness, and action on behalf of their child and other children with disability. Another study[19] also focused on the empowerment theory and extended it into a new theory of 'Networked empowerment' that describes how parents whose children have received a special needs diagnosis find other parents, mobilize resources, and become advocates. The fifth study[20] used the theoretical framework of medical sociologist Aaron Antonovsky[33–35], who was dedicated to understanding how people managed to demonstrate resilience despite going through extremely difficult life experiences. Antonovsky contends that the explanation is to be found in people's capacity to manage stressors, that is, 'demands to which there are no readily available or automatic adaptive responses'[35].

From the reviewed literature, we noted that digital platforms were predominantly used for information retrieval and social support. As noted by Gunderson[20], no two digital platforms were considered equivalent for deriving various types of information by their study participants. Therefore, parents chose to use either platform based on their respective needs. The criteria considered necessary to facilitate the utility of platforms was highlighted in two studies. According to Nicholl et al.[26], the most important attributes of platforms were: Relevance, accuracy and up-to-date information, trustworthiness, recommendation by health professionals, easy to understand information, and helpful references along with an appealing layout. Participants in Johnston and colleagues' study[25] echoed several of these factors adding that presentation (different languages, videos or audio recordings, pictures, easy to navigate, and information written in easy language) and connection functionality (blog, forum, access to professionals and other parents, access to owners of the website) increased the overall utility of a platform. The general expectation that digital platforms would have objective, up-to-date, and vital information on conditions of interest was also emphasized by participants in several other studies[17,19,21–23]. The types of information sought by parents included details about services and systems available[28,29], specialists for specific conditions[19,24], social workers[19], and appropriate schools and childcare[22]. Parents used these types of information to assist them in caring for their children as well as interacting with professionals involved in their care. They often felt empowered by the readily available information on digital platforms. In several studies, parents particularly felt the need to consult digital platforms soon after a diagnosis to learn more about the condition or prior to an upcoming doctor's visit[17,19–21,26].

Digital platforms also provided a means of communicating not only with parents familiar with the condition of interest but also scheduling appointments with professionals, seeking second opinions or alternative therapies[24], or communicating with family and friends[26]. For example, parents used websites such as CaringBridge and CarePages to provide updates on the status of children's health[28]. Digital platforms such as CaringBridge and CarePages offer the opportunity to post about the status of one's conditions with the primary aim of assisting others frequenting these platforms. Some parents chose to share relevant scientific research on the condition faced by their children for the benefit of others, especially after gaining more experience with services and diagnoses[15].

Participants in several studies stated that digital platforms would foster a feeling of support among the participants [17,19,21–23]. By consulting the posts by parents of children with similar symptoms and care pathways, most parents became more attenuated to what to expect and how best to care for their children[24]. Moreover, some participants in a study of Ammari and Schoenebeck[19] noted that posts from other parents, for example on health care services and medication, special education services, or specially designed clothes provided hope and decreased their anxiety and depression after a diagnosis. Several studies reported that parent-to-parent peer support either via social media groups or online support groups were vital in reducing feelings of isolation among parents of children with special needs[14,15,18,23]. The same was true for respondents in Gunderson[20], who reported that sole help from health professionals proved insufficient especially after initial diagnosis or during a deterioration phase of a condition. Where professionals or researchers participate in forums on digital platforms, respondents stressed the importance of their posts to reflect emotional empathy[22]. In addition, humor was considered a viable tool in minimizing the emotional toll of social media posts according to participants in the study by Ammari and colleagues[28].

Although digital platforms were preferred in most instances because virtual interactions were easier to establish and manage, some parents hoped for the development of hybrid social connections whereby virtual relationships would translate into occasional physical interactions[14]. In other work[19,28], online interactions through social media sites was reported to facilitate social support, especially for geographically restricted families with scarce resources in their immediate vicinities. However, social media sites were also reported to be not facilitative in linking newly diagnosed individuals and their families with experienced ones, or in connecting affected individuals to others with analogous experiences[28].

Concerns and suggestions for improvement in digital platforms

When using social media in the context of child disability, privacy issues were imminent among several parents as personal posts relating to photos and medical questions, for instance, were often restricted to closed groups[22,23,27]. Some studies showed that the majority of participants preferred closed over open online fora, such as closed Facebook groups to discuss personal information only with members of the group[17,19,23]. Furthermore, closed Facebook pages were preferred by participants in the study by Ammari and Schoenebeck[19] for organizing and strategizing activities whereas public groups were used to advocate for perceived necessary policy changes. While one study found that the number of respondents feeling rather or very comfortable with sharing medical and personal information in a closed group decreased when having professionals present[23], there was a general consensus in opinion about the presence of professionals on digital platforms, as they were considered necessary to facilitate robust information sharing according to some parents [18,23,25,28].

According to Fostervold Wells[15], issues of conflict of interest and privacy also arise when participants request to be 'friends' with their health professionals on social media websites. Furthermore, possible abuse of photographs of children and medical information was noted by one participant in the study by Rocha et al.[23]. Although parents reported feeling overall less judged online than offline, they dealt with judgement online by blocking or unfriending culprits, minimizing posts, reducing their engagement, as well as even deleting the respective digital platform account[28].

We also found that there were differences in digital platform use according to socio-demographics involved. For example, the study conducted by Tozzi and colleagues[24] found that individuals who were younger, active on social media, as well as already prone to communicating via electronic means were the most likely to discuss information found online with physicians. Conversely, the study by Knapp and colleagues[16] found that older individuals, non-college educated, non-English speaking people, and minorities such as African Americans were less likely to access information online[16]. The same study also found that these population groups compared to their reference group, were less likely to show e-Health literacy based on the eHEALS scale, a measure to evaluate the "ability to locate, evaluate, integrate, and apply information gained from electronic platforms"[16,36]. The language barrier of digital platforms also prevented many parents from interacting with and deriving optimum utility from digital platforms[25,27].

Digital platforms on which information was obscured and difficult to find also posed a great concern for participants[17]. Moreover, the prevalence and traction of mis- and disinformation on digital platforms was considered particularly problematic among participants of two studies[14,23]. Further, the expectation for unrealistic lifestyles[14,28] along with depressing posts[14,19,20,24] posed a mental health worry. For some parents the difficulty in weighing advice found on social media information against that of professionals[14,24] was also an issue of concern. Whereas posts linked to government sources were deemed important to increase the trustworthiness of information in some studies[17], other studies found this to be insufficient and advocated for posts to include information on the original cultural context[27]. Suggestions made in another study to increase the usefulness of social media platforms included targeted pages that connect children with similar ages and conditions together, consolidating pages on similar conditions, as well as facilitating the online interaction between more disease experienced parents with less experienced ones[28.] Finally, health apps focused on delivering interventions were encouraged to include and prioritize social support elements to improve their overall utility[29].

Discussion

Principal Results

The available literature shows that digital platforms used by parents of children affected by disability predominantly included social media but also search engines, health-related apps, and medical websites. Information retrieval and social support seeking were main reasons for their utilization with the general expectation to find and share objective, up-to date, and reliable information and guidance. In addition, main concerns for digital platform users included privacy issues and the digital divide across socio-demographic groups, including language barriers.

Social support from digital places

In our review, most of the literature reported that parents used commonly available social media platforms (e.g., Facebook, Twitter, Instagram) and other online forums, blogs, and discussion boards. Social media can be defined as digital platforms that provide users with the ability to share and discuss information publicly and within individual peer networks[37]. As such, they offer a social component that includes bidirectional communication among social media users allowing for social interaction and exchange. In previous work, research scholars have recognized social media platforms as so called "digital places", which can be defined as socially constructed spaces (i.e. environments) with individual meaning and utility to their users, similar to geographic places[37,38]. Following the nomenclature of Glanz et al[39], respondents in our reviewed studies used these digital places for informational- as well as for emotional support. It is noteworthy that some parents felt less charged online than offline, possibly due to the virtual character of digital places and more options to defriend, or retract from social contacts more easily than in the physical world. Participants in the reviewed studies expressed the general expectation to find and share objective, up-to-date and reliable information and guidance, which seems to be closely related to a feeling of empowerment. Importantly, this need for information seems to be closely related to needs of emotional and social support. Future research may extend the focus also on the multiple dimensions of digital places; how individual meaning and utility of these places may influence their use in the context of disabilities in children. Furthermore, future research should also look into the question how digital place use in this context might affect mental health and resilience in patients and family members, especially during the time of diagnosis and at critical events during the course of disease progression.

Ethical and private concerns reported in digital platform use

Older and low-educated individuals, as well as ethnic minorities were less likely to access information online compared to their younger, college-educated, white counterparts. This finding lends itself to the explanation that online digital platforms and resources are not accessible to everyone and once more indicates a digital divide also in the context of child disability. Our review also highlighted that women were the respondents in most of the reviewed studies: this may point toa gender bias, but it may also suggest that women take over the larger care burden in the family of children with disability. However, it is worth noting that the results on socio-demographics and digital platform use were rather old, that is, they were published in 2013[24] and 2011[16], when smartphones were not as widely used. According to the Pew Research Center, 53% of adults in the US owned a smartphone in 2013[40]. However, a 2021 survey conducted by the Pew Research Center showed that 85% of adults in the US own a smartphone[41]. Nevertheless, our findings from these two references do highlight a prevalent issue where older adults are often less likely to be familiar with the most recent social media platforms.

From a geographic perspective, the reviewed studies derive from many different countries and it is unclear whether there are patterns of digital platform use that are distinct in some regions or others. Some of the platforms might be specifically useful or even targeted to regional, national, or cultural audiences, which should be investigated in future studies.

Privacy issues were raised in various studies highlighting that affected individuals and parents felt more confident in closed fora and that they appreciated if professionals were verifying the information being discussed, while at the same time trying to maintain a healthy distance from professionals to discuss private issues in a safe space. This finding points to the ambivalent relationship parents of children with disabilities may develop with the child's healthcare providers.

No study in our review applied an experimental design involving the evaluation of digital platforms to test for the effects of distinct platform designs on distinct dimensions of support (i.e., emotional-, informational-, and instrumental support, as well as appraisal). This represents significant limitation in the available literature because it means limited evidence in this area, and difficult to draw conclusions about effectiveness of these platforms beyond anecdotal accounts from the explorative research summarized in this review. This is particularly true for patients with NMD on whom research in this field seems to be widely neglected so far despite the severeness of the diseases.

Our findings have major practical implications. Physicians and other health care providers, health care facilities, and health agencies should take advantage of digital platforms that provide social interaction options to meet and empower families of patients affected with rare diseases. This should be done by not only identifying and addressing patients' and parents' needs before, during, and after access but also recognizing and correcting any structural conditions that may affect individuals' opportunities to use such platforms.

Limitations

Our review is biased towards high-income countries and therefore the relevance of the findings for use across different settings globally is difficult to ascertain. Future studies should address under-represented cultural groups, languages, races, ethnicities, and countries to broaden our understanding of social media use in the context of pediatric diagnoses leading to disabilities and the inequities associated with it.

Conclusions

To date, only little scientifically sound knowledge is available on digital platform use and needs in the context of disabling diagnoses in children. Our study contributes to fill this gap, by highlighting which digital platforms families of children with disabilities visit, what they seek in them, and why. Most importantly, our findings remind us of the role of the social determinants in shaping the magnitude of individuals' access to and benefit from these platforms. As families of children with disabilities constitute an already vulnerable population, future research should seek to identify and critically examine the avoidable, unfair, and unjust conditions that may amplify forms of inequities in their access to support. This can be done by incessantly committing to engage a broad range of narratives, voices, and lived experience when conducting empirical research on digital platform uses among parents of children affected by disabilities .

Acknowledgements

AvH and AH conducted the study, reviewed the literature, and reported on the findings. MF supervised the review process. OG, SE, MS, MW, MF, and MvR designed

the study. OG took the lead in writing and prepared the first draft of the manuscript. All others contributed in writing. MW, MF, and MvR supervised the overall study. All authors approved the final manuscript.

We acknowledge funding from the Swiss School of Public Health (SSPH+) for the project RISE - Raising awareness for mental health in people affected by pediatric neuromuscular diagnoses (to OG and EA). The sponsor had no role in any step of the preparation of this manuscript.

Conflicts of Interest

None declared.

Abbreviations

NMD: Neuromuscular Disorder
RCT: randomized controlled trial

References

1. Maxey M, Beckert TE. Adolescents with Disabilities. *Adolesc Res Rev*. 2017;2(2):59-75. doi:10.1007/s40894-016-0043-y
2. Mueller CE, Prout HT. Psychosocial Adjustment of Adolescents and Young Adults With Intellectual Disabilities. *J Ment Health Res Intellect Disabil*. 2009;2(4):294-311. doi:10.1080/19315860903308572
3. Guyard A, Michelsen SI, Arnaud C, Lyons A, Cans C, Fauconnier J. Measuring the concept of impact of childhood disability on parents: Validation of a multidimensional measurement in a cerebral palsy population. *Res Dev Disabil*. 2012;33(5):1594-1604. doi:10.1016/j.ridd.2012.03.029
4. Thompson RJ, Gustafson KE. *Adaptation to Chronic Childhood Illness.* Washington: American Psychological Association; 1996. doi:10.1037/10188-000
5. Varni JW, Katz ER, Jr. RC, Dolgin M. Family Functioning Predictors of Adjustment in Children with Newly Diagnosed Cancer: A Prospective Analysis. *J Child Psychol Psychiatry*. 1996;37(3):321-328. doi:10.1111/j.1469-7610.1996.tb01409.x
6. Ziebland S, Wyke S. Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health? *Milbank Q*. 2012;90(2):219-249. doi:10.1111/j.1468-0009.2012.00662.x
7. Oldenburg B, Taylor CB, O'Neil A, Cocker F, Cameron LD. Using New Technologies to Improve the Prevention and Management of Chronic Conditions in Populations. *Annu Rev Public Health*. 2015;36(1):483-505.

doi:10.1146/annurev-publhealth-031914-122848
8. Sykora M. A treatise on Web 2.0 with a case study from the financial markets. 2012. https://dspace.lboro.ac.uk/2134/11473.
9. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Methodol Theory Pract*. 2005;8(1):19-32. doi:10.1080/1364557032000119616
10. Flanigan KM. Duchenne and Becker Muscular Dystrophies. *Neurol Clin*. 2014;32(3):671-688. doi:10.1016/j.ncl.2014.05.002
11. Crisafulli S, Sultana J, Fontana A, Salvo F, Messina S, Trifirò G. Global epidemiology of Duchenne muscular dystrophy: an updated systematic review and meta-analysis. *Orphanet J Rare Dis*. 2020;15(1):141. doi:10.1186/s13023-020-01430-8
12. Landfeldt E, Thompson R, Sejersen T, McMillan HJ, Kirschner J, Lochmüller H. Life expectancy at birth in Duchenne muscular dystrophy: a systematic review and meta-analysis. *Eur J Epidemiol*. 2020;35(7):643-653. doi:10.1007/s10654-020-00613-8
13. Elangkovan N, Dickson G. Gene Therapy for Duchenne Muscular Dystrophy. Jaiswal J, Nagaraju K, eds. *J Neuromuscul Dis*. 2021;8(s2):S303-S316. doi:10.3233/JND-210678
14. Terra AA. Connections: Social Media and Parents Raising Children with Profound Multiple Disabilities. *ProQuest Diss Theses*. 2020:198. https://search.proquest.com/docview/2394250611?accountid=168248%0Ahttp://www.yidu.edu.cn/educhina/educhina.do?artifact=&svalue=Connections%3A+Social+Media+and+Parents+Raising+Children+with+Profound+Multiple+Disabilities&stype=2&s=on%0Ahttp://pqdt.calis.ed.
15. Fostervold Wells LM. Using Social Media for Parental Support in Raising a Child with a Disability: A Critical Analysis of Facebook Postings. *Thesis*. 2016.
16. Knapp C, Madden V, Wang H, Sloyer P, Shenkman E. Internet Use and eHealth Literacy of Low-Income Parents Whose Children Have Special Health Care Needs. *J Med Internet Res*. 2011;13(3):e75. doi:10.2196/jmir.1697
17. Alsem MW, Ausems F, Verhoef M, Jongmans MJ, Meily-Visser JMA, Ketelaar M. Information seeking by parents of children with physical disabilities: An exploratory qualitative study. *Res Dev Disabil*. 2017;60:125-134. doi:10.1016/j.ridd.2016.11.015
18. Sharaievska I, Burk B. Recreation in Families with Children with Developmental Disabilities: Caregivers' Use of Online and Offline Support Groups. *Ther Recreation J*. 2018;52(1):42-57. doi:10.18666/TRJ-2018-V52-I1-8446
19. Ammari T, Schoenebeck S. Networked Empowerment on Facebook Groups for Parents of Children with Special Needs. In: *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. Vol 2015-April. New York, NY, USA: ACM; 2015:2805-2814. doi:10.1145/2702123.2702324
20. Gundersen T. 'One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder. *Sociol Health Illn*. 2011;33(1):81-95. doi:10.1111/j.1467-9566.2010.01277.x

21. Al-Daihani SM, Al-Ateeqi HI. Parents of children with disabilities in Kuwait: a study of their information seeking behaviour. *Heal Inf Libr J*. 2015;32(2):131-142. doi:10.1111/hir.12102
22. Russell DJ, Sprung J, McCauley D, et al. Knowledge Exchange and Discovery in the Age of Social Media: The Journey From Inception to Establishment of a Parent-Led Web-Based Research Advisory Community for Childhood Disability. *J Med Internet Res*. 2016;18(11):e293. doi:10.2196/jmir.5994
23. Rocha HM, Savatt JM, Riggs ER, Wagner JK, Faucett WA, Martin CL. Incorporating Social Media into your Support Tool Box: Points to Consider from Genetics-Based Communities. *J Genet Couns*. 2018;27(2):470-480. doi:10.1007/s10897-017-0170-z
24. Tozzi AE, Mingarelli R, Agricola E, et al. The internet user profile of Italian families of patients with rare diseases: a web survey. *Orphanet J Rare Dis*. 2013;8(1):76. doi:10.1186/1750-1172-8-76
25. Johnston C, Tracey DK, Mahmic S, Papps FA. *Getting the Best from DisabilityCare Australia: Families, Information and Decision Making: Report of a Project Undertaken for the Practical Design Fund Department of Families, Housing, Community Services and Indigenous Affairs*.; 2013.
26. Nicholl H, Tracey C, Begley T, King C, Lynch AM. Internet Use by Parents of Children With Rare Conditions: Findings From a Study on Parents' Web Information Needs. *J Med Internet Res*. 2017;19(2):e51. doi:10.2196/jmir.5834
27. Tracey D, Johnston C, Papps FA, Mahmic S. How do parents acquire information to support their child with a disability and navigate individualised funding schemes? *J Res Spec Educ Needs*. 2018;18(1):25-35. doi:10.1111/1471-3802.12390
28. Ammari T, Morris MR, Schoenebeck SY. Accessing social support and overcoming judgment on social media among parents of children with special needs. *Proc 8th Int Conf Weblogs Soc Media, ICWSM 2014*. 2014;(January 2014):22-31.
29. DeHoff BA, Staten LK, Rodgers RC, Denne SC. The Role of Online Social Support in Supporting and Educating Parents of Young Children With Special Health Care Needs in the United States: A Scoping Review. *J Med Internet Res*. 2016;18(12):e333. doi:10.2196/jmir.6722
30. Ahmed S. Internet and Parents with Children with Special Needs: A Meta-Analysis of PubMed Articles. *CSCW Work*. 2014.
31. White JM, Klein DM. *Family Theories*. 3rd ed. Los Angeles, CA: SAGE; 2008.
32. McMillan DW, Chavis DM. Sense of community: A definition and theory. *J Community Psychol*. 1986;14(1):6-23. doi:10.1002/1520-6629(198601)14:1<6::AID-JCOP2290140103>3.0.CO;2-I
33. Antonovsky A. *Unraveling the Mystery of Health : How People Manage Stress and Stay Well*. San Francisco, CA USA: Jossey-Bass; 1987.
34. Antonovsky A. The structure and properties of the sense of coherence scale. *Soc Sci Med*. 1993;36(6):725-733. doi:10.1016/0277-9536(93)90033-Z
35. Antonovsky A. *Health, Stress, and Coping*. San Francisco, CA USA: Jossey-Bass; 1979.

36. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *J Med Internet Res*. 2006;8(4):e27. doi:10.2196/jmir.8.4.e27
37. Shankardass K, Robertson C, Shaughnessy K, Sykora M, Feick R. A unified ecological framework for studying effects of digital places on well-being. *Soc Sci Med*. 2019;227(February 2018):119-127. doi:10.1016/j.socscimed.2018.09.022
38. Moon G. Conceptions of space and community in British health policy. *Soc Sci Med*. 1990;30(1):165-171. doi:10.1016/0277-9536(90)90339-T
39. Glanz K, Rimer BK, K Viswanath, eds. *Health Behavior and Health Education: Theory, Research, and Practice*. 4th ed. Jossey-Bass; 2008. https://www.med.upenn.edu/hbhe4/part3-ch9-key-constructs-social-support.shtml.
40. Smith A. Smartphone ownership 2013. *Pew Res Cent Washingt DC*. 2013:1-12. http://pewinternet.org/Reports/2013/Smartphone-Ownership-2013.aspx.
41. Perrin A. Mobile technology and home broadband 2021. 2021;(June). https://www.pewresearch.org/internet/2021/06/03/mobile-technology-and-home-broadband-2021/.

Tables and Figures

Table 1: Keyword searches conducted on title and abstract

Key Concepts	Search Terms
Parents/Caregivers	parent* OR caregiver* OR carer* OR mother* OR father*
	AND
Children affected by disability	‘child* disab*’ OR ‘child* disorder*’ OR ‘pediatric disab*’ OR ‘disabled persons’ OR ‘physical disab*’
	AND
Communication, exchange	communicat* OR experienc* OR challenge* OR connect* OR support* OR exchang*
	AND
Internet/social media, support	Internet* OR online* OR ‘social media*’ OR webs* OR virtual* OR ‘online support’ OR ‘Self-help Groups’ OR Facebook OR Twitter OR WhatsApp OR Reddit OR Instagram OR ‘mobile App*’

Table 2: Data extracted from included articles

Author, year	Study design (population size)	Location	Study objective	Target population	Main digital platform* (outcome measured#)
Gundersen, 2011[20]	Interviews (N=10)	Norway	Internet use for coping with chronic illness resulting from rare genetic disorders	Parents whose children have rare genetic disorders	I, II (a, b, c, e)
Knapp et al., 2011[16]	Survey (N=2371)	USA	Low-income parents of children with special needs' access and use; factors related to internet use; parents' eHealth literacy, and factors associated with higher eHealth literacy	Parents of children with special health care needs	I, II (a, d, e)
Tozzi et al, 2013[24]	Survey (N=516)	Italy	Details internet user profiles and how internet use affects decision making	Patients of rare diseases	I, II (a, c, e)
Johnston et al., 2013[25]	Mixed method (survey, N=522 + focus group, N=21)	Australia	How the internet can assist families with young disabled children to make effective intervention and support decisions	Families of young children with disabilities	I, II (a, d, e)
Ahmed, 2014[30]	Literature review (N=15)	Online	Summarize existing recommendations on internet use by parents of children with rare and difficult illnesses	Parents whose children have rare, difficult illnesses and special needs	I, II (c, d)
Ammari et al, 2014[28]	Mixed method (interview, N=18 + survey, N=205)	USA	Use of social media sites by parents of children with special needs for information and social support; perception and management of online and offline judgment; posts perceived to be socially appropriate to post on their own online profiles versus in shared online groups; how social media sites can better support special needs families	Parents of children with special needs	I (a, c, d)
Al-Daihani & Al-Ateeqi, 2015[21]	Survey (N=240)	Kuwait	Information seeking behavior of parents of children with disabilities	Parents of children in a school for special needs	I, II (a, c, e)
Ammari & Schoenebeck, 2015[19]	Semi-structured interviews (N=43)	Online	The use of social media needs by parents with special needs children	Parents of children with special needs	I (a, c, e)
Russell et al., 2016[22]	Quantitative assessment of Facebook likes, posts;	Canada, UK, Australia	Development and evaluation of Web-based research advisory community that links parents to researchers to improve research	Parents of children with special needs who used a Facebook group	I (a, b, c, d)

	survey (N=49)		and affected families/children's lives		
DeHoff et al., 2016[29]	Scoping review (N=na), expert interviews (N=na)	Online	Status of research on the usefulness of digital communication like social media, in providing informational and emotional support	Parents of young children with special health care needs	I, II (a, b, c, e)
Fostervold Wells, 2016[15]	Case study (N=1)	USA	What social media posts support parents in raising their children with a disability	Parents of a child with a disability	I (a)
Alsem et al., 2017[17]	Semi-structured interviews (15)	Netherlands	Information needs, process of seeking and evaluating information and the different sources of information for parents	Parents of children with disabilities	I, II (a, b)
Nicholl et. al, 2017[26]	Mixed method (survey, N=128 + focus group, N=8)	Ireland, Northern Ireland, US, UK	General internet usage patterns, types of information frequently searched for, and determine the effect the internet-sourced information on parents of children with rare conditions	Parents of children with rare conditions	I, II (a, b, d)
Sharaievska & Burk, 2018[18]	Semi-structured interviews (N=8)	USA	Role of online and offline support groups in the lives of families with children who have developmental disabilities.	Married mothers who had 1-5 children with developmental disabilities	I (a, e)
Rocha et al, 2018[23]	Survey (N=103)	Online	Understand the online behavior, perspectives, and norms of rare disease communities and to provide preliminary guidance to genetic counselors who wish to have discussions about social media support resources	Patients with newly-described or rare genetic findings from online patient registries	I (a, c, d)
Tracey et al., 2018[27]	Mixed method (survey, N=291 + focus group, N=56)	Australia	Information-seeking behavior of parents and their perceptions and evaluations of the various information sources available	Parents of children with disabilities	I, II (a, b, c, d, e)
Terra, 2020[14]	Semi-structured & open-ended interviews (N=5)	USA	Role of social media to empower and provide community for parents raising children with profound multiple disabilities	Parents of children with profound multiple disabilities	I (a, c)

***Digital platforms**: I. social media (e.g., Facebook, Twitter, email), II. Internet search engines, health apps, medical websites, or not specifically mentioned otherwise

#**Outcome measured**: a. reasons for use, b. expectations from use, c. concerns/shortcomings, d. suggestions for improvement, e. satisfaction and experience.

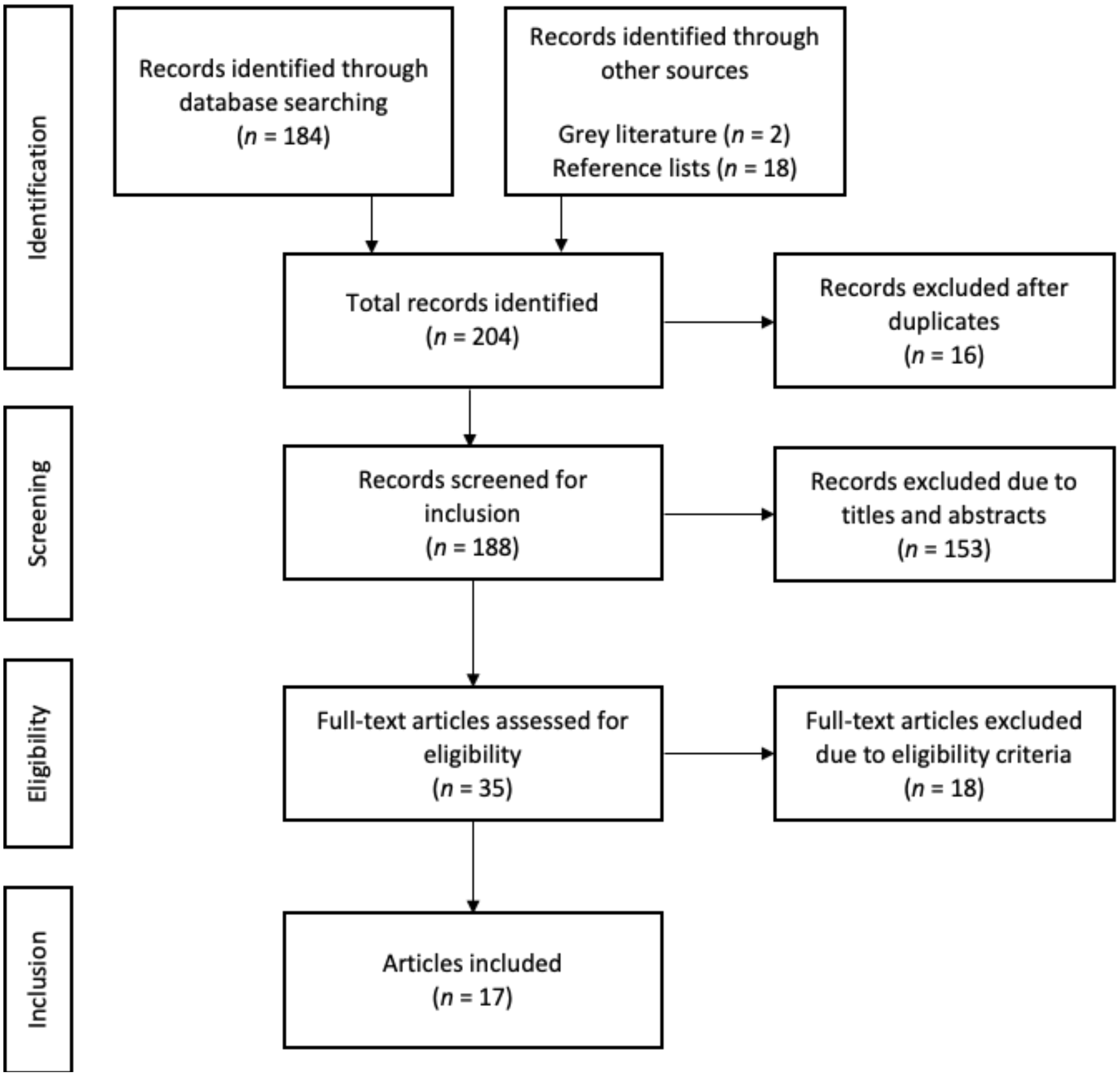


Figure 1: Flowchart

Appendix 1: Patient Association Websites

Patient Association websites

AANEM: https://www.aanem.org/Home

Australasian Neuromuscular Disease Network: https://www.ann.org.au

Duchenne Australia: https://www.duchenneaustralia.org

European Alliance of Neuromuscular Disorders Associations: http://www.eamda.eu

FSRMM: https://www.fsrmm.ch/home

German Muscular Society: https://www.dgm.org

Muscular Dystrophy Association: https://www.mda.org

Muscular Dystrophy Canada: https://muscle.ca

Muscular Dystrophy UK: https://www.musculardystrophyuk.org

Neuromuscular Disease Foundation: www.curehibm.org

Neuromuscular Disease Support Organizations: https://neurology.ufl.edu/divisions/neuromuscular/neuromuscular-support-organizations/

NMD4C: https://neuromuscularnetwork.ca

SMA Europe: https://www.sma-europe.eu

Swiss Muscular Society: https://www.muskelgesellschaft.ch

Swiss Duchenne Foundation: https://progena.ch/en/

Treat NMD: https://treat-nmd.org