

The Impact of Patient Knowledge and Provider Specialty on Shared Decision Making in Eczema Care Settings

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Introduction

Shared decision making (SDM) is used in clinical settings to help patients make treatment decisions in collaboration with their healthcare provider (HCP). SDM is well-suited for eczema (also known as atopic dermatitis), a chronic inflammatory skin disease with many treatment options and significant heterogeneity in the disease course, lived experience, and patient preference.^{1,2} Additionally, treatment demands can contribute to negative quality of life impacts, so patient understanding of potential benefits, risks, and expectations is imperative.³ There are a variety of factors that may contribute to SDM success, but the impact of both patient and HCP knowledge about eczema has not been elucidated. These factors are of particular importance, as not all patients have the ability to see eczema specialists, and lack of time during eczema-specific appointments may mean patient education is largely taking place outside of the healthcare setting.⁴ We sought to understand the impact of HCP specialty and patient eczema knowledge on SDM experience and confidence to engage in SDM.

Methods

The National Eczema Association conducted a 64-question web-based survey of adult patients and caregivers of children with atopic dermatitis (AD).² This study was identified as exempt by the Western Institutional Review Board Copernicus Group under 45 CFR § 46.104(d)(2), because the research only included survey procedures with adequate measures to protect the privacy and confidentiality of participants. Participants provided informed consent in accordance with the Declaration of Helsinki. SDM experience (measured with the SDM-Q9 instrument,⁵ scores transformed to 0–100) and self-reported confidence to engage in SDM (options: not confident at all/slightly confident/moderately confident vs very confident/extremely confident) were assessed. Respondents' perceived knowledge was assessed with the question: "How well informed do you feel you are about the underlying causes of eczema?" (options: very well-informed, adequately informed, not adequately informed). SDM experience and confidence were compared between the following groups: both (1) well-informed patients and (2) not adequately informed patients currently seeing specialists, and both (3) well-informed patients and (4) not informed patients who were seeing non-specialists. ANOVA was used for group comparison of SDM-Q9 scores and a Kruskal–Wallis test was used to compare proportions for SDM confidence.

Results

Responses from 767 adults and 177 caregivers (944/1345 who clicked on the email link; response rate of 70.1%) met the inclusion criteria (Table 1). SDM-Q9 scores (Figure 1) were significantly different between groups ($p < 0.001$). Tukey post-hoc testing revealed that respondents who felt well-informed had higher SDM-Q9 scores (ie experienced more SDM at their last AD consultation with their primary HCP) than those who did not feel adequately informed, regardless of whether they were seeing a specialist (71.9 for informed vs 51.8 not informed, $p < 0.001$) or non-specialist (70.3 informed

Table 1 Characteristics of the Study Population

	N=944
Connection to eczema % (n)	
Adult patient	81.2% (767)
Caregiver	18.8% (177)
Patient age (mean ± SD)	
Adult	47.5 ± 17.6
Child	7.5 ± 5.1
Patient gender % (n)	
Female	80.2% (757)
Male	18.4% (174)
Other	1.4% (13)
Respondent race % (n)	
White	66.9% (632)
Black or African American	12.6% (119)
Asian or Asian American	9.6% (91)
Native American or Alaskan Native	0.7% (7)
Native Hawaiian or Pacific Islander	0.3% (3)
Multiracial	5.1% (48)
Other/prefer not to say	4.7% (44)
Eczema RECAP score (mean ± SD)	11.4 ± 7.1
Primary provider type % (n)	
<i>Specialist</i>	
Dermatologist	68.8% (650)
Allergist	8.9% (84)
<i>Non-specialist</i>	
General or family physician	13.3% (126)
Physician assistant/nurse practitioner	2.6% (25)
Pediatrician	2.3% (22)
Other	3.9% (37)
Knowledge about causes of eczema % (n)	
Very well informed	30.3% (286)
Adequately informed	49.3% (466)
Not very well informed	20.3% (192)
Confidence to engage in SDM % (n)	
Not confident at all	3.8% (36)
Slightly confident	7.2% (68)
Moderately confident	19.6% (185)
Very confident	28.3% (267)
Extremely confident	41.1% (388)

vs 52.7 not informed, $p < 0.001$). There were no differences based on HCP specialty. Moreover, confidence to engage in SDM (Figure 1, Kruskal–Wallis test, $p < 0.001$) was higher for respondents who felt informed (~30% higher than those who were not adequately informed), with no differences based on HCP specialty.

Discussion

Access to AD specialists is not universal for all AD patients and caregivers. This work demonstrates that while provider specialty may not be a prerequisite for productive SDM, patient knowledge may be highly important. Previous work from this survey has also indicated that AD patients rate their own health literacy and ability to communicate about their

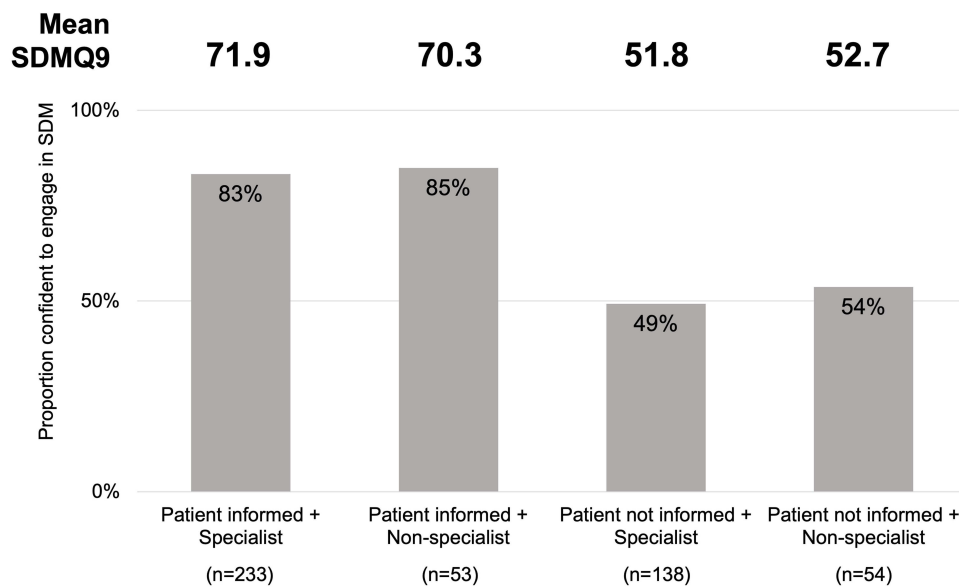


Figure 1 Impact of patient knowledge and provider specialty on SDM9 score and confidence to engage in SDM.

disease as highly important for SDM.⁴ As members of a patient advocacy organization, respondents in this study likely had been exposed to more AD resources, and potentially attained higher eczema-specific education than the wider AD population. Therefore, the proportion of patients nationwide who do not feel adequately informed about eczema, and who may not feel as confident engaging in SDM, is likely higher than the current work suggests.

In conclusion, time during AD appointments can be limited, but patients who prepare outside of that allotted time may leave more time for treatment-specific questions, interactive dialog, and for the HCP to provide quality care.⁶ Adequate patient knowledge and expression may also alleviate epistemic injustice and improve knowledge sharing, to help HCPs better understand the patient experience.⁷ This work highlights the value of comprehensive patient education across AD care settings.

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Disclosure

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References

- Silverberg JI, Gelfand JM, Margolis DJ, et al. Patient burden and quality of life in atopic dermatitis in US adults: a population-based cross-sectional study. *Ann Allergy Asthma Immunol.* 2018;121(3):340–347. doi:10.1016/j.anai.2018.07.006
- Thibau IJ, Loiselle AR, Latour E, Foster E, Smith Begolka W. Past, present, and future shared decision-making behavior among patients with eczema and caregivers. *JAMA Dermatol.* 2022;158(8):912–918. doi:10.1001/jamadermatol.2022.2441
- Ali F, Vyas J, Finlay AY. Counting the burden: atopic dermatitis and health-related quality of life. *Acta Derm Venereol.* 2020;100(12):adv00161. doi:10.2340/00015555-3511
- Foster E, Loiselle AR, Thibau IJ, Smith Begolka W. Factors facilitating shared decision making in eczema: met and unmet needs from the patient perspective. *JAAD Int.* 2023;11:95–102. doi:10.1016/j.jdin.2022.12.008

5. Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Educ Couns.* 2010;80(1):94–99. doi:10.1016/j.pec.2009.09.034
6. Townsend A, Leese J, Adam P, et al. eHealth, participatory medicine, and ethical care: a focus group study of patients' and health care providers' use of health-related internet information. *J Med Internet Res.* 2015;17(6):e3792. doi:10.2196/jmir.3792
7. Buchman DZ, Ho A, Goldberg DS. Investigating trust, expertise, and epistemic injustice in chronic pain. *J Bioeth Inq.* 2016;14(1):31–42. doi:10.1007/s11673-016-9761-x

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