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How to Use This Scoping Review:

- To aid in clinical care as a basis for asking parents if and how they access health information through social media
- To develop research programs investigating how health information is sourced on social media
- To inform policy relating to how parents source and use health information found on social media

Parents' use of social media as a health information source for their children: A scoping review

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Abstract

Background: Parents are increasingly using social media to inform health decisions for their children.

Objective: This scoping review examines (1) How do parents use social media to find health information for their children? (2) What motivates parents to engage with social media to seek health information for their children? (3) How do parents seek to understand and evaluate the health information they find on social media, and how does social media impact parental health information-seeking?

Methods: Scopus, CINAHL, PubMed, and Embase databases were searched, with open date parameters. Peer-reviewed studies that examined parents' and responsible caregivers' use of social media as a source of health information for their children (aged <18 years) were included.

Results: The 42 included studies spanned 2011 to 2020. More than half (n=24, 57%) were published in 2019 and 2020. Parents use social media for information about specific health concerns both before and after a medical diagnosis for their child. Parents are motivated to engage with social media as they seek out extensive information based on lived experience from other parents, as well as social support and community.

Conclusion: This scoping review reveals parents' motivation to use social media for health information, and how that can interact with, and impose on, clinical practice. It is important for those that provide pediatric health care to both understand and accommodate this permanent shift facilitated by social media, when working with parents that are seeking health information when making health decisions for their children.

What This Scoping Review Adds:

A concise overview of how parents use social media as part of their health information seeking process, what motivates parents to use social media, and how this use of social media can impact and impose on the provision of health care and clinical practice to children as it has been delivered up until now.

MeSH Keywords:

social media, health behavior, information-seeking behavior, parents, adolescent, child, preschool, infant.

Introduction

Parents are increasingly using social media to seek health information for their children.¹ Social media allows parents to form emotionally and socially supportive communities despite geographical barriers. It also facilitates the exchange of information between parents who might not have connected otherwise. However, social media may challenge parents' health literacy skills² in new ways due to the lack of expert input,³ and fact-checking regulatory gatekeeping that underpin the factual authority of traditional news media.^{4,5}

Engagement is central to social media,^{6,7} allowing multiple conversations to occur irrespective of geography and time. Information is exchanged between parents much like an ordinary conversation, but exchanges are digitized and available to those with access. This fundamental difference^{4,8} means parents may access evidence-based, user-generated information, but, unwittingly, also opinion which is not based on fact,⁹ and may even be contradictory. This also may create confusion,¹⁰ delay access to health care,¹¹ or increase the use of treatments without medical oversight,⁸ possibly harming children's health.

Researchers have investigated the quality of information on social media and the Internet; however, insight into parents' use of social media to seek health information for their children is limited.^{8,19} Accordingly, we conducted a scoping review of relevant peer-reviewed research to answer the following research questions: (1) How do parents use social media to find health information for their children? (2) What motivates parents to engage with social media to seek health information for their children? (3) How do parents seek to understand and evaluate the health information they find on social media, and how does social media impact parental health information seeking?

Methods

The PRISMA-ScR methodology was chosen due to the heterogeneity of study designs, platforms used, the variety of health issues parents sought information for, and this being a new area of study.^{12,13} The PRISMA-ScR allowed us to map the existing scholarly literature¹⁴ and identify future research directions,^{13,15} whilst also allowing for flexibility when deciding which literature sources were to be included and excluded by design¹⁴ and preserving research integrity and rigor. A review protocol was developed (but not registered) *a priori* in compliance with the protocol outlined in the Joanna Briggs Institute Manual of Evidence Synthesis¹⁶, using the SUMARI protocol template¹⁷ provided. The reporting for the scoping review was done in compliance with the PRISMA-ScR extension¹², using the PRISMA-ScR checklist.

The inclusion and exclusion criteria were determined *a priori*. Peer-reviewed scholarly research (published in English) that examined parents with a child aged between 0-18 years of age that specified social media as a source of health information were included. The term ‘parent’ is used here as an all-inclusive term, encompassing biological and non-biological caregivers responsible for the health decisions of a dependent child younger than 18 years. Studies were excluded if they included parents of children over 18 years of age, were concerning pregnancy/pre-natal care, or included children under the age of 18 years seeking their own health information. Studies on mHealth were excluded along with studies that did not clearly differentiate the use of the Internet from that of social media.

Embase, Scopus, CINAHL, and Medline were searched on 30 August 2020 with identical but translated search strategies. A targeted search of *Journal of Medical Internet Research* through PubMed (journal specified) was also conducted on 22 September 2020. All peer-reviewed empirical research was included, with all other search results being excluded to limit bias which is known to be inherent in editorials based on opinion, and lack of peer review for conference abstracts. Gray literature (literature that is produced by governments, academics, businesses and industry, but is not formally controlled or published by publishing houses¹⁸) was excluded due to the inability to determine quality,¹⁹ and impartiality.²⁴

The search terms used were developed with the assistance of an information services librarian. Search terms used across the databases were identical but translated to work for the requirements of each database (see Appendix 1). Date filters were left open (i.e., no date filters were used to limit results) to include studies across the entire social media lifespan and enable us to view changes and trends over time. The search strategy was executed by the first author with assistance from the consulting information services librarian.

The results from all searches were exported to Covidence²⁰ where duplicates were removed within the program, manually double-checked and deleted manually where required. Two reviewers screened all papers (EF and MB) by title, abstract and full paper according to the eligibility criteria that was inputted into Covidence to assist with consistency between reviewers and within screening for each reviewer. Inconsistencies were discussed between the two screening reviewers. Two papers that could not be resolved between the two screening reviewers were referred to the entire authorship team for discussion as to eligibility, resulting in one paper being included and one paper being excluded. Studies that appeared in records more than once were collapsed into a unit (first study published) for the purposes of analysis. The screening process was guided by the scoping review protocol¹⁶.

The data were extracted based on participant, concept, context in an iteratively adjusted data extraction tool (see Appendix 2) as set out in the scoping review protocol. Participant data was primarily focused on demographics. Concept data extraction focussed on data needed to directly answer the research questions—such as parent’s behaviour, motivation, and sentiment related to social media use for health information. Self-reported outcomes (what parents did with or as a result of the health information they found on social media) were also extracted to provide additional insights. Context data extraction focussed on study methodology and setting, including the country in which the study was conducted, the data collection methods and study designs used, the year of data collection, and the social media platforms investigated. Finally, the study data extracted was related to the meta data needed to inform the review. Once data extraction was completed, data synthesis was initiated on Microsoft Excel utilising data filters to

dynamically group studies together that had similarities, depending on the data point being explored at the time. Data were then mapped to allow for comprehensive analysis and cohesive results.

Results

Study characteristics

A total of 42 papers met the inclusion criteria (Figure 1). The publication dates spanned from 2011 to 2020 (Figure 2). Included studies used methodologies such as quantitative (n=15),^{1,21-34} qualitative (n=22),^{10,35-55} and mixed methodology (n=4)⁵⁶⁻⁵⁹ or review (n=1).⁶⁰ The majority of studies were conducted in the United States (US) (n=23),^{1,23,24,28,29,32-35,37,39-41,43,45,47,48,50,52,53,56,58,60} followed by Australia (n=6),^{27,38,42,51,54,55} Canada (n=4)^{10,30,44,49} and UK (n=2),^{22,57} Germany,²⁶ Ireland,⁵⁹ Israel,³⁶ Kuwait,³¹ Nigeria,²¹ Turkey,²⁵ and Scotland⁴⁶ each accounted for one study. Seven studies included only mothers,^{10,32,40,46-48,51} one study included only fathers⁵⁰ and 19 included both parents and/or caregivers.^{1,21,24,26,30,31,33,35,36,42,44,45,49,53,54,56-59} Table 3 provides an overview of the characteristics of the included studies.

A total of 10,198 participants are represented in this review, as well as 919 posts, 12,496 comments, and 17 Twitter accounts with 1,700 tweets. Study sample sizes varied from 10 to 4,174 participants. Papers included in this review spanned from 2011 to 2020 (Figure 2). In asking what are the patterns of parental use of social media to find health information for their children are, our review discovered the majority of quantitative studies of large social media platforms found that parents made extensive use of Facebook (10% to 100%)^{1,21–30,32–34,57–60} to access health information. Parents also commonly used Twitter (0.8% to 42.9%),^{21,23,24,26,28,30,58,59} Wikipedia (8.2 to 18%),^{1,22,26,33} and YouTube (14 to 16.3%)^{26,28,33,57,59,60} (Figure 3). Two studies reported discussion forum use (13.1% to 16%), including German medical forums²⁶ and dental forums²².

Facebook is the preferred platform for parents seeking pediatric health information, dominating other platforms from 2017, and featured twice as often as other platforms^{24–26,34,57,60} in 2019 (Figure 3). Facebook groups catering to parents with children with specific health concerns (e.g., Costello Syndrome, Hydrocephalus) were commonly reported, as well as geographically specified groups (e.g., an Autism Spectrum Facebook group in Malaysia).^{10,25,28,32–34,37,38,41,43,48,51,53,57,59} These Facebook groups were shown to be the most frequent facilitator of parents' engagement with social media for health information. Some parents were also part of closed Facebook groups (where parents apply to the group's administration to join, and engagement is inaccessible to non-members).^{10,37,51,53}

Characteristics of parents who use social media for health information

Across the nine studies reporting parents' highest qualification, between 6.3% to 52.4% of parents had completed high school or equivalent,^{1,23,24,26,28,29,31–33,35,44,46–48,56,57,59} while 14.2% to 78.2% had a bachelor's degree qualification.^{1,23,25,28,31–33,35,42,44,48,57,59} A later study⁵⁶ found higher educational attainment was associated with the use of social media for information, whereas studies before 2018 found a preference for social media information among parents with lower educational attainment.^{29,33,60} A 2020

US study of informational and emotional needs of parents of newborns with Severe Combined Immune Deficiency (SCID) found parents with higher levels of education were more likely to prefer social media as a source of health information ($P = 0.025$) than those with non-tertiary qualifications.⁵⁶ This is in direct contrast to a 2013 study that found parents who completed their education before or at the end of high school had a significant preference towards social media platforms for information in comparison to parents with tertiary qualifications ($P = 0.017$).³³ Mothers with lower educational qualifications were found to use YouTube as a source of health information concerning baby care or being a new mother ($P < 0.01$).

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Income^{1,23,24,28-30,33,57,58} or employment status³¹ was included as a descriptive statistic across ten quantitative studies. Two US studies used income as a variable. A 2013 study exploring the technology preferences of caregivers of children with hydrocephalus found a preference for social media for health information was associated with living above the poverty line ($P = 0.04$), being non-Anglo-Europeans ($P = 0.004$), having a lower income ($p=0.004$) and having a government (income assessed) insurance policy ($P = 0.005$).³³ A 2018 study of US mothers and immigrant Korean mothers to the US did not find income to be of significance when determining whether parents chose to use social media for health information or not.²⁸

Parents' motivations for using social media as a health information source

Parents' motivations for using social media as a health information source were reported in 33 studies. Motivations included seeking or giving information,^{11,21-23,25,27,28,31-35,37,38,40,43,45,46,50-52,54,56-60} seeking or giving support,^{1,27,35,38,40,49,50,53-56,58,60} seeking or giving advice,^{24,38,52,54,55,57,58} or seeking validation or reassurance for decisions made.^{48,51,54} Giving support was the predominant motivation, with a 2011 content analysis study reporting 96.8% of comments supported other forum members, followed by the giving of information (29.1%), seeking of support (17.1%), and seeking information (7.7%).⁵⁵ Other reasons parents sought health information on social media included immediacy,^{10,51} customization and detail of

information, and convenience.^{51,57} Engagement with social media for health information was associated with feelings of social support ($p < 0.001$) and empowerment ($p < 0.001$) in a study of pregnant women and mothers in the US.³²

Parents sought information pre-diagnosis,^{22,25} post-diagnosis,^{1,21,31,33–35,43,49,50,53,54,56,58,59} as well as to guide self-directed health care, either proactively^{24,32,37,42,45,46,55} or retrospectively as a result of previous health care being unsatisfactory^{38,57} (Table 4). The majority of parents searched with a particular health condition in mind. Twelve studies focused on parents seeking preventative health information- five studies related to vaccination, one study on Sudden Infant Death Syndrome [SIDS] prevention) and six studies focused on parents looking for general health information for their child, such as infant feeding,^{10,28,51} normal bowel movements,^{28,48} growth and development,^{28,48} sleep,²⁸ and behavioral changes.^{27,48} From this, one study found that some parents preferred health information from social media as they believed other parents were more educated regarding caregiving and self-management strategies than health care professionals.³⁵ Other parents used social media to access and discuss health information that would be considered peripheral to conventional medical advice, such as vaccine hesitancy information.³⁷

Sentiments and perceptions towards the use of social media as a source of health information

Sentiments towards using social media as a health information source differed with parents stating they had positive,^{10,25,27,32–35,38,48,50–53,57,59} mixed^{37,41,54} or negative sentiments^{1,31,45} about their experiences. Perceived benefits of using social media for health information included increasing social connections (making friends),^{27,48,51} having a safe and private place to discuss sensitive issues,^{27,38,51} obtaining support,^{27,34,35,38,44,48,52} gaining reassurance/validation for decisions already made,^{10,51} and the provision of accessible, immediate and detailed knowledge based on experience from other parents.^{1,10,25,30,33–35,38,40,43,48,49,51,53,57,60} Perceived drawbacks included finding unhelpful information about worst case scenarios (i.e. catastrophizing), information quality concerns,^{1,23,29,41,46,47} privacy concerns,⁵² and group

sentiments sometimes misleading those seeking information.^{24,39} Parents also described discomfort over occasional conflict between users,⁴⁵ leading to some parents feeling judged, maligned, or bullied.¹⁰

Benefits of using social media for health information included the normalization of challenges commonly faced by new parents, including Post Natal Depression (PND)/ Post-Partum Depression (PPD) and common breastfeeding challenges.¹⁰ Parents felt more educated about their child's condition⁵⁹ and empowered as to how best to manage it,^{38,59} as a result of accessing health information on social media, although some stated they experienced increased anxiety.⁵⁹ Increased self-efficacy was shown⁵⁹ as parents were able to come to rely less on social media health information for recurrent caregiving issues such as self-management of hydrocephalus shunt blockages³³ as well as the achievement of personal exclusively-expressed breastfeeding goals that were thought impossible before benefiting from social media support.³⁸ Parents who engaged with social media in a meaningful way were found to have higher perceptions of empowerment ($P = 0.001$) and social support ($P = <0.001$),³² as well as self-efficacy ($P < 0.01$).²³

Parents' evaluation of health information found on social media

In answering our research question concerning how parents understand health information found on social media, we identified 20 quantitative and qualitative papers examining how parents evaluate health information found on social media (i.e., health literacy skills).

Individual factors that impact parents' understanding of health information found on social media platforms

Health information sought from social media was viewed with both skepticism^{1,42,45,54} and acceptance⁴⁸ by parents. Parents sought to understand and evaluate credibility using methods including examining the source,^{35,42} translating information into their native language using Google Translate,⁴⁶ and assessing how the information was presented, including graphics, interactivity, use of media, and aesthetics.⁴² Some parents chose to obtain health information directly from peer-review journals seeing this as a way of

accessing credible information without media (mis)interpretation,^{30,41,48} while others did self-styled information triangulation by crowdsourcing information and determining consensus.^{35,42,48,52}

Many parents asked healthcare professionals to verify the information found on social media.^{1,25,35,45,48,52,54,59} Other less frequently used information validation strategies included assessing information based on gut feeling, inner wisdom, and intuition.¹⁰ Confusion and misinterpretation sometimes occurred³⁷ among parents due to the complexity of information¹⁰ presented, and the vocabulary used.⁴² This could sometimes result in information overload.¹⁰

Group factors that impact parents' understanding of health information found on social media platforms

Information and knowledge based on lived experience⁴⁰ were much more readily accepted by parents, with the perception being underpinned by their view that parents in the same predicament were inherently trustworthy³⁰ due to the shared experience of managing children with a chronic or life-threatening illness.^{30,35} In some cases, social media users were more trusted than healthcare professionals,³⁰ either by choice or by necessity, in the absence of clinical or evidence-based information.⁴³ In platform facilitated groups, information was viewed by group members as being more trustworthy if it came from more experienced members.^{33,38}

Conflicting information found on social media was a theme reported in five studies. Discrepancies were apparent between opinions put forward by group members,^{41,54} between group members and best practice medical guidelines,^{39,54} or between opinions put forward by group members and specific advice given by healthcare professionals.^{25,38} This resulted in confusion for users,^{10,25,36} with 49.8% of users in one study relying on the information from their healthcare professional and 14.9% relying on information found on social media (of which 87% relied on information found in patient and parent Facebook groups).²⁵ In one

study, the value placed on social media (Twitter and Facebook) by parents as an information source was found to have an inverse relationship with perceptions of vaccination benefit ($P < 0.01$).²⁴

Discussion

This review has revealed the patterns in parents' use of social media to source health information for their children, including both positive and negative aspects of this use. The characteristics of parents who use social media for health information for their children have shown interesting changes over the timespan of the included studies. While low levels of educational attainment among parents who preferred social media for health information were initially observed,^{29,33,60} that relationship has inverted since 2018, with more parents with higher levels of education using social media to source health information.⁵⁶ Income also shifted as a determinant of parents' use of social media for health information. A 2013 US study showed that living above the poverty line but having a lower income and having a government income-assessed health plan was associated with using social media for health information.³³ The use of social media for health information for these parents may have enabled access to health information that was previously inaccessible. More recent studies have found no such relationship between income or education and parents' use of social media for health information.²⁸ This increased use of social media in higher educated parents could be explained by an age-cohort effect⁶¹ and access to better technology, especially smartphones.⁶²

When answering our second research question, we found that parents are generally motivated to use social media for health information after healthcare has been sought rather than when trying to determine if healthcare is required. This suggests parents look to other parents in the same situation for information, support, and advice about how to manage their child's health condition, along with guidance on navigating the health system and required resources. Our review also found that parents can feel positive about using social media for health information seeking because of the perceived broader social benefits that result from interactions that would not have occurred otherwise. This supports and adds context to Gage-

Bouchard's finding³⁵ that parents trusted other parents more than their treating health care professionals when considering the caregiving and health management needs of the child outside the consultation room.

Our review found that parents often find it difficult to use social media to source health information and then adequately evaluate this information. Challenges included navigating, identifying, and managing conflicting information exist because information exchange on social media occurs within a dialogue which may compound confusion by introducing layers of nuance, emotion, complexity, and influence.⁶³

The influence of groups of like-minded people and the resulting confirmation bias cannot be underestimated. Group dynamics on social media can facilitate 'echo chambers',⁶⁴ which occur when only the dominant information or opinion within a group is heard, with dissenting information or opinions being minimized or excluded. This results in the same message being repeated without variation, resulting in the group members coming to view this information as the singular truth. This is especially prevalent within social media groups of like-minded people, such as anti-vaccination social media groups, where the group dominion repels divergent opinions or evidence and reinforces dominant approved opinions.⁶⁵ These groups are often influential, with ambivalent members being seen to become more agreeable to the group's ideology within a single discursive interaction.³⁷ This often occurs after other members inform them of the group's consensus on the risks of vaccinations, whether by a conversation thread or by hyperlinking to other resources.³⁷

Echo chambers reinforce misinformation on social media⁶⁶ and obstruct individuals from accessing evidence-based health information. Despite this, there has been a significant increase in parents' use of social media for health information, particularly on Facebook, since 2019.⁶⁷ This correlates with Facebook's tweaking of their algorithm in 2019 to boost group recommendations to the top of a user's "newsfeed".⁶⁷ Facebook did this to create more "meaningful communities" on its platform, where like-minded people (with comparable confirmation biases) could meet and interact. It has brought with it a significant increase in user engagement,⁶⁸ which is Facebook's primary commodity.⁶⁹

Many parents seek evidence-based health information. Their reliance on abstracts (in lieu of full journal articles) for health information^{70,71} is one indication of the demand and need for primary, objective, evidence-based health information to be more accessible. However, while this stark information poverty^{43,72} exists, health information available on social media, despite sometimes lacking an evidence base, may be utilized because the desired information is sequestered behind paywalls and the distinct lack of alternative resources that are as easily accessible, convenient and easily understood as what social media offers. Our results indicate the need to provide training on parents' use of social media for health information for future pediatric clinicians. Such training should explain how parents now routinely seek^{21,22,27,28,33}, use^{22,26,28,59}, and share²⁶ health information (being mindful that for some parents, social media is a preferred source of health information⁴⁷). Training could also identify key medical misinformation risks⁷³, scaffold ways to find high quality pediatric health information⁴⁸, and highlight the clinician's potential to counter misinformation building on the ongoing trust in doctors and drawing on fact-checking resources.⁷³

Future directions

The results of this scoping review suggest it would be prudent for clinicians to assume that many parents consult social media after their clinical interactions to seek further health information. The information found may be used in conjunction with information provided during the clinical consult, or it may be used instead of the evidence-based information provided. Further research is needed on how best to address this via health counselling. To date, most research touching on this calls for the health literacy upskilling of patients by clinicians during their health counselling. It needs to be acknowledged that health care professionals are often not in the position to give parents the appropriate health media literacy training that would be needed to effectively combat social media misinformation. As such, innovative tools to help

parents navigate to reliable health information are urgently needed to minimize the potential impacts of medical misinformation on children's health.

Limitations

Due to the selection strategy, potentially relevant articles on parents' use of social media alongside their use of Internet and mHealth apps may have been excluded. The effects of specific social media and other internet sources require more disentangling than is possible here because study designs often lack separation of parental source choices. While it was beyond the scope of this review to analyze research in languages other than English, it is acknowledged the issue transcends geographical borders.

Conclusion

Current data show that parents are increasingly using social media for health information needs, as it facilitates the exchange of timely and tailored information and enables significant social support between users. However, social interaction can facilitate the exchange of opinion masquerading as factual information. Despite parents' best efforts, the current information terrain does not lend itself to effective information seeking. Social media's unique challenges need to be urgently analyzed to enable the development of effective health literacy education to promote safe and effective social media navigation for health information seeking.

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Conflict of Interest

No funding was received for any aspect of this study. The authors have no conflicts of interest to declare.

Appendix

1. Database Search Strategies
2. Data Extraction Tool

References

1. Bryan MA, Evans Y, Morishita C, Midamba N, Moreno M. Parental perceptions of the internet and social media as a source of pediatric health information. *Acad Pediatr*. 2020;20(1):31-38. doi:10.1016/j.acap.2019.09.009
2. Livingstone S. Media literacy and the challenge of new information and communication technologies. *Commun Rev*. 2004;7(1):3-14. doi:10.1080/10714420490280152
3. Schudson M. The objectivity norm in American journalism*. *Journalism*. 2001;2(2):149-170. doi:10.1177/146488490100200201
4. Van Dijck J. *The Culture of Connectivity: A Critical History of Social Media*. Oxford University Press; 2013. doi:10.1093/acprof:oso/9780199970773.001.0001
5. Fortinsky KJ, Fournier MR, Benchimol EI. Internet and electronic resources for inflammatory bowel disease: A primer for providers and patients. *Inflamm Bowel Dis*. 2012;18(6):1156-1163. doi:10.1002/ibd.22834
6. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of social media. *Bus Horiz*. 2010;53(1):59-68. doi:10.1016/j.bushor.2009.09.003
7. O'Reilly T. What is Web 2.0: Design patterns and business models for the next generation of software. *Communications Strategies*. 2007;1:17.
8. Hamm MP, Chisholm A, Shulhan J, et al. Social media use among patients and caregivers: A scoping review. *BMJ Open*. 2013;3(5):e002819. doi:10.1136/bmjopen-2013-002819
9. Dylko I, McCluskey M. Media effects in an era of rapid technological transformation: A case of user-generated content and political participation. *Commun Theory*. 2012;22(3):250-278. doi:10.1111/j.1468-2885.2012.01409.x
10. Price S.L., Aston M., Monaghan J., et al. Maternal knowing and social networks: Understanding first-time mothers' search for information and support through online and offline social networks. *Qual Health Res*. 2018;28(10):1552-1563. doi:10.1177/1049732317748314

11. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: A qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *J Med Internet Res*. 2014;16(12):e262. doi:10.2196/jmir.3706
12. Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *Ann Intern Med*. 2018;169(7):467. doi:10.7326/M18-0850
13. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *null*. 2005;8(1):19-32. doi:10.1080/1364557032000119616
14. Peters MDJ, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *JBIEvid Implement*. 2015;13(3):141-146. doi:10.1097/XEB.0000000000000050
15. Levac D, Colquhoun H, O'Brien KK. Scoping studies: Advancing the methodology. *Implement Sci*. 2010;5(1):69. doi:10.1186/1748-5908-5-69
16. 11.2 Development of a scoping review protocol - JBI Manual for Evidence Synthesis - JBI Global Wiki. Accessed November 7, 2021. <https://jbi-global-wiki.refined.site/space/MANUAL/3283910908/11.2+Development+of+a+scoping+review+protocol>
17. JBI Global. JBI Manual for Evidence Synthesis. Accessed November 2, 2021. https://jbi-global-wiki.refined.site/space/MANUAL/3342368772/Downloadable+PDF+-+current+version?attachment=/download/attachments/3342368772/JBIMES_2021April.pdf&type=application/pdf
18. Schöpfel J. Towards a Prague Definition of Grey Literature. In: *Towards a Prague Definition of Grey Literature. Twelfth International Conference on Grey Literature: Transparency in Grey Literature*. ; 2010:pp.11-26. Accessed October 31, 2021. http://greynet.org/images/GL12_S1P,_Sch_pfel.pdf
19. Students 4 Best Evidence. Grey literature and their sources. Students 4 Best Evidence. Published May 7, 2021. Accessed October 31, 2021. https://s4be.cochrane.org/?p=16596&preview=true&preview_id=16596
20. Covidence - Better systematic review management. <https://www.covidence.org/>
21. Adekunle AA, James O, Adeyemo WL. Health information seeking through social media and search engines by parents of children with orofacial cleft in Nigeria. *Cleft Palate Craniofac J*. 2020;57(4):444-447. doi:10.1177/1055665619884447
22. Bamashmous N., Cunningham S.J., Parekh S. Information seeking behaviour of dental trauma patients and their parents. *Dent Traumatol*. 2020;36(6):590-597. doi:10.1111/edt.12581
23. Kim SC, Hawkins KH. The psychology of social media communication in influencing prevention intentions during the 2019 U.S. measles outbreak. *Comput Hum Behav*. 2020;111. doi:10.1016/j.chb.2020.106428
24. Hwang J., Shah D.V. Health information sources, perceived vaccination benefits, and maintenance of childhood vaccination schedules. *Health Commun*. 2019;34(11):1279-1288. doi:10.1080/10410236.2018.1481707
25. Kulhas Celik I., Buyuktiryaki B., Civelek E., Kocabas C.N. Internet use habits of parents with children suffering from food allergy. *Arch Argent Pediatr*. 2019;17(3):134-139. doi:10.21911/aai.485

26. Peterlein CD, Bosch M, Timmesfeld N, Fuchs-Winkelmann S. Parental internet search in the field of pediatric orthopedics. *Eur J Pediatr*. 2019;178(6):929-935. doi:10.1007/s00431-019-03369-w
27. Baker B, Yang I. Social media as social support in pregnancy and the postpartum. *Sex Reprod Healthc*. 2018;17:31-34. doi:10.1016/j.srhc.2018.05.003
28. Lee HS. A comparative study on the health information needs, seeking and source preferences among mothers of young healthy children: American mothers compared to recent immigrant Korean mothers. *Inf Res*. 2018;23(4). Accessed December 9, 2020. <http://www.informationr.net/ir/23-4/paper803.html>
29. Walker LO, Mackert MS, Ahn J, et al. e-Health and new moms: Contextual factors associated with sources of health information. *Public Health Nurs*. 2017;34(6):561-568. doi:10.1111/phn.12347
30. Sharpe K, Di Pietro N, Jacob KJ, Illes J. A dichotomy of information-seeking and information-trusting: Stem cell interventions and children with neurodevelopmental disorders. *Stem Cell Rev Rep*. 2016;12(4):438-447. doi:10.1007/s12015-016-9667-3
31. Al-Daihani S.M., Al-Ateeqi H.I. Parents of children with disabilities in Kuwait: A study of their information seeking behaviour. *Health Info Libr J*. 2015;32(2). doi:10.1111/hir.12102
32. Holtz B, Smock A, Reyes-Gastelum D. Connected motherhood: Social support for moms and moms-to-be on Facebook. *Telemed e-Health*. 2015;21(5):415-421. doi:10.1089/tmj.2014.0118
33. Naftel RP, Safiano NA, Falola MI, Shannon CN, Wellons III JC, Johnston Jr. JM. Technology preferences among caregivers of children with hydrocephalus: Clinical article. *J Neurosurg Pediatr*. 2013;11(1):26-36. doi:10.3171/2012.9.PEDS12208
34. Zhao Y, Zhang J, Wu M. Finding users' voice on social media: An investigation of online support groups for autism-affected users on Facebook. *Int J Environ Res Public Health*. 2019;16(23). doi:10.3390/ijerph16234804
35. Gage-Bouchard E.A., LaValley S., Devonish J.A. Deciphering the signal from the noise: Caregivers' information appraisal and credibility assessment of cancer-related information exchanged on social networking sites. *Cancer Control*. 2019;26(1). doi:10.1177/1073274819841609
36. Orr D, Baram-Tsabari A, Landsman K. Social media as a platform for health-related public debates and discussions: The Polio vaccine on Facebook. *Isr J Health Policy Res*. 2016;5(101584158):34.
37. Bradshaw AS, Shelton SS, Wollney E, Treise D, Auguste K. Pro-vaxxers get out: Anti-vaccination advocates influence undecided first-time, pregnant, and new mothers on Facebook. *Health Commun*. 2020;36(6):693-702. doi:10.1080/10410236.2020.1712037
38. Clapton-Caputo E, Sweet L, Muller A. A qualitative study of expectations and experiences of women using a social media support group when exclusively expressing breastmilk to feed their infant. *Women Birth*. Published online 2020. doi:10.1016/j.wombi.2020.06.010
39. Jenkins M.C., Moreno M.A. Vaccination discussion among parents on social media: A content analysis of comments on parenting blogs. *J Health Commun*. 2020;25(3):232-242. doi:10.1080/10810730.2020.1737761
40. Lebron C.N., St. George S.M., Eckembrecher D.G., Alvarez L.M. "Am I doing this wrong?" Breastfeeding mothers' use of an online forum. *Matern Child Nutr*. 2020;16(1):e12890. doi:10.1111/mcn.12890

41. Pretorius K, Choi E, Kang S, Mackert M. Sudden Infant Death Syndrome on Facebook: Qualitative descriptive content analysis to guide prevention efforts. *J Med Internet Res.* 2020;22(7):e18474. doi:10.2196/18474
42. Thorpe M, Taylor J, Cole R. Parents' use of information accessed through social media to make immunisation decisions for their young children. *Health Promot J Aust.* 2020;32(2):189-196. doi:10.1002/hpja.336
43. Wang T, Lund B. Categories of information need expressed by parents of individuals with rare genetic disorders in a Facebook community group: A case study with implications for information professionals. *J Consum.* 2020;24(1):20-34. doi:10.1080/15398285.2020.1713700
44. Castro AR, Chougui K, Bilodeau C, Tsimicalis A. Exploring the views of osteogenesis imperfecta caregivers on internet-based technologies: Qualitative descriptive study. *J Med Internet Res.* 2019;21(12). doi:10.2196/15924
45. Deas J, Bean SJ, Sokolovska I, Fautin C. Childhood vaccine attitudes and information sources among Oregon parents and guardians. *Health Promot Pract.* 2019;20(4):529-538. doi:10.1177/1524839918778830
46. Gorman DR, Bielecki K, Willocks LJ, Pollock KG. A qualitative study of vaccination behaviour amongst female Polish migrants in Edinburgh, Scotland. *Vaccine.* 2019;37(20):2741-2747. doi:10.1016/j.vaccine.2019.03.073
47. Koskan AM, Dominick LN, Helitzer DL. Rural caregivers' willingness for community pharmacists to administer the HPV vaccine to their age-eligible children. *J Cancer Educ.* 2019;36(1):189-198. doi:10.1007/s13187-019-01617-z
48. Moon RY, Mathews A, Oden R, Carlin R. Mothers' perceptions of the internet and social media as sources of parenting and health information: Qualitative study. *J Med Internet Res.* 2019;21(7):e14289-e14289. doi:10.2196/14289
49. Rehman S, Lyons K, McEwen R, Sellen K. Motives for sharing illness experiences on Twitter: conversations of parents with children diagnosed with cancer. *Inf Commun Soc.* 2018;21(4):578-593. doi:10.1080/1369118X.2017.1299778
50. Kim H.N., Wyatt T.H., Li X., Gaylord M. Use of social media by fathers of premature infants. *J Perinat Neonatal Nurs.* 2016;30(4):359-366.
51. Lupton D. The use and value of digital media for information about pregnancy and early motherhood: A focus group study. *BMC Pregnancy Childbirth.* 2016;16(1). doi:10.1186/s12884-016-0971-3
52. Criss S, Woo Baidal JA, Goldman RE, Perkins M, Cunningham C, Taveras EM. The role of health information sources in decision-making among Hispanic mothers during their children's first 1000 days of life. *Matern Child Health J.* 2015;19(11):2536-2543. doi:10.1007/s10995-015-1774-2
53. Mohd Roffeei SH, Abdullah N, Basar SKR. Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs). *Int J Med Inform.* 2015;84(5):375-385. doi:10.1016/j.ijmedinf.2015.01.015
54. Appleton J, Fowler C, Brown N. Friend or foe? An exploratory study of Australian parents' use of asynchronous discussion boards in childhood obesity. *Collegian.* 2014;21(2):151-158. doi:10.1016/j.colegn.2014.02.005

55. Cowie GA, Hill S, Robinson P. Using an online service for breastfeeding support: What mothers want to discuss. *Health Promot J Austr.* 2011;22(2):113-118. doi:10.1071/he11113
56. Raspa M, Lynch M, Squiers L, et al. Information and emotional support needs of families whose infant was diagnosed with SCID through newborn screening. *Front Immunol.* 2020;11:885. doi:10.3389/fimmu.2020.00885
57. Garcia AL, Looby S, McLean-Guthrie K, Parrett A. An exploration of complementary feeding practices, information needs and sources. *Int J Environ Res Public Health.* 2019;16(22). doi:10.3390/ijerph16224311
58. Gibson AN, Kaplan S, Vardell E. A survey of information source preferences of parents of individuals with Autism Spectrum Disorder. *J Autism Dev Disord.* 2017;47(7):2189-2204. doi:10.1007/s10803-017-3127-z
59. 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
60. Pretorius K, Johnson KE, Rew L. An integrative review: Understanding parental use of social media to influence infant and child health. *Matern Child Health J.* 2019;23(10):1360-1370. doi:10.1007/s10995-019-02781-w
61. Hruska J, Maresova P. Use of social media platforms among adults in the United States—behavior on social media. *Societies.* 2020;10(1). doi:10.3390/soc10010027
62. Ortiz-Ospina E. The Rise of Social Media. Our World in Data. Published September 18, 2019. Accessed November 23, 2021. <https://ourworldindata.org/rise-of-social-media#licence>
63. Witteman HO, Fagerlin A, Exe N, Trottier ME, Zikmund-Fisher BJ. One-sided social media comments influenced opinions and intentions about home birth: an experimental study. *Health Aff.* 2016;35(4):726-733. doi:10.1377/hlthaff.2015.1382
64. Hall Jamieson K, Cappella JN. *Echo Chamber: Rush Limbaugh and the Conservative Media Establishment.* Oxford University Press; 2010. Accessed October 18, 2020. <https://doi.org/10.1002/j.1538-165X.2009.tb01921.x>
65. Pariser Eli. *The Filter Bubble : What the Internet Is Hiding from You.* Penguin Press; 2011.
66. Shoup J.A., Narwaney K.J., Wagner N.M., et al. Social media vaccine websites: A comparative analysis of public and moderated websites. *Health Educ Behav.* 2019;46(3):454-462. doi:10.1177/1090198118818253
67. Facebook. Day 1 of F8 2019: Building new products and features for a privacy-focused social platform - about Facebook. Published April 30, 2019. Accessed November 21, 2020. <https://about.fb.com/news/2019/04/f8-2019-day-1/>
68. Rodriguez S. Mark Zuckerberg shifted Facebook's focus to groups after the 2016 election, and it's changed how people use the site. CNBC. Published February 16, 2020. Accessed November 21, 2020. <https://www.cnbc.com/2020/02/16/zuckerbergs-focus-on-facebook-groups-increases-facebook-engagement.html>
69. Cooper P. How the Facebook algorithm works in 2020 and how to work with it. Hootsuite. Published January 27, 2020. Accessed November 21, 2020. <https://blog.hootsuite.com/facebook-algorithm/>

70. Frey EFJ. Open access: remember the limitations of abstracts and the role of professional endorsement. *BMJ*. 2019;365. doi:10.1136/bmj.l2252
71. Koopman P. How to write an abstract. *Carnegie Mellon University*. 1997;31:2013. <https://users.ece.cmu.edu/~koopman/essays/abstract.html>
72. Drushel BE. HIV/AIDS, social capital, and online social networks. *J Homosex*. 2013;60(8):1230-1249. doi:10.1080/00918369.2013.784114
73. Melki J, Tamim H, Hadid D, Makki M, Amine JE, Hitti E. Mitigating infodemics: The relationship between news exposure and trust and belief in COVID-19 fake news and social media spreading. *PLOS ONE*. 2021;16(6):e0252830. doi:10.1371/journal.pone.0252830

Tables and Figures

Figure 1: PRISMA- ScR Flow Chart

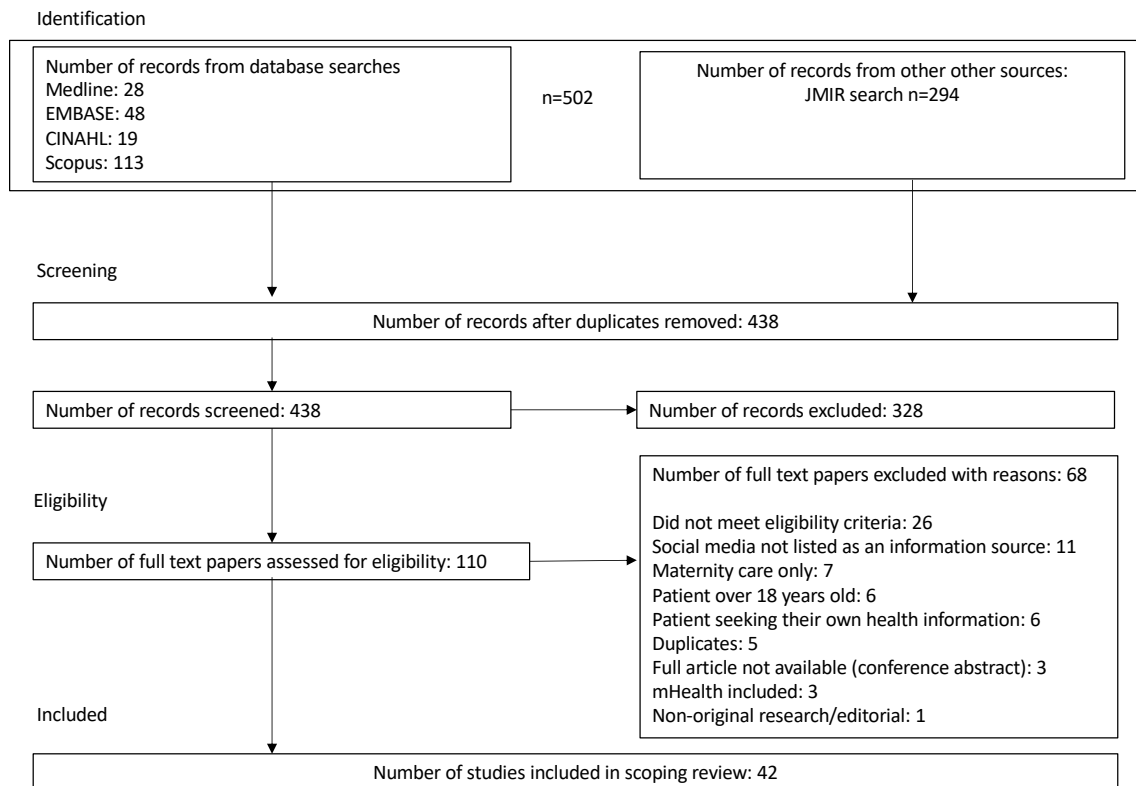


Table 1: Overview of the Characteristics of the Included Studies

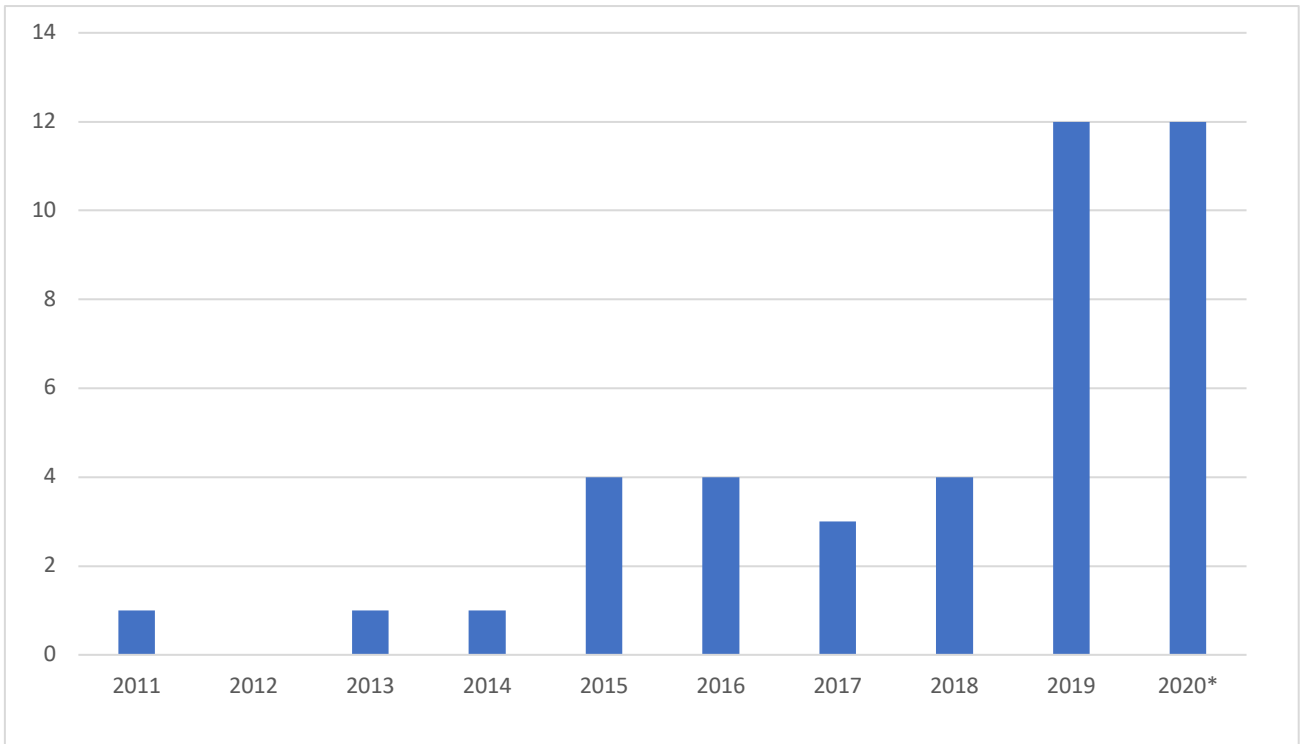
Author	Year	Country	Study design	Total data set (n=)	Health concern	SM platforms used	Funding Statement
Adekunle ²¹	2020	Nigeria	Survey	50 participants	Orofacial cleft	Facebook Instagram Twitter	None declared
Bamashmous et al. ²²	2020	UK	Survey	70 participants	Dental trauma	YouTube Wikipedia Facebook Dental forums	Absent
Bradshaw et al. ³⁷	2020	US	Content analysis	258 participants	Vaccines	Facebook	Absent
Bryan et al. ¹	2020	US	Survey	551 participants	General information	Facebook Wikis blogs	Bright futures Young Investigators Award from Academic Pediatric Association and Maternal Health Bureau
Clapton-Caputo et al. ³⁸	2020	Australia	Interview	76 participants	Breastfeeding	Facebook	None declared
Jenkins et al. ³⁹	2020	US	Content analysis	64 participants	Vaccines	Blogs (comments)	Absent

Kim et al. ²³	2020	US	Survey	4174 participants	Measles	Facebook Twitter Instagram Pinterest	Supported by the Department of Communication at George Mason University
Lebron et al. ⁴⁰	2020	US	Content analysis	258 posts/ 1445 comments	Breastfeeding	Babycentre.com forum	Absent
Pretorius et al. ⁴¹	2020	US	Content analysis	20 posts/ 912 comments/ 512 mothers in one Facebook group	Sudden Infant Death Syndrome	Facebook	- Sigma Theta Tau - National Association of Pediatric Nurse Practitioners
Raspa et al. ⁵⁶	2020	US	Interview Survey	7 participants 76 participants	Severe Combined Immune Disorder	Not specified	Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HSS) (Grant #SC1MC31881).
Thorpe et al. ⁴²	2020	Australia	Interview	14 participants	Vaccines	Facebook YouTube Instagram Pinterest LinkedIn Twitter	None declared
Wang and Lund ⁴³	2020	US	Content analysis	100 comments	Rare genetic disorders	Facebook	None declared
Castro et al. ⁴⁴	2019	Canada	Interview	18 participants	Osteogenesis imperfecta	YouTube Facebook	- Tunis Shriners, - Newton Foundation, - Scotiabank, - Canadian Institutes of Health Research: Institute of Health Services and Policy Research Travel Awards (summer 2018) - McGill University Ingram School of Nursing Summer Bursary Program of 2019
Deas et al. ⁴⁵	2019	US	Interview Focus group	6 participants 33 participants	Vaccines	Not specified	- Intercommunity Health Network Coordinated Care Organization - Corvallis Clinic Foundation - Community Health Centers of Benton and Linn Counties - Anonymous individuals
Gage-Bouchard et al. ³⁵	2019	US	Interview	40 participants	Childhood cancer	Facebook	- Supportive Care Research Grant from St Baldrick's Foundation - National Cancer Institute (NCI) grant P30CA016056
Garcia et al. ⁵⁷	2019	UK	Interview Survey	64 participants 21 participants	Feeding	Facebook YouTube	Absent
Gorman et al. ⁴⁶	2019	Scotland	Focus group	13 participants	Vaccines	Facebook Wikipedia	None declared
Hwang and Shah ²⁴	2019	US	Survey-secondary analysis	4174 participants	Vaccines	Facebook Twitter	Absent
Koskan et al. ⁴⁷	2019	US	Interview	26 participants	Vaccines	Facebook	Absent

Kulhas Celik et al. ²⁵	2019	Turkey	Survey	458 participants	Food allergies	Facebook	Absent
Moon et al. ⁴⁸	2019	US	Interview Focus group	28 participants	General information	Facebook	National Institute for Minority Health and Health Disparities 1R01MD007702
Peterlein et al. ²⁶	2019	Germany	Survey	519 participants	Orthopedics	Wikipedia Facebook YouTube Netdoktor.de Other forums Twitter Myspace	None declared
Pretorius et al. ⁶⁰	2019	US	Integrative review	12 papers	General support	Facebook YouTube	Absent
Zhao et al. ³⁴	2019	US	Network analysis	5 Facebook groups	Autism Spectrum Disorder	Facebook	Jiangsu Province Social Science Foundation (#19TQC005)
Baker and Yang ²⁷	2018	Australia	Survey	117 participants	General support	Facebook	Sigma Theta Tau, Gamma Omega Chapter at Virginia Commonwealth University
Lee ²⁸	2018	US	Survey	480 participants	General information	Facebook Instagram Forums YouTube Flickr Twitter	Absent
Price et al. ¹⁰	2018	Canada	Focus group e-interview	19 participants	General information	Forums Blogs Facebook	Bridge Funding from Canadian Institutes of Health Research (CIHR)
Rehman et al. ⁴⁹	2018	Canada	Content analysis	1700 tweets	Childhood cancer	Twitter	None declared
Gibson et al. ⁵⁸	2017	US	Interview Survey	6 participants 629 participants	Autism Spectrum Disorder	Facebook Twitter Pinterest Forums	None declared
Nicholl et al. ⁵⁹	2017	Ireland	Focus group Survey	8 participants 121 participants	Non-specific childhood disabilities	Facebook Twitter LinkedIn Blog	Saoirse Foundation
Walker et al. ²⁹	2017	US	Survey	165 participants	General information	Babycentre.com forum YouTube Facebook	St David's Center for Health Promotion and Disease Prevention Research in Underserved Population, School of Nursing, The University of Texas at Austin.
Kim et al. ⁵⁰	2016	US	Content analysis	29 social networking sites/ 131 posts	Premature infants	Blogs Facebook forums	None declared
Lupton ⁵¹	2016	Australia	Focus group	36 participants	General information	Pinterest Instagram Facebook YouTube	Personal research funds received from University of Canberra, Australia.

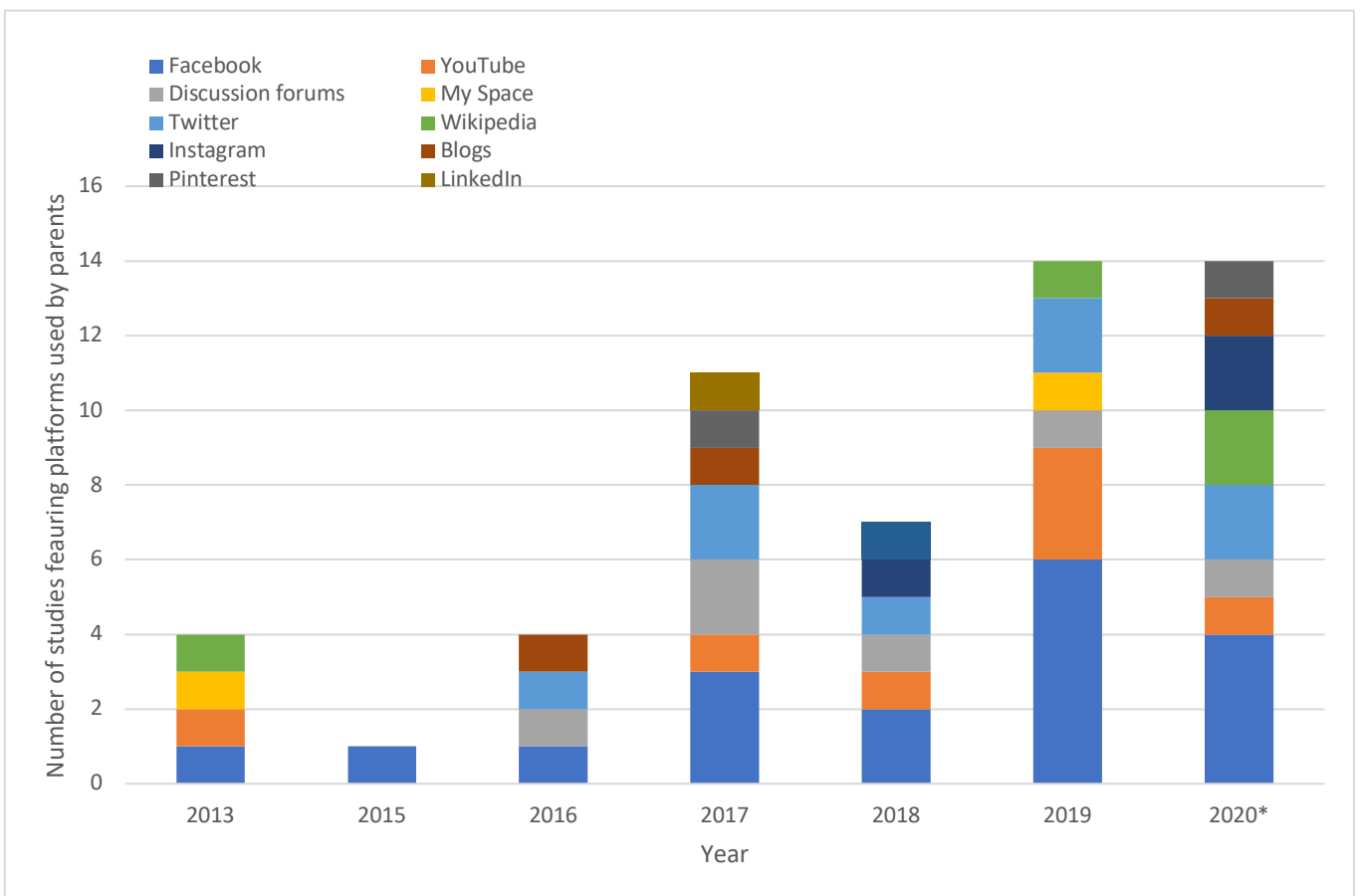
Orr et al. ³⁶	2016	Israel	Content analysis	7 social media platforms / 2289 Facebook comments	Vaccines	Facebook	- I-CORE Program of the Planning and Budgeting Committee, The Israel Science Foundation (1716/12) - Israel Science Foundation grant (1599/15).
Sharpe et al. ³⁰	2016	Canada	Survey	34 participants	Autism Spectrum Disorder Cerebral Palsy	Facebook Twitter Blogs Forums	- Stem Cell Network, Public Policy Impact grant: Stem cell therapies for neurodevelopmental disorders: Science, media and public opinion (13/5226 (PP68)) - NeuroDevNet, Inc.
Al-Daihani and Al-Ateeqi ³¹	2015	Kuwait	Survey	240 participants	Non-specific childhood disabilities	Not specified	Absent
Criss et al. ⁵²	2015	US	Focus group	49 participants	General information	YouTube Facebook babycentre.com forum	JWB: NIH grants - R01MD003963 - 3T32DK7477-30 S1 SC: - Predoctoral training grant from NIH award # 3R25CA057711 - Initiative to maximize Student Diversity Aware # GM055353-13 - Maternal and Child Health Bureau Award #T03MC07648
Holtz et al. ³²	2015	US	Survey	647 participants	Non-specific childhood disabilities	Facebook	None declared
Mohd Roffeei et al. ⁵³	2015	US	Content analysis	381 Facebook posts + 3256 Facebook comments	Autism Spectrum Disorder	Facebook	University of Malaya High Impact Research Grant (No. UM.C/625/1/HIR/MOHE /FCSIT/16/H-22001-00-B00016)
Appleton et al. ⁵⁴	2014	Australia	Content analysis	2 discussion forums/ 34 threads	Childhood obesity	Forums	None declared
Naftel et al. ³³	2013	US	Survey	300 participants	Hydrocephalus	Wikipedia Facebook YouTube Myspace	Absent
Cowie et al. ⁵⁵	2011	Australia	Content analysis	1614 posts/206 users on 1 discussion forum	Breastfeeding	ABA Forum	Absent

Figure 2: Number per year of scholarly papers featuring parents' use of social media for pediatric health information



* Jan – August 2020 only

Figure 3: Platforms represented in quantitative studies of parents' health information seeking (2013-2020)^{1,21-30,32-34,57-60}



*Jan-August 2020 only

Table 2: Context motivating parents' health information seeking on social media

Author	Year	Health concern/question	Function of information seeking on social media
Adekunle et al. ²¹	2020	Cleft palate	Post diagnosis information seeking
Bamashmous et al. ²²	2020	Dental trauma	Pre-consultation self-triage
Bradshaw et al. ³⁷	2020	Vaccination	Self-directed health decision making
Bryan et al. ¹	2020	Rare childhood conditions & special needs	Post diagnosis information
Clapton-Caputo et al. ³⁸	2020	Breastfeeding	Self-directed health care
Lebron et al. ⁴⁰	2020	Breastfeeding	Self-management- support seeking
Raspa et al. ⁵⁶	2020	Severe Combined Immune Disorder	Post diagnosis information seeking
Thorpe et al. ⁴²	2020	Vaccination	Self-directed health decision making
Wang & Lund ⁴³	2020	Costello Syndrome	Post diagnosis information and support
Deas et al. ⁴⁵	2019	Vaccination	Self-directed health decision making
Gage Bouchard et al. ³⁵	2019	Childhood cancer	Post diagnosis caregiving information
Garcia et al. ⁵⁷	2019	Complementary feeding	Self-directed health care
Gorman et al. ⁴⁶	2019	Vaccination	Self-directed health decision making
Hwang & Shah ²⁴	2019	Vaccination	Self-directed health decision making
Kulhas-Celik et al. ²⁵	2019	Food allergy	Pre-consultation self-triage
Moon et al. ⁴⁸	2019	General information	
Pretorius et al. ⁶⁰	2019	General information	
Zhao et al. ³⁴	2019	Autism Spectrum Disorder	Post diagnosis information and support
Baker & Yang ²⁷	2018	General information	
Lee ²⁸	2018	General information	
Price et al. ¹⁰	2018	General information	
Rehman et al. ⁴⁹	2018	Childhood cancer	Post diagnosis support and health promotion
Gibson et al. ⁵⁸	2017	Autism	Post diagnosis information and support
Nicholl et al. ⁵⁹	2017	Rare childhood conditions	Post diagnosis information and support
Kim et al. ⁵⁰	2016	Premature child in Neonatal Intensive Care Unit	Post diagnosis information and support
Lupton ⁵¹	2016	General information	
Al-Daihani & Al-Ateeqi ³¹	2015	General childhood disabilities	Post diagnosis information
Criss et al. ⁵²	2015	General information	

Holtz et al. ³²	2015	Vaccination	Self-directed health decision making
Mohd Roffeei et al. ⁵³	2015	Autism Spectrum Disorder	Post diagnosis information and support
Appleton et al. ⁵⁴	2014	Childhood obesity	Post diagnosis information and support
Naftel et al. ³³	2013	Hydrocephalus	Post diagnosis information and support
Cowie et al. ⁵⁵	2011	Breastfeeding	Self-directed health care

Appendices

Appendix 1: Database Search Strategies

Scopus search – 30 August 2020

("Social Media" OR Facebook OR Twitter OR YouTube OR Wechat OR Pinterest OR Instagram OR "online social networks" OR Reddit OR Whatsapp OR "Facebook messenger" OR Snapchat OR TikTok OR QQ OR QZone OR Sina Weibo OR Kuaishou) AND Health AND ((information OR consumer) W/3 (behavior#r* OR seeking OR engagement OR need*)) AND (Parent OR caregiv* OR guardian OR father OR mother OR carer)

Results: 113

Medline search – 30 August 2020

(Social media or facebook or Twitter or Youtube or Wechat or Pinterest or Instagram or "online social networks" or Reddit or WhatsApp or messenger or snapchat or tiktok or QQ or Qzone or "Sina Weibo" or Kuaishou).tw. or Social Media/ and Health.tw. or exp Health/ and (((information or consumer) adj3 (behavior?r* or seeking or engagement or need*)).tw. or Consumer Health Information/ or Information Seeking Behavior/) and consumer health information/ or information seeking and (parent* or carer* or caregive* or father* or mother* or guardian*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

Results: 28

EMBASE search – 30 August 2020

(Social media or facebook or Twitter or Youtube or Wechat or Pinterest or Instagram or "online social networks" or Reddit or WhatsApp or messenger or snapchat or tiktok or QQ or Qzone or "Sina Weibo" or Kuaishou).tw. or Social Media/ and Health.tw. or exp Health/ and ((information) ADJ3 (seek* OR evaluat* OR apprais* OR assess*)) and (parent* or carer* or caregive* or father* or mother* or guardian*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

Results: 48

CINAHL search – 30 August 2020

(TI facebook OR AB facebook) OR (TI twitter OR AB twitter) OR (TI YouTube OR AB YouTube) OR (TI WeChat OR AB WeChat) OR (TI instagram OR AB Instagram) OR (TI Pinterest OR AB Pinterest) OR (TI Reddit OR AB Reddit) OR (TI "online social networks" OR AB "online social networks") OR (MH "Social Media+") AND (TI health OR AB health) OR (MH "Health+") AND (((information OR consumer) ADJ3 (behavior?r* OR seeking OR engagement OR need*)).tw) OR (MH "Consumer health information") OR (MH "Information seeking") AND TX mother OR TX father OR TX guardian OR TX carer OR TX caregiver OR TX parent*

Results: 19

PUBMED (JMIR) search – 22 September 2020

"((((("health information") AND (((("J Med Internet Res"[jour])) AND (((parent*) OR (father*)) OR (mother*)) OR (care*))) AND (((("Web 2.0") OR ("social media"))",,,"health information"[All Fields] AND ("J Med Internet Res"[Journal] AND ("parent*"[All Fields] OR "father*"[All Fields] OR "mother*"[All Fields] OR "care*"[All Fields])) AND ("Web 2.0"[All Fields] OR "social media"[All Fields])"

Results: 294

Appendix 2: Final Data Extraction Tool

Participants	
Ages of parents	
Education level of parent	
Income/Socio-Economic Status of participants	
Participant description/ breakdown for study: Demographics (Discrete stats)	
Specific patient group? 1. Yes/No	
Specific Patient group? 2. Patient have a specific or diagnosed condition?	
Specific patient group? 3. Patient part of a minority? (race, disability, etc.)	
Concept	
Stage of information seeking: Diagnosis, general info seeking, first aid, seeking treatment etc.	
Condition/ health concern: as noted in study, including general information	
Stage of info seeking in regard to professional health care input: Post diagnosis/Pre Consultation/Self-management or Self-care	
Health literacy skills: Did the parent demonstrate any health literacy skills? eg. Did they anything to check the validity or accuracy of the information they found on social media? If so, what? What other information sources did they use?	
Motivations: Why are they using social media to source health information? Is it proactive (to decide if health care is needed?) or reactive (eg. after a diagnosis?)	
Ordinary use of social media (non-health) as reported in study	
Ordinary use of social media for health related issues	
Outcomes What was the result of their use of social media for health information? Was it positive or negative? (eg. did they take the information to their health care provider to discuss further? Or did they act on it without further input?)	
Perceived benefits of using social media for health information as per parent	
Perceived disadvantages of using social media for health information as per parent	
Percentage of sample that would like to receive health information on SM.	
Prevalence of SM use for health information as reported in study	
Type of participation on social media: posters, lurkers etc.	
Where health care providers fit: Patient expectations or desire for HCP input and provision of information	
Sentiment of parents regarding social media for health information: positive, neutral, negative	
Content analysis: themes	
Behaviours- What are their behaviours in regard to SM and health information? Are they in groups, part of a forum etc?	
Context	
Country in which the study conducted	
Data collection methods	
Method of recruitment of participants	
Social media platforms (central to study)	
Social media platforms mentioned in study	
Study design	
Aim of study	
Total number of participants/ valid responses	
Year of data collection	
Study	
Author of study	
Year of paper publication	
Paper title	
Journal of paper	
Study ID (Covidence)	
Email for corresponding author	
Years between data collection and publishing (guide to currency of study when published)	