

Original Paper

Digital Platform Uses for Help and Support Seeking of Parents With Children Affected by Disabilities: Scoping Review

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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. As a result, information (eg, 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 of platforms that are most frequently used or preferred among parents and caregivers of children 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 to 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, as well as the experiences made with using these platforms reported in the included studies; and (3) identify any privacy and ethical concerns emerging in the available literature in relation to the use of these platforms.

Methods: We conducted a scoping review of 5 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. The main ethical concerns for digital platform users included hampered access due to language barriers, privacy issues, and perceived suboptimal advice (eg, due to missing empathy of medical professionals). Older and non-college-educated individuals and 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 health care systems seem to be insufficient for satisfying knowledge and support needs through traditional channels.

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KEYWORDS

digital place; pediatric diagnoses; conditions; disability; neuromuscular; information and support seeking; online; social media; peer support; lived experience; parents; children; youth; review; scoping review; trauma; caregivers

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