



# The Utility and Validity of the Alopecia Areata Symptom Impact Scale in Measuring Disease-Related Symptoms and their Effect on Functioning

Tito R. Mendoza<sup>1</sup>, Joyce Osei<sup>2</sup> and Madeleine Duvic<sup>2</sup>

Alopecia areata (AA) is an autoimmune disease that causes hair loss. Although persons with the disease can be physically described as having varying degrees of hair loss, the condition has significant ramifications on an individual's well-being. We previously reported the preliminary psychometric properties of the Alopecia Areata Symptom Impact Scale (AASIS), a disease-specific measure that asks participants about their AA symptoms and how these symptoms interfere with their daily functioning. The goals of this article are to provide a detailed description of the development of the AASIS items and to offer a psychometric update for the measure. Preliminary items for the AASIS were developed on the basis of responses from 1,649 participants to 125 health-related quality-of-life questions/items from the National Alopecia Areata Registry. Clinicians affiliated with the registry were asked to rate the relevance of these items for content validity. Cluster analysis and clinician ratings were used to reduce the number of items. The resulting 13-item AASIS was administered to 452 participants, who were also cognitively debriefed. Results showed that the AASIS is a valid and reliable measure of AA symptoms and their impact on functioning.

*Journal of Investigative Dermatology Symposium Proceedings* (2018) 19, S41–S46; doi:10.1016/j.jisp.2017.10.009

## INTRODUCTION

Alopecia areata (AA) is an organ-specific autoimmune disease that causes loss of hair on the scalp and other areas of the body. It is hypothesized to be an immune attack whereby T cells target the hair follicles, causing loss of anagen hair. The early stages include patchy hair loss on the scalp, but the disease can progress to full scalp and body hair loss.

The apparent lack of hair can be considered a sign of AA, but the emotional and social consequences of lack of hair are of even greater concern to patients with AA. In developing a measure that will assess the severity of symptoms of AA, the psychological and social impacts of these physiological changes should also be considered. Assessing these disease consequences is best performed by directly asking patients about their condition. Patient-rated assessments are referred to as patient-reported outcomes. The U.S. Food and Drug Administration (FDA) defines a *patient-reported outcome* as a measurement of any aspect of a patient's health status that comes directly from the patient and is not influenced by his/her physician or caregiver (FDA, 2009).

Clinicians caring for AA patients have used tools such as the Dermatology Life Quality Index, the Skindex-16, and the Brief Fear of Negative Evaluation Scale to measure their patients' quality of life. However, most of these measures were designed for other skin disorders and are not specific to AA. Two other measures, the Alopecia Areata–Quality of Life Index (Fabbrocini et al., 2013) and the Alopecia Areata QOL (Endo et al., 2012) are specific to AA as quality-of-life measures. However, we proposed to develop a measure that evaluates how patients with AA feel and function. An assessment tool designed with this guiding principle tends to be proximal instead of distal to the effect of the disease or condition. We included items that measure the severity of symptoms associated with the disease and then assessed the impact of these symptoms on daily functioning. The disease-specific measure we developed is called the Alopecia Areata Symptom Impact Scale (AASIS; Figure 1) (Mendoza et al., 2013).

We previously reported the preliminary psychometric properties of the AASIS (Mendoza et al., 2013). We found that the AASIS showed desirable psychometric properties and that patients reported the items to be easily understood, clear, and concise. However, in that brief report, details of the item development were incomplete. The goals of this manuscript are twofold. First, we describe the development of a measure specifically geared toward symptoms and their impact on functioning in AA participants. This was accomplished by analyzing health-related quality-of-life data collected via the National Alopecia Areata Registry (NAAR) in screening potential items for the AASIS, by soliciting clinician input about the relevance of the NAAR items for possible inclusion to the instrument, by describing the results of interviews of

<sup>1</sup>Department of Symptom Research, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA; and <sup>2</sup>Department of Dermatology, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA

Correspondence: Tito R. Mendoza, Department of Symptom Research, The University of Texas MD Anderson Cancer Center, 1400 Pressler Street, Unit 1450, Houston, Texas 77030, USA. E-mail: [tmendoza@mdanderson.org](mailto:tmendoza@mdanderson.org)

Abbreviations: AA, alopecia areata; AASIS, Alopecia Areata Symptom Impact Scale; CVI, content validity index; FDA, U.S. Food and Drug Administration; NAAR, National Alopecia Areata Registry

**Figure 1. The Alopecia Areata Symptom Impact Scale (AASIS).** The AASIS is a 13-item, disease-specific measure that asks patients with AA about the severity of their symptoms and how these symptoms interfere with their daily functioning. These items represent how patients feel and function. The AASIS uses a 0–10 numeric rating scale that patients find simple to understand and that is easily translated into different languages.

**Alopecia Areata Symptom Impact Scale (AASIS)**

Alopecia areata is a condition that may affect you. Please rate how severe the following symptoms of your alopecia areata have been **in the past week**. Please select one response from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

	Not Present										As bad as you can imagine
Scalp hair loss	0	1	2	3	4	5	6	7	8	9	10
Body or eye lashes hair loss	0	1	2	3	4	5	6	7	8	9	10
Tingling/numbness of the scalp	0	1	2	3	4	5	6	7	8	9	10
Itchy or painful skin	0	1	2	3	4	5	6	7	8	9	10
Irritated skin	0	1	2	3	4	5	6	7	8	9	10
Feeling anxious or worry	0	1	2	3	4	5	6	7	8	9	10
Feeling sad	0	1	2	3	4	5	6	7	8	9	10

Your alopecia areata may interfere with your daily functioning. Please rate how the following items were interfered with by alopecia areata **in the past week**: Please select one response from 0 (did not interfere) to 10 (interfered completely) for each item.

	Did not Interfere										Interfered completely
Work	0	1	2	3	4	5	6	7	8	9	10
Enjoyment of life	0	1	2	3	4	5	6	7	8	9	10
Interaction with others	0	1	2	3	4	5	6	7	8	9	10
Daily activities	0	1	2	3	4	5	6	7	8	9	10
Sexual relationships	0	1	2	3	4	5	6	7	8	9	10
Quality of life	0	1	2	3	4	5	6	7	8	9	10

Copyright 2013 The University of Texas MD Anderson Cancer Center  
All rights reserved

AA patients about what concerns them the most, and by asking patients about the ease of responding to the questions about symptoms and whether any additional symptoms or concerns were not covered in the instrument. Second, we provide additional psychometric evidence for the use of the AASIS in clinical practice, clinical trials, and epidemiological studies.

**RESULTS**

**Cluster analysis**

Cluster analysis gives an overall view of the structure of patient responses to the total set of items. Two of the authors (TM and MD) made the determination of which items were deemed similar enough so that redundant items were

eliminated from inclusion in the AASIS. We generated a dendrogram (not shown) that depicted how the 125 items eventually coalesced into a single cluster. Of interest were items that were rated similarly early in the clusters. For example, *sexual activity* and *sexual interest* were rated similarly and resulted in including *sexual relationships* as an item. Another example were items such as *feel sad* and *feel depressed* that eventually led to including *feeling sad*.

**Content Validity Index (CVI)**

An expert panel of 13 dermatologist/clinicians rated the relevance of each symptom or symptom-related item in the NAAR. The AASIS items are not exactly the same as items in the NAAR. Thus, [Table 1](#) shows the summary statistics of the

Download English Version:

<https://daneshyari.com/en/article/8716473>

Download Persian Version:

<https://daneshyari.com/article/8716473>

[Daneshyari.com](https://daneshyari.com)