**Title**: Navigating Misinformation: Parental Stress and Information-Seeking Behaviors in the Context of Autism Spectrum Disorder

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**Introduction**: The growth of social-media platforms has increased the amount of publicly available information on autism. Unfortunately, the accuracy and credibility of such content is varied. In a literature review of 32 studies on coverage of autism across YouTube, Twitter, and Facebook, seven (22%) identified misinformation regarding causes and cures for autism (Jawed, Graham, & Smith, 2023). A mixed-methods study exploring parent-health literacy revealed that parents access information about autism most frequently from specific websites (e.g., Autism Speaks), search engines (e.g., Google), and social-media sites (e.g., Instagram; Lindly et al., 2021). Further, existing literature indicates that higher parental satisfaction was associated with higher perceived collaboration with professionals, higher perceived helpfulness of received information, and lower parental stress (Moh & Magiati, 2012). However, little is known about parents' sense of competence and their understanding of autism, and how this may influence their stress levels. For this reason, the current study aims to investigate how parents’ perceptions of information quality relate to their stress levels and overall confidence in navigating autism-related information.

**Method**: The sample for this study consisted of parents (n=96) who reported having a child diagnosed with autism. Participants were administered an online Qualtrics survey that included the Health Information National Trends Survey (HINTS) and the Parent Stress Scale (PSS; Berry & Jones, 1995). The HINTS regularly collects nationally representative data about the United States public’s knowledge of, attitudes toward, and use of cancer- and health-related information (National Cancer Institute, 2022). Questions from the HINTS were adapted to specifically target information-seeking behaviours related to autism (Appendix A). Perceived difficulty distinguishing factual from inaccurate information on social media (“perceived discernment difficulty”) was measured by assessing agreement with the following statement: “I find it hard to tell whether health information on social media is true or false.” Respondents’ frustration with obtaining information about autism was measured by assessing agreement with the following statement: “You felt frustrated during your search for the information.” Response options for both of these items ranged from strongly agree (1) to strongly disagree (4) . Trust in healthcare providers was measured via the following item: “In general, how much would you trust information about autism from a doctor, psychologist, or other healthcare provider?” Response options ranged from not a lot (1) to a lot (4). Parent stress was operationalized using the PSS, an 18-item questionnaire used to measure the levels of stress experienced by caregivers, accounting for both the positive and negative aspects of parenting. Descriptive statistics were used to characterize the sample and results from the HINTS and PSS using frequencies with proportions and means with standard deviations, as appropriate.

**Results**: The majority of participants reported ever having looked for information on autism from any source (n = 94, 99%). More than three quarters of participants indicated that it took a lot of effort to get the information they needed (n = 96; M = 1.52, SD = 0.680), feeling frustrated during their search for information (n = 95, M = 1.80, SD = 0.723), concerned about the quality of information (n = 95; M = 1.59, SD = 0.55), and finding the information difficult to understand (n =95; M = 1.96, SD = 0.862). Additionally, physicians, psychologists, and other healthcare providers were rated the highest regarding trustworthiness of information about autism compared to family and friends, government health agencies, charitable organizations, religious organizations and leaders, and scientists. Current analyses will employ multiple regression to understand caregiver levels of stress as associated with information-seeking frustration, perceived discernment difficulty, and perceived comprehension of autism information. Additionally, we will examine the potential moderating role of “degree of trust in healthcare providers” as influencing the strength of the relationship between caregiver stress, information-seeking frustration, and perceived discernment difficulty.

**Discussion:** While parents are encouraged to ask questions and learn more about autism, they may easily become misinformed because of the prevalence of misinformation about ASD on social media and other web-based platforms. The current study reveals that while nearly all participants (99%) actively sought information about autism, yet a significant majority reported substantial effort and frustration in obtaining reliable resources. Concerns regarding the credibility and comprehensibility of information were prevalent, underscoring the necessity for improved quality in available resources. Additionally, healthcare providers were viewed as the most trustworthy sources of information, highlighting their crucial role in supporting parents. Yet, the accessibility of these professionals is often hindered by prohibitively long waitlists, sometimes spanning several months or even years (Kanne & Bishop, 2020). This limited access strains parents’ ability to secure timely interventions and reliable information, particularly as healthcare providers, who are overburdened by high caseloads, may lack the time to offer proactive, accessible resources (Malik-Soni et al., 2022). Additional results will be discussed relative to how information seeking influences caregiver stress and well-being, as well as in the context of methods for increasing the public’s accessibility to scientific autism-services information and health-literacy intervention programs.

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# APPENDIX A HEALTH INFORMATION NATIONAL TRENDS SURVEY – AUTISM ADAPTATION

1. Have you ever looked for information about autism\* from any source?
   1. Yes
   2. No
2. Based on the results of your most recent search for information about autism\*, how much do you agree or disagree with each of the following statements?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | *Strongly Agree* | *Somewhat Agree* | *Somewhat Disagree* | *Strongly Disagree* |
| It took a lot of effort to get the information you needed. |  |  |  |  |
| You felt frustrated during your search for the information. |  |  |  |  |
| You were concerned about the quality of the information. |  |  |  |  |
| The information you found was hard to understand. |  |  |  |  |

1. In general, how much would you trust information about autism\* from each of the following?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | *Not a lot* | *A little* | *Some* | *A lot* |
| A doctor, psychologist, or other healthcare provider |  |  |  |  |
| Family or friends |  |  |  |  |
|  | *Not a lot* | *A little* | *Some* | *A lot* |
| Government health agencies |  |  |  |  |
| Charitable organizations |  |  |  |  |
| Religious organizations and leaders |  |  |  |  |
| Scientists |  |  |  |  |

1. The following questions are about your communication with all of your child's doctors, nurses, educators, or other professionals you saw during the past 12 months. How often did they do each of the following?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | *Always* | *Usually* | *Sometimes* | *Never* |
| Give you the chance to ask all the autism\*\*\* related questions you had. |  |  |  |  |
| Give the attention you needed to your feelings and emotions. |  |  |  |  |
| Involve you in decisions about your child's\*\* care as much as you wanted. |  |  |  |  |
| Make sure you understood the things you needed to do to take care of your child's\*\* health. |  |  |  |  |
| Explain things in a way you could understand |  |  |  |  |
|  | *Always* | *Usually* | *Sometimes* | *Never* |
| Spend enough time with you |  |  |  |  |
| Help you deal with feelings of uncertainty about your health or healthcare |  |  |  |  |

1. How much do you agree or disagree with the following statements?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | *Strongly Agree* | *Somewhat Agree* | *Somewhat Disagree* | *Strongly Disagree* |
| I use information from social media to make decisions about my child's\*\* healthcare |  |  |  |  |
| I use information from social media in discussions with my child's\* healthcare provider |  |  |  |  |
| I find it hard to tell whether information on social media is true or false |  |  |  |  |
| Most of the people in my social media networks have the same views about Autism\* as me |  |  |  |  |

\*”autism” adapted from “cancer”

\*\* “your/my child” adapted from “you”

\*\*\* “autism” adapted from “cancer”