




RESEARCH ARTICLE

Health care satisfaction and medical literacy habits among caregivers of individuals with Down syndrome

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Abstract

Patients with Down syndrome have significant specialized health care needs. Our objective was to understand the needs, satisfaction, and online habits of caregivers as they care for persons with Down syndrome. A mixed-method survey was distributed through REDCap from April 2022 to June 2022 in the United States; a Spanish-translated version was distributed through SurveyMonkey from August 2022 to March 2023 in Mexico. We received 290 completed responses from the United States and 58 from caregivers in Mexico. We found that current health care options are not meeting the needs of many individuals with DS in both the United States (39.7%) and Mexico (46.6%). Caregivers expressed frustrations with the inaccessibility and inapplicability of health care information. In particular, they often found the volume of information overwhelming, given their limited medical background. Additionally, health care recommendations were not customized and lacked practical recommendations. Most caregivers in both the United States (72.1%) and Mexico (82.8%) believe it is not easy to find answers to medical questions about their loved ones with DS. Online platforms with customized, specific health information related to DS could offer innovative solutions to these unmet needs for families and primary care providers.

KEYWORDS

caregiver, Down syndrome, healthcare, medical literacy, perspectives, trisomy 21

1 | INTRODUCTION

Down syndrome (DS) is the most common chromosomal cause of intellectual disability among live births (Besser et al., 2007; Hook et al., 1981). The estimated prevalence of DS is 1/792 newborns in the United States (de Graaf et al., 2015). In Mexico, the latest reported prevalence ranged from 3.73 to 11.37 cases per 10,000 births from 2008 to 2011 (Sierra Romero et al., 2014). With the average lifespan of people with DS now approaching 60 years (Antonarakis et al., 2020; de Graaf et al., 2015), researchers estimate that there are about 217,000 people with DS in the United States,

while for Mexico the latest estimate was 28,680 cases in 2019 (Global Burden of Disease, 2019).

Patients with DS are prone to multiple chronic conditions and developmental delays. Caregivers of individuals with DS often need support as they navigate these co-occurring diagnoses (Lee et al., 2021). In both the United States and Mexico, families with children having DS face significant economic and caregiving challenges (Adelman et al., 2014; Martínez-Valverde et al., 2019; Sáenz Vela et al., 2021). To set the context for these challenges, we looked at the trends in healthcare spending in the United States and Mexico for the general population. In 2019, Mexico spent USD 48.73, by person

annually in prepaid private spending, USD 243.48 in out-of-pocket spending, and USD 287.53 in government health spending. By comparison, in 2019, the US spent USD 4386 per person annually in prepaid private spending, USD 1310, per person in out-of-pocket spending, and USD 5887 in government health spending (Micah et al., 2023). DS Specialty clinics can provide medical expertise and caretaking guidelines to support families of loved ones with DS. In recent years, the Mexican government has made commendable efforts in enhancing access to health services for individuals with DS (Lavin et al., 2020). At DS specialty care clinics in the United States and Mexico, both physical and virtual, families can receive support from multidisciplinary teams to stay up to date with published health care guidelines (Arizmendi et al., 2021; Bull et al., 2022; Chung et al., 2021; Smith, 2001). While the positive impact of such specialty clinics is known (Chung et al., 2021; Daniels et al., 2022; Hickey et al., 2023; Skotko et al., 2013), only ~5% of the eligible population in the United States can access these clinics, due, in part, to their geographic inaccessibility (Joslyn et al., 2020; Santoro et al., 2021). While studies exist that describe perceived barriers to specialty care in the United States (Chung et al., 2023; King et al., 2022; Krell et al., 2023) and Mexico (Corona-Rivera et al., 2019; Martínez-Valverde et al., 2019), few comparative studies exist.

Given the difficulties of accessing specialty care in the United States and Mexico, we sought to better understand the role of the internet and other online resources in providing consumer information specifically related to the health care needs of individuals with DS in the United States and Mexico. Previous research explored caregivers' use of online health care resources when caring for patients with cancer (Coleman et al., 2005; James et al., 2007), stroke (Pierce et al., 2009), and advanced age (Kernisan et al., 2010). In these cases, many patients accessed specialized information from afar related to information on treatments, prognosis, and financial resources. One important takeaway to online medical literacy across these cases was that facilitated access to information on the internet by health professionals was effective at broadening access to this medium (James et al., 2007). By contrast, the medical literacy habits of caregivers in the context of DS has not been well-studied. Studying caregivers' online medical literacy habits about DS could inform future digital resources.

The purpose of this study is to build on this previous literature to (1) better understand unmet needs for caregivers in the United States and Mexico who have family members with DS; (2) understand frustrations and attitudes of caregiver experiences in the United States and Mexico; and (3) identify how these unmet needs and frustrations inform the medical literacy habits of caregivers in the United States and Mexico. This information could then be used to synthesize culturally appropriate recommendations to improve health care experiences in both cultures.

2 | MATERIALS AND METHODS

2.1 | Editorial policies and ethical considerations

The research plan was approved by the Simpson College Institutional Review Board. The study consisted of a voluntary electronic survey

sent to caregivers of individuals with DS in the United States and Mexico. There was no compensation for participation in this survey, and informed consent was included at the start. This survey did not require participants to enter any identifiable information but included open-ended questions. Participants could elect to provide their e-mail addresses at the conclusion of the survey.

2.2 | Design

A novel survey was developed by a team of experts consisting of a Down syndrome specialist, a specialist in marketing research, and a mathematician. The instrument was developed in consultation with the clinical and research teams from the Down Syndrome Program and the Laboratory of Computer Science at Massachusetts General Hospital (MGH).

From January to March 2022, the team reviewed and iterated the survey; optimizing the survey to ensure it addressed the research objectives and that it contained questions caregivers could answer without confusion. While designing the survey tool, the team started with the study objectives and then developed questions to address each objective. The team members pulled from their collective experiences from previous DS and health-related surveys, market research, and statistics to develop a robust survey tool. Once the team had a survey, they felt met the objectives and required about 10 min to complete, they piloted the survey among caregivers of loved ones with DS and incorporated their input. The team was careful to balance length and quality of the survey tool. Importantly, the final survey contained several questions addressing each of the survey objectives across the four survey sections. The Flesch Reading Ease is 62.03 with a Flesch-Kincaid Grade Level of 5.48.

The survey opened with an initial screening question to verify that respondents were caregivers of an individual with DS. The survey consisted of close and open-ended questions and had four parts: (1) questions about caregivers' needs and how well current offerings deliver these needs, (2) questions designed to gauge how involved the caregiver is in the care of their loved one with DS, (3) questions about how caregivers prefer to receive health-related information and how easy it is for them to find the answers they are searching for, and (4) demographics. In each section there were a variety of questions, including ordinal, closed- and open-ended questions (See Supplementary Materials, sections 12–13, for surveys).

2.3 | Distribution

2.3.1 | United States

The survey was distributed and managed using REDCap electronic data capture tools hosted at Vanderbilt University and licensed to Simpson College (Harris et al., 2009, 2019). REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data capture; (2) audit trails for

tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for data integration and interoperability with external sources. We fielded the survey for approximately 2 months (April 27, 2022, to June 30, 2022) to convenience samples. We distributed the survey through public social media postings by Dr. Brian Skotko (~12,000 people), the MGH Down Syndrome Program social media pages (~5000 people), Lumind IDSC Down Syndrome Foundation (~13,000 people), and Massachusetts Down Syndrome Congress (~9000 people). A research newsletter was also sent out to MGH DS clinic contacts (~1500 people) as well as those in the clinic that expressed interest in research in the past. E-mails with recruitment language were also sent to a variety of DS non-profit organizations in all 50 states including Gigi's Playhouses, Special Olympics, and national DS organizations. We also distributed the survey through DS-Connect, a US based contact database housed by the National Institutes of Health. These organizations were asked to invite their constituents and explain the objectives and benefits of the survey for people with DS.

2.3.2 | Mexico

The survey was first translated into Spanish by a team member (K.K.E. O.) with English certifications from Cambridge University and Test of English as a Foreign Language (TOEFL). To assess the translation according to cultural and lifestyle differences between the United States and Mexico, we adapted the questions about medical services in the United States that are not in Mexico and added some questions about the economic situation in Mexico, keeping both versions of the survey as similar as possible. The survey was generally an exact translation for most of the questions. Novel questions were also included to evaluate the socioeconomic level according to the index created by the Mexican Association of Market Intelligence and Opinion Agencies for the Mexican population, replacing the income question in dollars from the survey for the US. In questions about research available to caregivers, the options were adapted to the health care institutions in Mexico. To validate the survey, we used the translation and back-translation methodology, which has had good results in psychological sciences and health research (Klotz et al., 2023; Ozolins et al., 2020). Following best practices in this methodology, the translators were part of the research group of investigation, with translation guidance and advice integrated into all stages of the research design (Ozolins et al., 2020). The final version of the survey was uploaded to Survey Monkey (www.surveymonkey.com), an online data collection and management system that provides immediate tracking and analysis. The survey was electronically available from August 2022 to March 2023. The sample collected from the survey responses was a convenience sample. Organizations in Mexico focusing on DS were invited to participate through phone calls, e-mails, or messages using the contact information on their websites. These organizations were asked to invite their population and explain the objectives and benefits of the survey for people with DS; each organization was

encouraged to share the survey in their public WhatsApp groups, Facebook, and other social media platforms.

2.4 | Study participants

Participants were required to be caregivers of loved ones with DS in the United States or Mexico. An initial screening question asked respondents to choose from a list of medical conditions that applied to their loved ones. If DS was not selected, the participant was not able to advance to the survey.

2.5 | Data analysis

We performed a mixed methods analysis of all complete survey responses. Survey responses without all questions answered were excluded from analysis, and the number of participants completing survey questions are reported where appropriate.

2.5.1 | Quantitative analyses

We used RStudio version 4.2.2 (2023) for all data cleaning and quantitative statistical analyses. Means and percentages were used to summarize demographics and closed-response questions. We used a Pearson χ^2 test with Yates' continuity correction to compare responses to close-ended questions. For a comparison of results involving ordinal data, we used the nonparametric Mann-Whitney *U*-test for independent samples. All reported statistical results are based on two-tailed tests and significance levels of $p < 0.05$. Subgroup analyses were performed for the US respondents: (1) caregivers of individuals with DS aged ≤ 21 years versus caregivers of individuals with DS aged > 21 years; (2) caregivers who indicated on the survey that their needs were not met versus caregivers who indicated on the survey that their needs were met; (3) caregivers whose annual household income was self-reported as $> \$75,000$ versus caregivers whose annual household income was self-reported as $\leq \$75,000$; and (4) caregivers who lived in the Northeast or Midwest versus caregivers who lived in the South, West, or Puerto Rico. The threshold of 21 years for the first subgroup was determined to be consistent with the recommendations in clinical guidelines (Bull et al., 2022; Tsou et al., 2020). The cut-off of \$75,000 in the second subgroup was determined based on the median household income of \$74,580 in the United States in 2022 (Census.gov). These geographic divisions were based on high and low access, as modeled by Joslyn et al. (2020).

Univariate logistic regression models were used to assess the associations between survey items reflecting caregivers' experiences obtaining health care for their loved ones with DS. The three dependent variables were (1) unmet health care needs; (2) needed help with caregiving; and (3) difficulty finding answers to health care questions. Dependent variables were defined by dichotomizing Likert-scale items to reflect greater versus lesser difficulty with a given aspect of

caregiving. The independent variables included demographics, caregiver frustrations, important health care resources for caregivers, sources of information, and important endorsements. Estimates of the odds ratio (OR) from each model reflect the relative likelihood (odds) of having greater difficulty with caregiving in one group compared to another, for example, the likelihood that a white caregiver has difficulty with caregiving divided by the likelihood that non-white caregiver has difficulty with caregiving. ORs are presented with 95% confidence intervals and *p* values indicating whether the OR differs significantly from one, since an OR of one indicates no difference in between the groups. Separate models were used to assess associations in the United States and Mexico survey data.

2.5.2 | Qualitative analyses

For the qualitative data, we analyzed the open-ended survey responses from the United States and Mexico separately. The open-ended responses were first translated from Spanish to English. We read through all 290 responses. We used a grounded theory approach (Martin, 1986; Strauss & Corbin, 1994) to identify common themes arising from the responses, such as general categories such as “location,” “care provider,” and “services.” For responses from the United States, each category was then divided into specific issues such as “mental health services,” “therapies (e.g., physical therapy, occupational therapy, speech therapy),” and “adult DS care.” From there, we developed a coding scheme. Two independent researchers then used the scheme to assess a randomized sample of the 290 responses. Any disagreements were discussed and resolved through consensus. Once the coding guide was complete, we condensed the codes into themes related to the research questions (Merriam & Tisdell, 2015), keeping any theme with a response rate of 5% or higher. Throughout this process, the researchers reviewed all emerging categories and themes. The quotations reported in this manuscript are representative of the themes from our coding guide, as determined by the researchers through extensive discussion. The themes regarding the caregivers' experiences can be found in Tables S1 and S2a,b.

3 | RESULTS

3.1 | Participants

3.1.1 | United States

From April to June 2022, survey responses from 290 families of individuals with DS across 41 states and Puerto Rico were received from the United States (Table 1). A significant majority of respondents were mothers of individuals with DS. Most respondents self-identified as white (91.4%) and had a child under 21 years (67.6%). The observed race disparity is due to the nature of convenience sampling and the recruitment partner-organizations having largely white membership.

TABLE 1 Demographic details of the 290 families in the United States and 58 families in Mexico of individuals with Down syndrome who responded to our 2022 survey on their digital healthcare experiences.

	United States (n = 290) % of total	Mexico (n = 58) % of total
Race of individual with DS		
White	91.4%	55.2%
Black	5.9%	0.0%
Other	4.1%	27.6%
Native American	1.7%	6.9%
Prefer not to answer	1.0%	19.0%
Pacific Islander	0.0%	0.0%
Ethnicity of individuals of DS		
Not Hispanic	91.4%	1.7%
Hispanic	7.9%	91.4%
Prefer not to answer	1.7%	6.9%
Household annual income (United States)		
<\$25,000	5.3%	
\$25,001–\$50,000	13.3%	
\$50,001–\$75,000	11.0%	
\$75,001–\$150,000	32.3%	
\$150,001–\$210,000	13.3%	
>\$210,000	10.3%	
Highest level of education (Mexico)		
None/Primary school		3.0%
Secondary school		6.9%
Business/Tech school		8.6%
High school		15.5%
Bachelor's degree		37.9%
Master's degree		17.2%
Age of individual with DS		
Youth (≤ 21)	67.6%	93.1%
Adult (> 21)	32.5%	6.9%
Insurance type		
Both	39.2%	19.0%
Public	32.7%	50.0%
Private	26.6%	10.3%
Neither	1.5%	20.9%
Region (US)		
Midwest	5.3%	
South	13.3%	
Northeast	11.0%	
West	32.3%	
None	13.3%	
Biological sex of individual with DS		
Male	52.8%	51.7%
Female	47.2%	48.3%

(Continues)

TABLE 1 (Continued)

	United States (n = 290) % of total	Mexico (n = 58) % of total
Relationship to individual with DS		
Biological mother	90.3%	89.66%
Step-mother	0.3%	0.0%
Foster or adopted mother		
Biological father	2.8%	8.62%
Step-father		
Foster or adopted father		
Biological brother		
Step- or half-brother		
Biological sister	1.7%	1.72%
Step- or half-sister		
Other		

Most respondents self-reported an average household income of \$75,001–\$150,000, and 66.2% of caregivers indicated they had private insurance coverage for their loved ones with DS. All respondents who completed the US survey completed it in English.

3.1.2 | Mexico

From August 2022 to March 2023, survey responses from 58 families of individuals with DS were received in Mexico (Table 1). Most respondents were mothers. All respondents self-identified as Hispanic, and 55.2% identified as white. Most families who responded had a child under 21 years (93.1%). Some families (20.9%) indicated that they did not have either public or private insurance. According to the Mexican instrument for the evaluation of socioeconomic level included in the survey, which classifies households into seven classes, 36.5% of families were in level A/B, 25% C+, 9.6% level C, 11.5% level C-, 11.5% level D+, 5.8% level D, and 0% level E. In this classification, from level C+ downwards, more than 37% of income is spent on food, and most heads of household have a high school education or less. All respondents of the Mexico survey completed it in Spanish.

3.2 | Caregivers' unmet needs

Many caregivers in the United States (39.6%) and Mexico (46.6%) indicated that the needs of their loved one with DS were not fully met (no significant difference between United States and Mexico, $p = 0.07$; Table S3). In the United States, this was more often the case for families with lower incomes (significant difference between high-income and low-income caregivers in the United States, $p < 0.001$;

Table S4). Families with public insurance or no insurance were 79% more likely to have unmet needs than families with private insurances ($p < 0.01$; Table S8). 10.7% of caregivers in the United States and 34.5% in Mexico responded that they could “really use help on multiple fronts” in caring for their child (significant difference between United States and Mexico, $p < 0.001$; Table S3). Demographic variables were not predictive for those in this category in the United States (Table S8). In Mexico, families with public or no insurance were 487% more likely to need help on multiple fronts than those with private insurance ($p = 0.03$; Table S9).

Regardless of insurance coverage or income, many caregivers were concerned that they did not have access to the best medical professionals (46.2% in the United States, 87.9% in Mexico, $p < 0.001$). Additionally, caregivers felt that their loved one may not be receiving care that is in full adherence to DS medical guidelines (42.8% in the United States, 65.6% in Mexico, $p < 0.01$), more so among caregivers in the United States who have children with DS ages ≤ 21 years versus caregivers in the United States who have older adults with DS (significant difference between caregivers of youth and caregivers of adults in the United States, $p = 0.01$; Table S5). Many respondents also felt that primary care physicians (PCPs) might be missing something important (42.1% in the United States, 53.4% in Mexico, $p = 0.15$), and that medical care was not affordable (16.2% in the United States, 72.4% in Mexico, $p < 0.001$; Figure 1). Participants in the United States who had children ≤ 21 years old were more likely to feel that they did not have sufficient time to juggle all of the medical aspects (significant difference between caregivers of youth and caregivers of adults in the United States, $p = 0.01$), whereas caregivers in the United States who had children > 21 years were more likely to wish that they had access to the best medical professionals (significant difference between caregivers of youth and caregivers of adults in the United States, $p = 0.02$; Table S5). In the United States, in comparison to caregivers who felt that health care options were sufficient, respondents who felt that health care options were not meeting the needs of their child were more likely to wonder (a) if their child was receiving care that was in full adherence to the DS health care screening guidelines (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p = 0.01$), including lab work (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.001$); (b) whether the PCP might be missing something important (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.01$); and (c) whether the person with DS might have co-occurring conditions (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient < 0.01 ; Table S6). Respondents who had lower incomes were also more likely to be concerned about having sufficient time to juggle all of the medical appointments (significant difference between

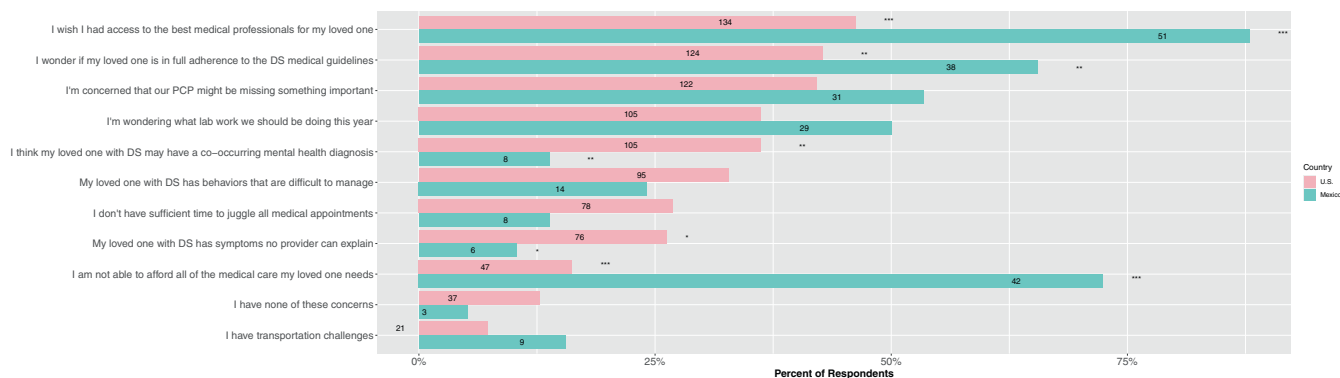


FIGURE 1 Caregiver responses to “Which of the following are concerns you currently have about caring for your loved one with Down syndrome? Check ALL that apply.” Numbers within bars represent the number of respondents choosing this option. DS, Down syndrome; PCP, primary care providers. Statistical differences between United States and Mexico: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

high-income and low-income caregivers in the United States, $p < 0.01$; Table S4). There were no major regional differences in the United States (Table S7).

The open-ended responses supported these findings (Supplemental Materials Tables S1 and S2a,b). Participants reported concern with expertise from medical care providers (40.6% in the United States, 12.1% in Mexico, $p < 0.001$), availability of services (27.3% in the United States, 29.3% in Mexico, $p = 0.76$), cost to access services (24.7% in the United States, 31.0% in Mexico, $p = 0.32$), and location of facilities (18.5% in the United States, 13.8% in Mexico, $p = 0.40$). Survey participants in the United States indicated that it was difficult to be a caregiver of a loved one with DS (9.2%). This theme was not prevalent in participant responses from Mexico. Similarly, the need for more resources dedicated to education and inclusion was a theme in Mexico (10.3%), but not in the United States.

One caregiver in the United States further commented: “Current options only include seeing physicians who are not specifically trained to care for people with Down syndrome. It would be optimal to see physicians that are aware of and compliant with current protocol and known differences of people with DS.” A caregiver in Mexico corroborated: “Basically, [individuals with DS] are taken more into account for activities and preferential aspects in some places. We still have a long way to go in terms of more accessible specialties” (See Tables S1 and S2a,b for more responses).

3.3 | Caregivers' frustrations and attitudes

We found that many caregivers are concerned that they do not have access to the best medical professionals when caring for their loved one with DS. Therefore, these participants search for answers to their medical questions on their own. Caregivers reported that the health-related information found through their search process was often inapplicable or inaccessible (Figure 2). Caregivers were frustrated that:

1. there was too much information, scattered all over the internet (54.1% in the United States, 39.7% in Mexico, $p = 0.06$), and more

so for caregivers in the United States who had children 21 years of age or younger (Table S5);

2. because they do not have medical training, they may be overlooking treatments or testing their child needs (45.5% in the United States, 53.4% in Mexico, $p = 0.34$);
3. that the information was too generic for their loved one's specific needs (45.5% in the United States, 34.5% in Mexico, $p = 0.16$); that the information did not answer their specific questions (40.0% in the United States, 29.3% in Mexico, $p = 0.17$);
4. and that they could not find practical recommendations that told them exactly what to do, why, and when (39.7% in both the United States and Mexico, $p = 1.00$).

In the United States, caregivers who felt that health care options were not meeting the needs of their child were more likely to express concern that they were overlooking or missing something (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.01$), that the information was too generic (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.05$), did not answer specific questions (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.01$), and not practical (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.01$) in comparison to caregivers who felt that health care options were sufficient (Table S6). In Mexico, respondents with no insurance or public insurance were 390% more likely to report having difficulty finding accurate medical information than families with private insurance (significant difference between caregivers with no insurance or public insurance compared to caregivers with private insurance in Mexico, $p = 0.025$; Table S9). One caregiver in the United States summed up this process: “The information and services are scattered over multiple platforms,

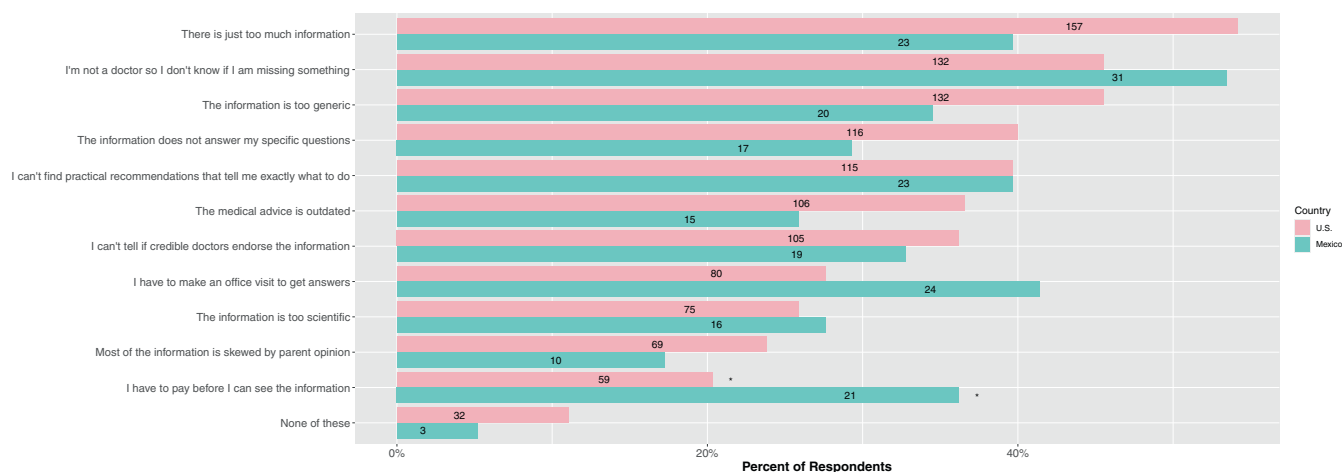


FIGURE 2 Caregiver responses to “What frustrations do you encounter when you go to find answers to medical questions you have about caring for your loved one with Down syndrome? Check ALL that apply.” Numbers within bars represent the number of respondents choosing this option. Statistical differences between United States and Mexico: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

sources, and providers. A portal to pull it all together would be SO helpful” (for similar themes, see Table S1). Caregivers who had children ≤ 21 years were more likely than caregivers who had older children to feel that the online information is skewed by parent opinion rather than by medical facts (significant difference between caregivers of youth and caregivers of adults in the United States, $p < 0.001$) or was outdated (significant difference between caregivers of youth and caregivers of adults in the United States, $p < 0.01$; Table S5).

Many respondents felt an emotional burden regarding their perceived need to play the role of specialist in lieu of access to expert care. The majority of caregivers agreed that they felt that they had to be the keeper of and expert on all the health information (92.1% in the United States, 89.6% in Mexico, $p = 0.03$); that it was a continual journey with new challenges and questions that needed to be addressed (86.6% in the United States, 98.3% in Mexico, $p < 0.001$); and they wondered if they could do more (86.2% in the United States, 94.8% in Mexico, $p = 0.05$; Figure 3), especially so for respondents in the United States who have children with DS ≤ 21 years versus those with older children (significant difference between caregivers of youth and caregivers of adults in the United States, $p = 0.02$). Caregivers in the United States who have children with unmet medical needs were more likely to feel alone (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.001$) and say that thinking about health care would “bring them to tears,” (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.001$) in comparison to caregivers whose children had sufficiently met medical needs (Table S6). They were also more likely to respond that they had to be the keeper of an expert on health information (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to

those who felt that the options were not sufficient, $p < 0.001$) and wondered if they should be doing more (significant difference between caregivers in the United States who indicated their loved one's health care needs were met compared to those who felt that the options were not sufficient, $p < 0.001$; Table S6). One caregiver from the United States indicated, “I'm clearly the expert which is exhausting” (For additional responses, see Table S1).

Statistically, more caregivers in Mexico (89.6%) than in the United States (65.8%) agreed that they wanted an online source that they could trust (significant difference between the United States and Mexico, $p < 0.001$). Additionally, more caregivers in Mexico (96.5%) than in the United States (69.3%) agreed that they enjoyed helping their loved one with DS with their health care needs (significant difference between the United States and Mexico, $p < 0.001$; Table S3).

3.4 | Caregivers' information search process

Participants were asked about the ease of finding answers to their medical questions concerning their loved ones with DS. Most caregivers described that finding information about DS was difficult, with respondents from Mexico (82.8%) endorsing this significantly more than those in the United States (72.1%) ($p < 0.01$; See Table S3 for analyses and Figure S1 for specific itemization of important and difficult resources to attain.) In the United States, demographic variables did not predict which participants had more difficulty in finding answers (Table S8). Caregivers also indicated these sentiments in their open-ended responses. One caregiver in Mexico said, “The obstacles that the public health systems. ... put in the way of your care. It is very difficult, slow and [there are] too many procedures to be able to have a test or to see a specialist.” A caregiver in the United States said, “The system is confusing, parents are often left to their own devices to do research and determine the best options for their child, and there are gaps in services especially when a child is older into

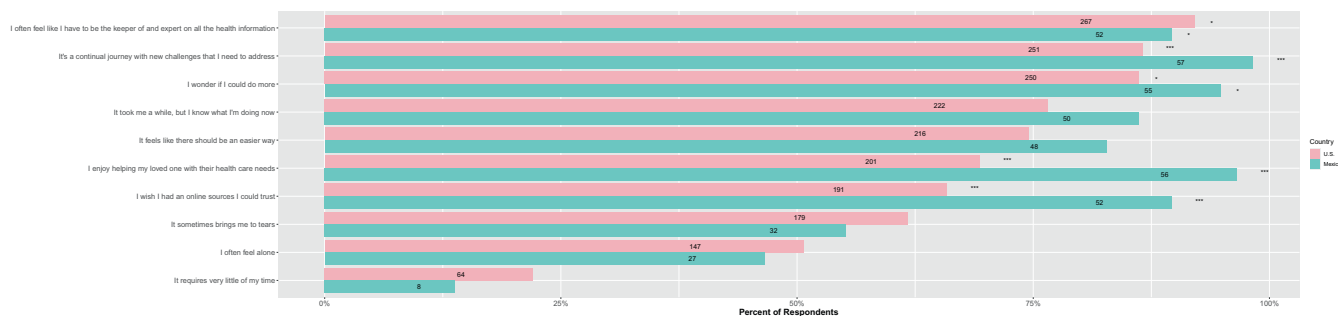


FIGURE 3 Caregiver responses to “When thinking about the HEALTH CARE NEEDS for your loved one with Down syndrome, how much do you agree with the following statements?” Numbers within bars represent the number of respondents choosing “Strongly agree” or “Agree.” Statistical differences between United States and Mexico: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

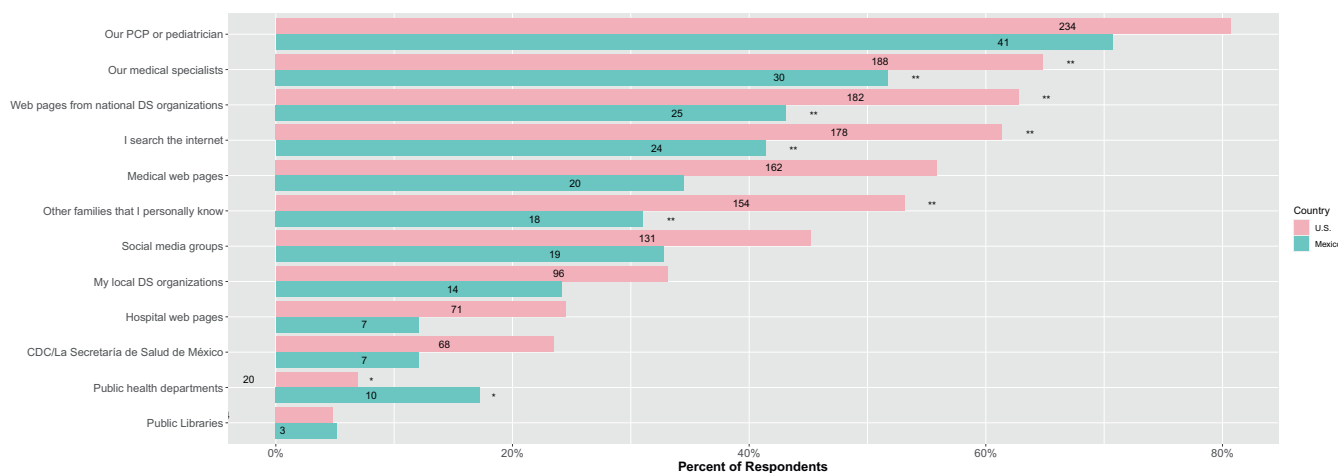


FIGURE 4 Caregiver responses to “Which of the following are places where you go to find answers to medical questions you have about caring for your loved one with Down syndrome? Select ALL that apply.” Numbers within bars represent the number of respondents choosing this option. DS, Down syndrome; PCP, primary care providers. Statistical differences between United States and Mexico: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

adolescence and young adulthood.” (For additional responses, see Tables S1 and S2a,b).

Participants were asked about the resources they used to find DS-related health information (Figure 4). Most respondents in both the United States and Mexico preferred consulting their primary care provider/pediatrician (80.7% in United States, 70.7% in Mexico, $p = 0.13$) or medical specialists (64.8% in United States, 51.7% in Mexico, $p = 0.08$). Participants also used the internet to find DS-related health information, including web pages associated with national DS organizations (62.8% in the United States, 43.1% in Mexico, $p < 0.01$), search engines including Google and Bing (61.4% in the United States, 41.4% in Mexico, $p < 0.01$), medical web pages (55.9% in the United States, 34.5% in Mexico, $p < 0.01$), social media such as Facebook, Twitter, and so forth (45.2% in the United States, 32.8% in Mexico, $p = 0.11$), local DS organizations (33.1% in the United States, 24.1% in Mexico, $p = 0.24$), and hospital web pages (24.5% in the United States, 12.1% in Mexico, $p < 0.01$). In the United States, caregivers who have children ≤ 21 years were more

likely to turn to primary care providers (significant difference between caregivers of youth and caregivers of adults in the United States, $p = 0.02$), hospital web pages (significant difference between caregivers of youth and caregivers of adults in the United States, $p < 0.001$), and social media groups (significant difference between caregivers of youth and caregivers of adults in the United States, $p < 0.001$) than their counterparts with older children (Table S3).

Beyond the internet, 53.1% of caregivers in the United States indicated that they sought advice from families that they knew, while only 31.0% of caregivers in Mexico used this resource (significant difference between United States and Mexico, $p < 0.01$). In Mexico, 17.2% of caregivers utilized public health departments to answer their health-related questions on DS, while only 6.9% of their counterparts in the United States utilized this resource (significant difference between United States and Mexico, $p = 0.02$).

We also asked respondents to indicate which items were important to them when seeking answers to medical questions about their loved one with DS (Figure 5). In both countries, caregivers found it

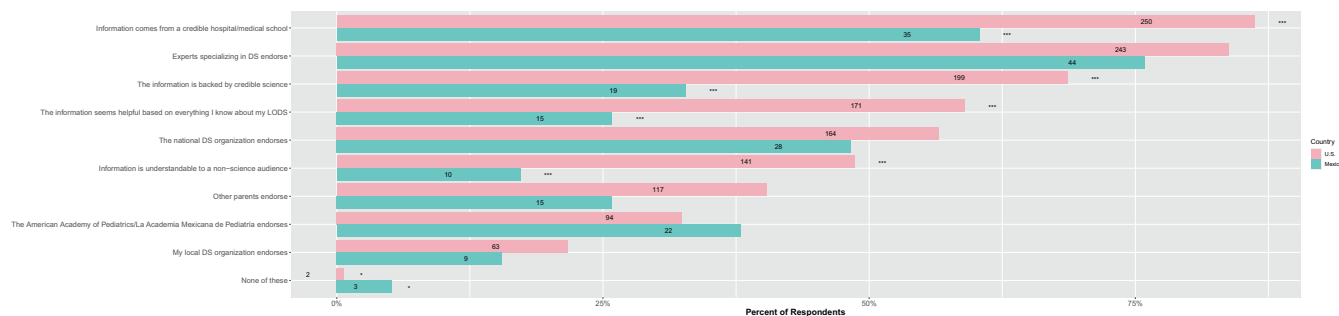


FIGURE 5 Caregiver responses to “Which of the following items are important to you when seeking answers to medical questions about your loved one with Down syndrome? Select ALL that apply.” Numbers within bars represent the number of respondents choosing this option. DS, Down syndrome; LODS, loved one with Down syndrome. Statistical differences between United States and Mexico: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

important that the information came from a credible hospital or medical school (86.2% in the United States, 60.3% in Mexico, $p < 0.001$), that experts specializing in DS endorsed the information (83.8% in the United States, 75.9% in Mexico, $p = 0.21$), and that the information be backed by credible science (68.6% in the United States, 32.8% in Mexico, $p < 0.001$). In the United States, caregivers who have children ≤ 21 years were more likely to value information from credible hospitals and medical schools (significant difference between caregivers of youth and caregivers of adults in the United States, $p = 0.04$) and value information that was understandable to a non-scientific audience (significant difference between caregivers of youth and caregivers of adults in the United States, $p < 0.001$; Table S5).

We further asked caregivers about their out-of-pocket health expenses for their loved ones with DS. We defined “out-of-pocket” expenses as extra activities (e.g., therapies or health-related items) that they had chosen to invest in for their loved one's wellbeing. In the United States, 75.5% of caregivers indicated that they used their own money to cover out-of-pocket expenses, while 96.6% of caregivers in Mexico indicated that they had this expense (significant difference between United States and Mexico, $p < 0.001$). In the United States this was more often the case for respondents who had children ≤ 21 years than for respondents with older children (significant difference between caregivers of youth and caregivers of adults in the United States, $p < 0.001$; Table S5) (See Figures S4–S5 for an itemization of specific out-of-pocket expenses). Caregivers indicated that care was often expensive. A caregiver in the United States reported, “I don't like that only very few providers offered physical therapy, occupational therapy and speech therapy...We had to go to out of network providers. It got expensive and really work intensive to recoup some of the expenses from our private health Insurance. [Medicaid] was not an option.” A caregiver in Mexico stated, “The options offered in medicine, treatments and therapies are very expensive” (For additional responses, see Tables S1 and S2a,b).

4 | DISCUSSION

Many families in the United States and Mexico felt that current health care options were not meeting the needs of their loved ones

with DS. This was apparent across all subgroups but particularly for families of lower income in the United States and those without private insurance in Mexico. A majority of families in both countries were concerned that they did not have access to the best medical professionals. Most caregivers reported that searching for health-related information about DS was difficult. They often turned to online sources, which they sometimes found too generic and often scattered throughout the internet. Many caregivers described the burden of having to “play doctor,” and some respondents felt that they might be missing something important for their loved one with DS. The most valued online resources were from medical institutions, backed by credible science, with endorsements from experts specializing in DS. However, there is no way of knowing the quality or empiricism of the information caregivers are finding on the internet.

Our findings are consistent with previous studies. Researchers have found that caregivers of loved ones with DS prioritize health maintenance, which includes establishing patient care and preventative measures (Cabrera et al., 2022). However, caregivers of patients with chronic illness are untrained and often feel ill-prepared to provide adequate healthcare to their loved ones. In these situations, the caregivers become the expert for their loved one, but struggle to communicate effectively with the medical field (Balling & McCubbin, 2001; Bhat et al., 2023). This is similar to our findings where caregivers felt the need to “play the doctor.”

Researchers found that caregivers of children with DS felt that social media was accessible and beneficial for social support, but that caregivers would benefit from more services provided by local or national DS organizations (Hart & Neil, 2021). Previous studies on spinal cord injuries found that caregivers found the internet a valuable resource, attributing comfort with this modality and ease of access as an explanation for its greater use (Edwards et al., 2002; Ferguson et al., 2021). Previous research has also called out the need for information sources that are easily accessible but also provide users with reliable information (Ferguson et al., 2021; Matter et al., 2009). Consistent with our finding that caregivers often relied upon primary care providers for medical information about DS, Cosgrove et al. (2023) found that caregivers of children with DS wanted increased communication with their PCP and help with care coordination. These

caregivers cited challenges including information management, information sharing, and use of health care guidelines.

Our results are also similar to Krell et al. (2023), where caregivers of patients with DS who are Black, African American, of African descent, or of mixed race mentioned that healthcare professionals, including PCPs, were their top sources of trusted information. These caregivers emphasized the importance of finding medical providers who were willing to learn more about DS. This theme was also apparent in Hart and Neil (2021), where caregivers of children with DS in the United States reported that they experienced difficulty accessing supports for their child owing to their geographical location, inadequate notification of services and the limited number of services available, as well as a lack of prepared staff to assist caregivers and provide specific training for caregivers.

Similar to studies on digital resources for cancer, stroke, and elder care situations, our findings suggest that digital resources, endorsed by experts in the medical field, could address an unmet need for some caregivers. This is a relevant need given the public health risks posed by medical misinformation that is available on the internet (Mian & Khan, 2020; Waszak et al., 2018) study suggests that empowering the role of PCPs as a source of DS-related information would improve access to and quality of the information. One online platform, assessed through a national randomized control trial, is “Down Syndrome Clinic to You” (DSC2U; dsc2u.org). DSC2U is an asynchronous, web-based platform that auto-generates customized health and wellness recommendations for DS. Caregivers answer a series of questions related to co-occurring diagnoses, educational and life skill resources for DS, resources for physical therapy, occupational therapy, speech therapy, and more. Based on the specific needs of the caregiver, DSC2U outputs two documents, one a set of guidelines for the caregiver and the other a report for PCPs to discuss with caregivers. DSC2U was shown to be effective in improving adherence to DS medical guidelines within primary care settings (Chung et al., 2021). Available in both English and Spanish, DSC2U was also created with the input of caregiver stakeholders. In our current study, many caregivers felt that their medical providers lacked expertise about DS. DSC2U addresses that gap by providing caregivers with a customized checklist that can be shared with the PCPs, who also reported high levels of satisfaction with the tool (Chung et al., 2021).

Our study is not without limitations. We used a convenience sample since, to date, there is no population-based database of people with DS and their families. Our respondents from the United States were largely female, white, and well educated, and our respondents from Mexico were predominantly female and caregivers for children, not adults, with DS. DS occurs naturally in all races and ethnicities, regardless of socioeconomic status. As such, our finding might not be generalizable to all families who have persons with DS in the United States and Mexico. Online survey tools may be associated with additional limitations related to sampling, access, and verification of survey participants (Siva Durga Prasad Nayak & Narayan, 2019; Wright, 2005). Our analyses were also subject to nonresponse bias, as the survey was distributed blindly via a computer-based distribution method to a non-targeted population. A response rate could not be

calculated as the actual number of eligible participants who were contacted is unknown. Our survey instrument was also not validated, and although we reviewed and revised our survey based on clinical observations, there is potential for bias in the survey questions themselves. Respondents may have had a differing understanding of questions than were intended. Our translation and back-translation methodology has limitations including inconsistency in the detection of presumed flaws, where many problems may remain hidden (Behr, 2017). Additionally, the US survey and the Mexico survey were available on different platforms (REDCap and SurveyMonkey, respectively). This could have impacted the results, especially in terms of deterring fraudulent responses (Matheis et al., 2023).

5 | CONCLUSION

Many families feel that the needs of their loved ones with DS are inadequately addressed and search online for answers. Oftentimes, though, they report that the information is too scattered or too generic to be of specific help to their families. Coupling their trust in primary care providers with novel online health care platforms could create valuable solutions in addressing these needs.

AUTHOR CONTRIBUTIONS

Heidi Berger: Conceptualization, data curation, methodology, project administration, formal analysis, funding acquisition, writing—original draft and writing—review and editing. **Nora Horick:** Formal analysis, writing—original draft and writing—review and editing. **Kenia Kristel Esparza Ocampo:** Data curation, methodology. **Javier Magana Gomez:** Conceptualization, data curation, methodology, writing—original draft, and writing—review and editing. **Kenneth Norris:** Data curation, formal analysis, writing—original draft, and writing—review and editing. **Brian G. Skotko:** Conceptualization, methodology, writing—original draft, and writing—review and editing. **Katelyn Smith:** Data curation, formal analysis, writing—original draft, and writing—review and editing. **Jill Wittman:** Conceptualization, methodology, formal analysis, writing—original draft, and writing—review and editing. **Allison Young:** Data curation, formal analysis.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA*, 311(10), 1052. <https://doi.org/10.1001/jama.2014.304>
- Antonarakis, S. E., Skotko, B. G., Rafii, M. S., Strydom, A., Pape, S. E., Bianchi, D. W., Sherman, S. L., & Reeves, R. H. (2020). Down syndrome. *Nature Reviews Disease Primers*, 6(1), 1–20. <https://doi.org/10.1038/s41572-019-0143-7>
- Arizmendi, K. A. F., Robledo, T. T. V., Díaz, G. E., & del Puente, L. C. G. (2021). Seguimiento médico de los niños con síndrome de Down. *Acta Pediátrica de México*, 42(3), 142–148. <https://doi.org/10.18233/APM42No3pp142-1482176>
- Balling, K., & McCubbin, M. (2001). Hospitalized children with chronic illness: Parental caregiving needs and valuing parental expertise. *Journal of Pediatric Nursing*, 16(2), 110–119. <https://doi.org/10.1053/jpdn.2001.23157>
- Behr, D. (2017). Assessing the use of back translation: The shortcomings of back translation as a quality testing method. *International Journal of Social Research Methodology*, 20(6), 573–584. <https://doi.org/10.1080/13645579.2016.1252188>
- Besser, L. M., Shin, M., Kucik, J. E., & Correa, A. (2007). Prevalence of Down syndrome among children and adolescents in metropolitan Atlanta. *Birth Defects Research Part A: Clinical and Molecular Teratology*, 79(11), 765–774. <https://doi.org/10.1002/bdra.20404>
- Bhat, K. S., Hall, A. K., Kuo, T., & Kumar, N. (2023). “We are half-doctors”: Family caregivers as boundary actors in chronic disease management. *Proceedings of the ACM on Human-Computer Interaction*, 7(CSCW1), 1–29. <https://doi.org/10.1145/3579545>
- Bull, M. J., Trotter, T., Santoro, S. L., Christensen, C., Grout, R. W., & The Council on Genetics. (2022). Health supervision for children and adolescents with Down syndrome. *Pediatrics*, 149(5), e2022057010. <https://doi.org/10.1542/peds.2022-057010>
- Cabrera, M. J., Haugen, K., Krell, K., Torres, A., & Santoro, S. L. (2022). Pre-visit concerns: What caregivers hope to address at a specialty clinic for Down syndrome. *European Journal of Medical Genetics*, 65(8), 104550. <https://doi.org/10.1016/j.ejmg.2022.104550>
- Chung, J., Donelan, K., Macklin, E. A., Schwartz, A., Elsharkawi, I., Torres, A., Hsieh, Y. G., Parker, H., Lorenz, S., Patsiogiannis, V., Santoro, S. L., Wylie, M., Clarke, L., Estey, G., Baker, S., Bauer, P. E., Bull, M., Chicoine, B., Cullen, S., ... Skotko, B. G. (2021). Correction: A randomized controlled trial of an online health tool about Down syndrome. *Genetics in Medicine*, 23(1), 236. <https://doi.org/10.1038/s41436-020-01033-5>
- Chung, J., Krell, K., Pless, A., Jr., Michael, C., Torres, A., Baker, S., Blake, J. M., Caughman, K., Cullen, S., Gallagher, M., Hoke-Chandler, R., Maina, J., McLuckie, D., O'Neill, K., Peña, A., Royal, D., Slape, M., Spinazzi, N. A., Torres, C. G., & Skotko, B. G. (2023). Healthcare experiences of patients with Down syndrome from primarily Spanish-speaking households. *American Journal of Medical Genetics Part A*, 191(8), 2132–2141. <https://doi.org/10.1002/ajmg.a.63250>
- Coleman, J., Olsen, S. J., Sauter, P. K., Baker, D., Hodgins, M. B., Stanfield, C., Emerling, A., Hruban, R. H., & Nolan, M. T. (2005). The effect of a frequently asked questions module on a pancreatic cancer web site patient/family chat room. *Cancer Nursing*, 28(6), 460–468.
- Corona-Rivera, J. R., Martínez-Macias, F. J., Bobadilla-Morales, L., Corona-Rivera, A., Peña-Padilla, C., Rios-Flores, I. M., Flores-Guevara, P. A., Orozco-Vela, M., Aranda-Sánchez, C. I., & Brukman-Jiménez, S. A. (2019). Prevalence and risk factors for Down syndrome: A hospital-based single-center study in Western Mexico. *American Journal of Medical Genetics Part A*, 179(3), 435–441. <https://doi.org/10.1002/ajmg.a.61044>
- Cosgrove, B., Knafl, K., & Van Riper, M. (2023). A mixed methods analysis of care coordination needs and desirable features of an M-Health Application to support caregivers of children with Down syndrome. *Journal of Pediatric Health Care*, 37(1), 30–39. <https://doi.org/10.1016/j.pedhc.2022.08.002>
- Daniels, D., Wolter-Warmerdam, K., Holland, S., & Hickey, F. (2022). Reach out and read implementation in a pediatric Down syndrome clinic. *Journal of Pediatric Health Care*, 36(3), 231–239. <https://doi.org/10.1016/j.pedhc.2021.10.003>
- Edwards, L., Krassioukov, A., & Fehlings, M. G. (2002). Importance of access to research information among individuals with spinal cord injury: Results of an evidenced-based questionnaire. *Spinal Cord*, 40(10), 529–535. <https://doi.org/10.1038/sj.sc.3101364>
- Ferguson, K., Mitro, J. P., Bhanji, A., Yang, S., Gerber, L., Cai, C., Garfinkel, S., & Weinstein, A. A. (2021). Qualitative investigation of health information resources for caregivers and individuals living with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, 27(4), 79–98. <https://doi.org/10.46292/sci20-00032>
- GBD Results. (2019). Institute for Health Metrics and Evaluation. Retrieved September 27, 2023, from <https://vizhub.healthdata.org/gbd-results>
- de Graaf, G., Buckley, F., & Skotko, B. G. (2015). Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States. *American Journal of Medical Genetics Part A*, 167(4), 756–767. <https://doi.org/10.1002/ajmg.a.37001>
- Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., McLeod, L., Delacqua, G., Delacqua, F., Kirby, J., & Duda, S. N. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*, 95, 103208. <https://doi.org/10.1016/j.jbi.2019.103208>
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>
- Hart, K. M., & Neil, N. (2021). Down syndrome caregivers' support needs: A mixed-method participatory approach. *Journal of Intellectual Disability Research*, 65(1), 60–76. <https://doi.org/10.1111/jir.12791>
- Hickey, F., Wolter-Warmerdam, K., Winders, P., Holland, S., Kelminson, K., & Daniels, D. (2023). Ten-year impact of a Down syndrome pediatric clinic. *Journal of Policy and Practice in Intellectual Disabilities*, 1–9. <https://doi.org/10.1111/jppi.12471>
- Hook, E. B., Schreinemachers, D. M., & Cross, P. K. (1981). Use of prenatal cytogenetic diagnosis in New York state. *New England Journal of Medicine*, 305(23), 1410–1413. <https://doi.org/10.1056/NEJM198112033052312>
- James, N., Daniels, H., Rahman, R., McConkey, C., Derry, J., & Young, A. (2007). A study of information seeking by cancer patients and their carers. *Clinical Oncology*, 19(5), 356–362. <https://doi.org/10.1016/j.clon.2007.02.005>
- Joslyn, N., Berger, H., & Skotko, B. G. (2020). Geospatial analyses of accessibility to Down syndrome specialty care. *The Journal of Pediatrics*, 218, 146–150. <https://doi.org/10.1016/j.jpeds.2019.10.058>
- Kernisan, L. P., Sudore, R. L., & Knight, S. J. (2010). Information-seeking at a caregiving website: A qualitative analysis. *Journal of Medical Internet Research*, 12(3), e1548. <https://doi.org/10.2196/jmir.1548>
- King, E., Remington, M., & Berger, H. (2022). Family perspectives on gaps in health care for people with Down syndrome. *American Journal of Medical Genetics Part A*, 188(4), 1160–1169. <https://doi.org/10.1002/ajmg.a.62635>
- Klotz, A. C., Swider, B. W., & Kwon, S. H. (2023). Back-translation practices in organizational research: Avoiding loss in translation. *Journal of*

- Applied Psychology*, 108(5), 699–727. <https://doi.org/10.1037/apl0001050>
- Krell, K., Pless, A., Jr., Michael, C., Torres, A., Chung, J., Baker, S., Blake, J. M., Caughman, K., Cullen, S., Gallagher, M., Hoke-Chandler, R., Maina, J., McLuckie, D., O'Neill, K., Peña, A., Royal, D., Slape, M., Spinazzi, N. A., Torres, C. G., & Skotko, B. G. (2023). Health-care experiences of patients with Down syndrome who are Black, African American, of African descent, or of mixed race. *American Journal of Medical Genetics Part A*, 191(3), 742–752. <https://doi.org/10.1002/ajmg.a.63069>
- Lavin, C., Francis, G., Mason, L., & LeSueur, R. (2020). Perceptions of inclusive education in Mexico City: An exploratory study. *International Journal of Disability, Development and Education*, 69(3), 1065–1079. <https://doi.org/10.1080/1034912X.2020.1749572>
- Lee, E. Y., Neil, N., & Friesen, D. C. (2021). Support needs, coping, and stress among parents and caregivers of people with Down syndrome. *Research in Developmental Disabilities*, 119, 104113. <https://doi.org/10.1016/j.ridd.2021.104113>
- Martin, P. (1986). Grounded theory and organizational research. *The Journal of Applied Behavioral Science*, 22(2), 141–157. <https://doi.org/10.1177/002188638602200207>
- Martínez-Valverde, S., Salinas-Escudero, G., García-Delgado, C., Garduño-Espinosa, J., Morán-Barroso, V. F., Granados-García, V., Tiro-Sánchez, M. T., Toledano-Toledano, F., & Aldaz-Rodríguez, M. V. (2019). Out-of-pocket expenditures and care time for children with Down syndrome: A single-hospital study in Mexico City. *PLoS One*, 14(1), e0208076. <https://doi.org/10.1371/journal.pone.0208076>
- Matheis, M., Takahashi, K., & Richard, S. (2023). Bots are getting smarter: Online survey data collection in the age of sophisticated AI. Retrieved October 21, 2023, from <https://hdl.handle.net/10125/104883>
- Matter, B., Feinberg, M., Schomer, K., Harniss, M., Brown, P., & Johnson, K. (2009). Information needs of people with spinal cord injuries. *The Journal of Spinal Cord Medicine*, 32(5), 545–554.
- Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.
- Mian, A., & Khan, S. (2020). Coronavirus: The spread of misinformation. *BMC Medicine*, 18(1), 89. <https://doi.org/10.1186/s12916-020-01556-3>
- Micah, A. E., Bhangdia, K., Cogswell, I. E., Lasher, D., Lidral-Porter, B., Maddison, E. R., Nguyen, T. N. N., Patel, N., Pedroza, P., Solorio, J., Stutzman, H., Tsakalos, G., Wang, Y., Warriner, W., Zhao, Y., Zlavog, B. S., Abbafati, C., Abbas, J., Abbasi-Kangevari, M., ... Dieleman, J. L. (2023). Global investments in pandemic preparedness and COVID-19: Development assistance and domestic spending on health between 1990 and 2026. *The Lancet Global Health*, 11(3), e385–e413. [https://doi.org/10.1016/S2214-109X\(23\)00007-4](https://doi.org/10.1016/S2214-109X(23)00007-4)
- Ozolins, U., Hale, S., Cheng, S. X., Hyatt, A., & Schofield, P. (2020). Translation and back-translation methodology in health research—A critique. *Expert Review of Pharmacoeconomics & Outcomes Research*, 20, 69–77. <https://doi.org/10.1080/14737167.2020.1734453>
- Pierce, L. L., Steiner, V. L., Khuder, S. A., Govoni, A. L., & Horn, L. J. (2009). The effect of a Web-based stroke intervention on carers' well-being and survivors' use of healthcare services. *Disability and Rehabilitation*, 31(20), 1676–1684. <https://doi.org/10.1080/09638280902751972>
- Sáenz Vela, H. M., Guzmán Giraldo, Á. M., Sáenz Vela, H. M., & Guzmán Giraldo, Á. M. (2021). Gasto catastrófico y utilización de servicios de salud, México 2018. *Revista de economía*, 38(97), 65–87. <https://doi.org/10.33937/reveco.2021.218>
- Santoro, S. L., Campbell, A., Balasubramanian, A., Haugen, K., Schafer, K., & Mobley, W. (2021). Specialty clinics for adults with Down syndrome: A clinic survey. *American Journal of Medical Genetics. Part A*, 185(6), 1767–1775. <https://doi.org/10.1002/ajmg.a.62169>
- Sierra Romero, M. d. C., Navarrete Hernández, E., Canún Serrano, S., Reyes Pablo, A. E., & Valdés Hernández, J. (2014). Prevalencia del síndrome de Down en México utilizando los certificados de nacimiento vivo y de muerte fetal durante el periodo 2008-2011. *Boletín Médico del Hospital Infantil de México*, 71(5), 292–297.
- Siva Durga Prasad Nayak, M., & Narayan, K. A. (2019). Strengths and weakness of online surveys. *IOSR Journal of Humanities and Social Sciences*, 24, 31–38. <https://doi.org/10.9790/0837-2405053138>
- Skotko, B. G., Davidson, E. J., & Weintraub, G. S. (2013). Contributions of a specialty clinic for children and adolescents with Down syndrome. *American Journal of Medical Genetics Part A*, 161(3), 430–437. <https://doi.org/10.1002/ajmg.a.35795>
- Smith, D. S. (2001). Health care management of adults with Down syndrome. *American Family Physician*, 64(6), 1031–1039.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273–285). Sage Publications, Inc.
- Tsou, A. Y., Bulova, P., Capone, G., Chicoine, B., Gelaro, B., Harville, T. O., Martin, B. A., McGuire, D. E., McKelvey, K. D., Peterson, M., Tyler, C., Wells, M., Whitten, M. S., & Global Down Syndrome Foundation Medical Care Guidelines for Adults with Down Syndrome Workgroup. (2020). Medical care of adults with Down syndrome: A clinical guideline. *JAMA*, 324(15), 1543. <https://doi.org/10.1001/jama.2020.17024>
- Waszak, P. M., Kasprzycka-Waszak, W., & Kubanek, A. (2018). The spread of medical fake news in social media—The pilot quantitative study. *Health Policy and Technology*, 7(2), 115–118. <https://doi.org/10.1016/j.hlpt.2018.03.002>
- Wright, K. B. (2005). Researching internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*, 10(3), JCMC1034. <https://doi.org/10.1111/j.1083-6101.2005.tb00259.x>

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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