Health-related Social Media Use by Parents of Children with Rheumatic Diseases

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Background/Purpose:

Disease and treatment burdens are high for children living with rheumatic diseases. Pediatric patients and their families lack a mature evidence base to guide treatment decisions and often need higher levels of psychosocial support than may be available in traditional healthcare settings. In this context, engaging with others facing similar challenges and health problems via social media may be helpful and impactful for healthcare decision-making.

In this study, we sought to understand attitudes, beliefs, and behaviors concerning social media use among parents of children with rheumatic diseases, and how such engagement might affect decision-making about their child's health care.

Methods:

We worked with PARTNERS, a patient-powered research network, to disseminate an online survey through nine patient support groups that help families with children with rheumatic diseases. The survey was distributed through email, website links, and on these groups' social media accounts. Surveys were completed anonymously under implied consent between January 22 - April 2, 2019. The study was deemed exempt by the Boston Children's Hospital IRB.

Parents responded to questions about their child's rheumatic disease diagnosis and disease activity, use of social media, child's health (PROMIS Parent Proxy Scale v1.0 – Global Health 7[1]), parent's global health (PROMIS Scale v1.2 - Global Health[2,3]), and perceived availability of helpful information or advice (PROMIS Item Bank v2.0 - Informational Support – Short Form 8a[4]). Exclusion criteria are seen in Figure 1. Child's health was classified as "good" if child's Global Health T-score was ≥40; it was "poor" if child's Global Health T-score was <40.

Results:

712 participants were included in the current analysis. Participant characteristics are shown in Table 1. Child's health and disease activity varied significantly depending on the the child's diagnosis. Disease activity, as noted by the parent, are shown in Figure 2.

Virtually all families (98.7%) had used Facebook to view/read about other families with children with similar rheumatic diseases. The benefits of these interactions are shown in Figure 3. How this information translated to decision-making regarding their child's health care is shown in Figure 4.
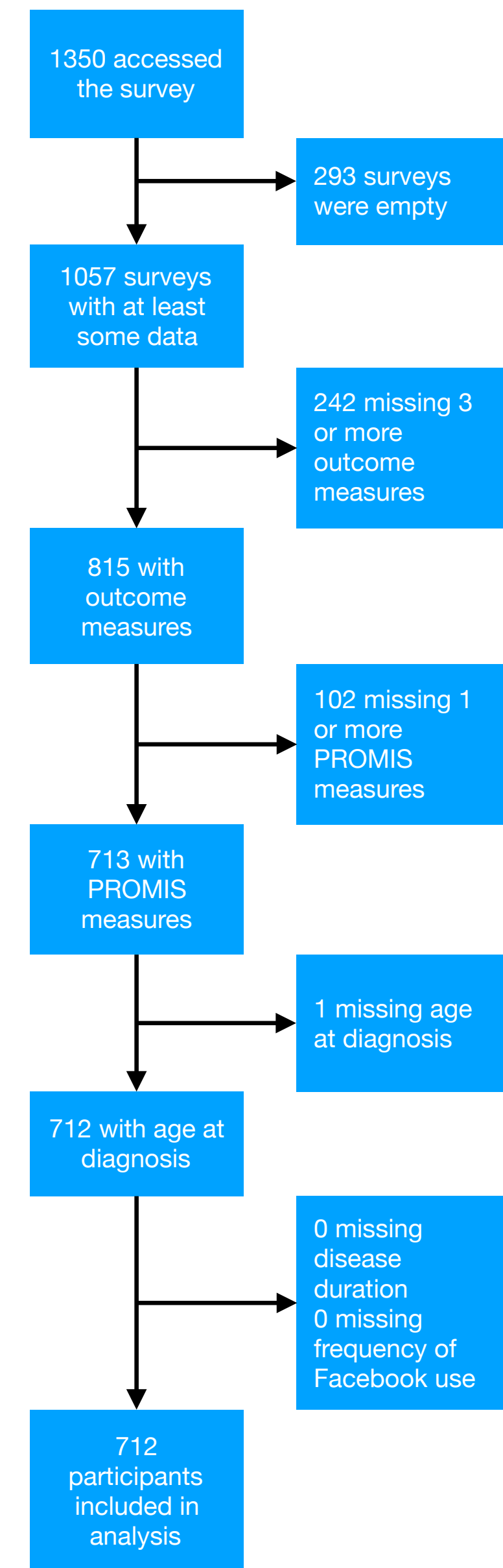

Figure 1: Exclusion criteria

- 1350 accessed the survey
- 293 surveys were empty
- 1057 surveys with at least some data
- 242 missing 3 or more outcome measures
- 815 with outcome measures
- 102 missing 1 or more PROMIS measures
- 713 with PROMIS measures
- 1 missing age at diagnosis
- 712 with age at diagnosis
- 0 missing disease duration, 0 missing frequency of Facebook use
- 712 participants included in analysis

	Total		Child's Health				
			Good		Poor		
	N or x̄	% or SD	N or x̄	% or sd	N or x̄	% or sd	p-value
	712	100%	145	20.37%	567	79.63%	
Parent characteristics							
Physical health MEAN, SD	41.83	7.58	44.53	8.17	41.14	7.27	<.0001
Mental health MEAN, SD	42.21	7.34	46.27	7.32	41.17	6.98	<.0001
Informational support MEAN, SD	53.59	10.16	57.25	9.18	52.65	10.20	<.0001
Percentage that use Facebook to view/read about other families with a child with similar rheumatic conditions							0.0734
Do not use this site	9	1.3%	5	55.6%	4	44.4%	
Every few weeks	27	3.8%	6	22.2%	21	77.8%	
A few times a week	103	14.5%	25	24.3%	78	75.7%	
About once a day	308	43.3%	58	18.8%	250	81.2%	
Several times a day	265	37.2%	51	19.3%	214	80.8%	
Child characteristics							
Diagnosis							<.0001
Juvenile idiopathic arthritis	193	27.1%	32	16.6%	161	83.4%	
Juvenile dermatomyositis	157	22.1%	59	37.6%	98	62.4%	
Autoinflammatory disease	132	18.5%	21	15.9%	111	84.1%	
Other	76	10.7%	13	17.1%	63	82.9%	
Autoimmune encephalitis	62	8.7%	3	4.8%	59	95.2%	
Lupus	34	4.8%	8	23.5%	26	76.5%	
Vasculitis	18	2.5%	2	11.1%	16	88.9%	
Scleroderma	15	2.1%	2	13.3%	13	86.7%	
CRMO	14	2.0%	3	21.4%	11	78.6%	
Sjogren's syndrome	11	1.5%	2	18.2%	9	81.8%	
Disease duration MEAN, SD	4.49	3.91	4.61	3.77	4.46	3.95	<.0001
Age at diagnosis MEAN, SD	6.98	4.65	6.50	4.45	7.11	4.69	<.0001
Current age MEAN, SD	11.47	5.50	11.10	5.46	11.57	5.51	<.0001
Health (Parent proxy) MEAN, SD	33.49	8.28	46.18	4.71	30.25	5.36	<.0001
Disease activity							<.0001
Complete remission	65	9.1%	32	49.2%	33	50.8%	
Stable on meds	316	44.4%	86	27.2%	230	72.8%	
Flare	330	46.4%	26	7.9%	304	92.1%	

Table 1: Participant characteristics. Child's health was classified as "good" if child's Global Health T-score was ≥40; it was "poor" if child's Global Health T-score was <40.
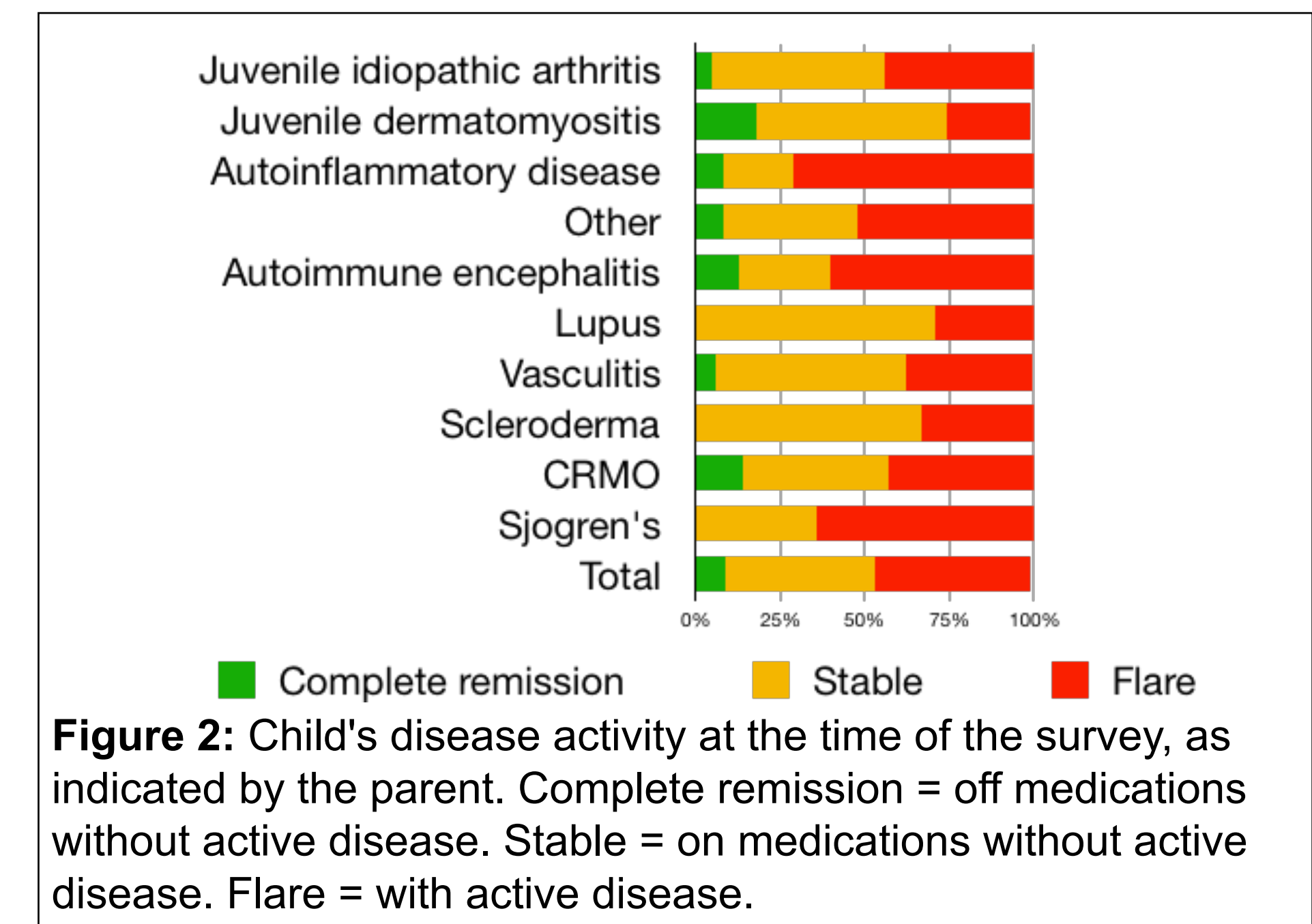

Figure 2: Child's disease activity at the time of the survey, as indicated by the parent. Complete remission = off medications without active disease. Stable = on medications without active disease. Flare = with active disease.

Figure 3: Percentage of parents who "agree" or "strongly agree" to the question: "Reading about other families who have a child with a rheumatic condition similar to your child's…"

- Provides me with information about treatments for my child's rheumatic condition — 73.2%
- Allows me to see how other physicians are treating children with similar rheumatic conditions to my child's — 67.3%
- Allows me to see how other families with a child with a rheumatic condition are living their lives — 63.5%
- Helps me to feel less alone with my child's rheumatic condition — 55.6%
- Allows me to meet/connect with other parents with children with similar rheumatic conditions to my child's — 52.2%
- Provides me with information about my child's condition that I can understand — 47.1%
- Helps me to feel more prepared when talking to my doctor/care team about my child's rheumatic condition — 36.1%
- Provides me with health information about my child that I cannot find anywhere else — 32.6%
- Provides me with health information about my child that my doctors/care team cannot provide — 30.2%
- Helps me to talk to my doctor about his/her rheumatic condition — 29.1%
- Helps me to talk to my friends about my child's rheumatic condition — 27%

Figure 4: Percentage of parents who answered "somewhat" or "a great deal" to the question: "To what extent has what you learned about your child's rheumatic condition from social media affected…"

- How you manage your child's symptoms — 72.2%
- How you address social/mental health issues associated with your child's disease — 68.7%
- How you manage medication side effects — 68.3%
- Your decisions on which medications to use to treat your child's illness — 44.5%
- Your choice of doctors that care for your child — 42.7%
- Your decision whether or not to treat your child's illness — 42.3%
- Your relationship with your rheumatologist — 32.7%

Conclusion:

- **Health-related social media use by parents of children with rheumatic diseases was widespread in this large cohort of parents recruited online through patient support organizations**. Virtually all parents had accessed Facebook to read about other families with children with rheumatic diseases. The greatest benefit from online interactions resulted from decreasing feelings of isolation of the parent and normalizing the diagnosis of a rheumatic illness in a child.

- **Online interactions translated into behavior changes, mainly involving managing their child's symptoms, medication side effects, as well as the social and mental health issues that accompany the disease.** Almost half of parents reported that these online interactions affected their decision on which medication to use to treat their child's illness, suggesting a potentially powerful real-world effect of these online interactions.

- **Despite a somewhat sicker patient population in this cohort than the average US population, parents were slightly more likely than the US population to feel they have access to helpful information, perhaps because of their use of social media and patient support organizations.**

An important limitation of our findings is that participants were recruited from social media and patient support organizations, likely biasing for a more engaged population; results may not generalize to the broader population of children with rheumatic diseases. However, the vast number of responses for very rare diseases suggests we were able to capture a substantial proportion of families with children with rheumatic diseases.

A better understanding of parental needs may allow us to create interventions that could help provide greater support for families and improve health outcomes for children with rheumatic diseases.
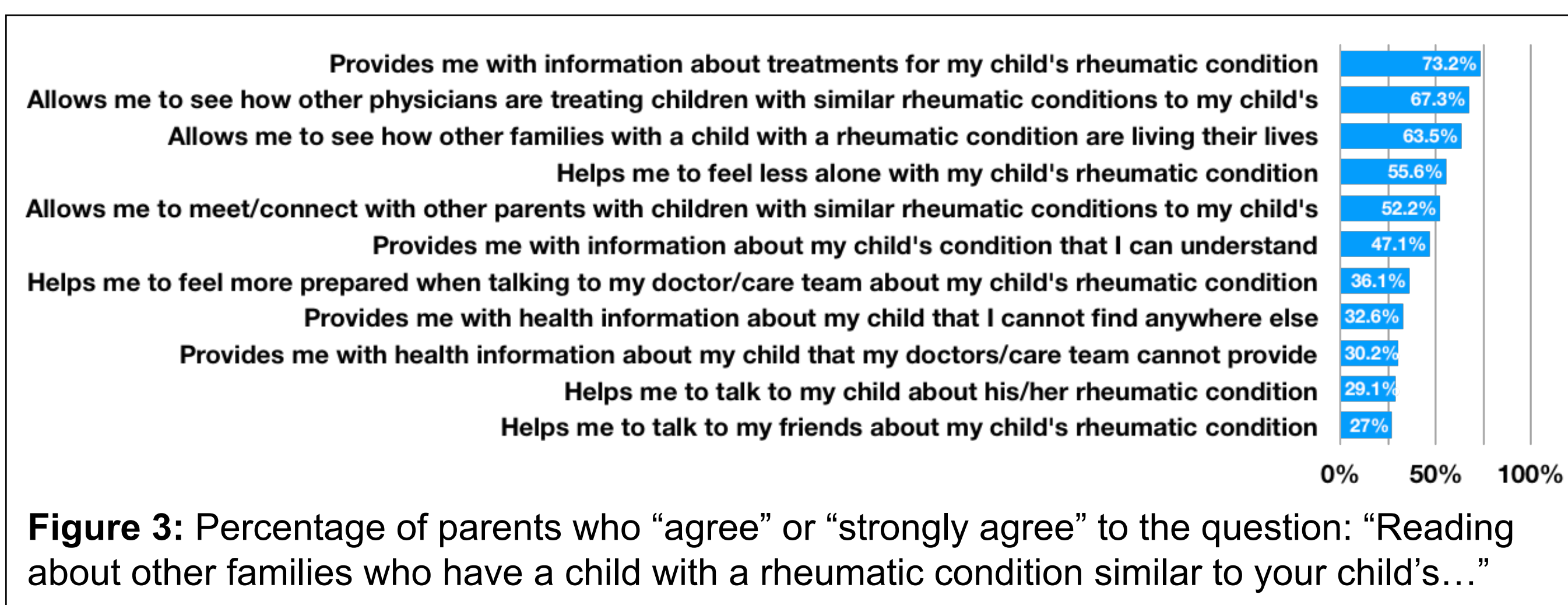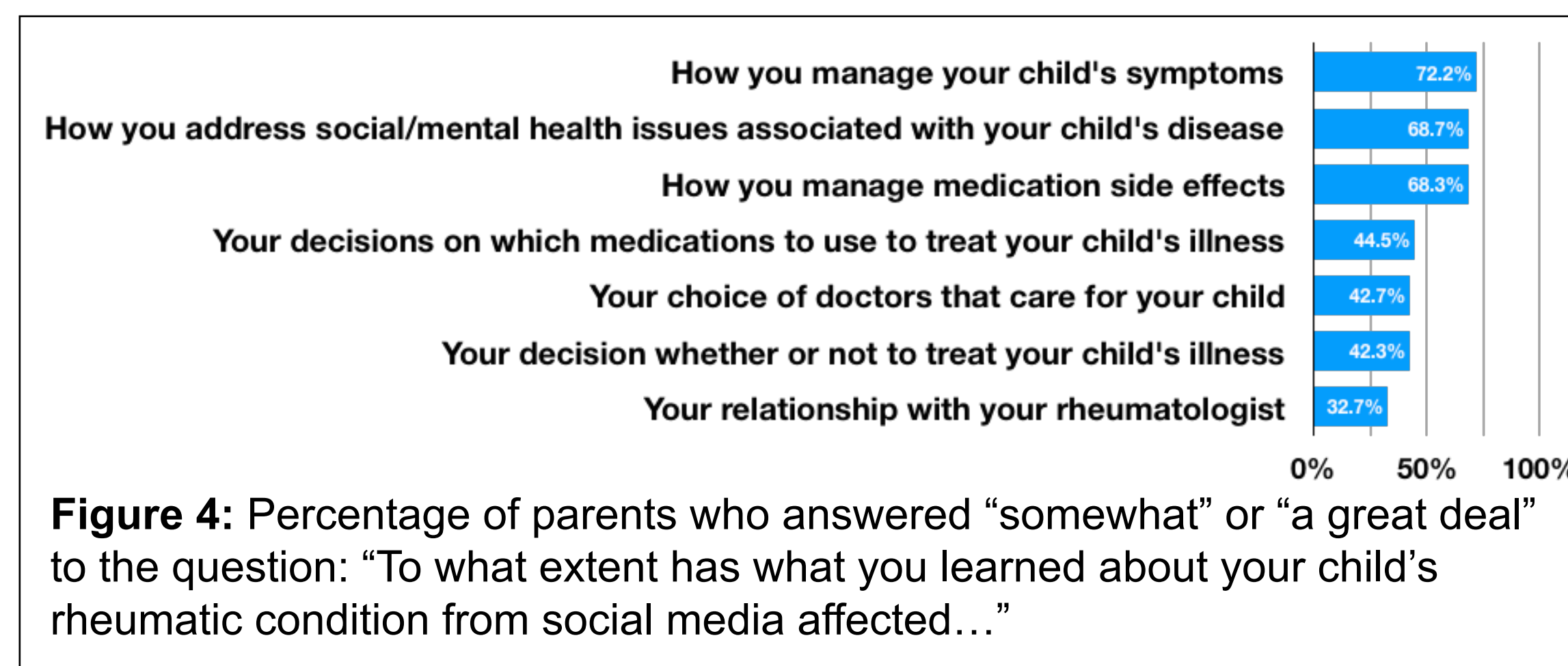
References

1. Forrest, C.B., Bevans, K.B., Pratiwadi, R., Moon, J., Teneralli, R.E., Minton, J.M., & Tucker, C.A. (2014). Development of the PROMIS (R) Pediatric Global Health (Pgh-7) Measure. Quality of Life Research, 23(4), 1221-1231.
2. Hays, R. D., Bjorner, J., Revicki, R. A., Spritzer, K. L., & Cella, D. (2009). Development of physical and mental health summary scores from the Patient Reported Outcomes Measurement Information System (PROMIS) global items. Quality of Life Research, 18(7), 873-80.
3. Hays RD, Spritzer KL, Thompson WW & Celia D (2015). US general population estimate for "excellent" to "poor" self rated health item. Journal of General Internal Medicine, 30(10), 1511-1516.
4. Hahn, E. A., DeWalt, D. A., Bode, R. K., Garcia, S. F., DeVellis, R. F., Correia, H., et al. (2014). New English and Spanish social health measures will facilitate evaluating health determinants. Health Psychology, 33(5), 490–499.

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