

Psychosocial and occupational burden on caregivers of adolescents with AA in Australia

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INTRODUCTION

- Alopecia areata (AA) is a T-cell mediated autoimmune, non-scarring hair-loss disease of the scalp, face, and/or body¹. In Australia, the incidence was 0.278 per 1000 person-years, with the highest rates observed among individuals aged 19-34 years.²
- The symptoms of AA can lead to significant emotional and psychological distress for both patients and their caregivers³⁻⁵ manifested as anxiety, sadness/depression, and guilt/helplessness.⁵
- Evaluating the impact of AA on caregivers' QoL is crucial for recognising their needs and determining necessary healthcare and social supports to manage the burden of the disease and improve healthcare services.
- Though, a few studies have investigated the psychosocial and occupational impact of AA on the parents and caregivers^{4,6}, none of them were performed in the Australian setting.

OBJECTIVE

- To investigate the impact of AA on psychosocial well-being, work productivity and quality of life among caregivers of adolescent patients in Australia.

METHODS

- A non-interventional, cross-sectional online survey was conducted among dyadic and non-dyadic caregivers of adolescent patients with AA in Australia between April 2023 to July 2023.

Dyadic Caregivers

Caregivers whose dependant also participated in the survey.

Non-dyadic Caregivers

Caregivers whose dependant refused or unable to participate in the survey.

Eligibility and Participant recruitment

- Individuals, aged > 18 years, who were either a parent or legal guardian of patients aged 12-17 years with a self-reported, medically confirmed diagnosis of AA for at least 3 months before the survey completion date, who can read English language, and provided informed consent for participation, were included in this survey.
- Australia Alopecia Areata Foundation (AAAF) assisted with the nation-wide recruitment of study participants.

Assessments

- Three patient-reported outcomes (PROs) instruments were used:
 - The quality of life of caregivers was evaluated with Quality of Life in Child's Chronic Disease Questionnaire (QLCCDQ)
 - Anxiety and depression symptoms were assessed with the Hospital Anxiety and Depression Scale (HADS)
 - The Work Productivity and Activity Impairment (WPAI) questionnaire determined the impact of AA on work productivity of caregivers.

Limitations

- The study has certain limitations due to sample bias, and the inherent constraints associated with online self-reported surveys.
- It may not represent the experiences of non-English speakers, those without internet or mobile access, or those outside of the AAAF network.
- Nevertheless, the broad participant outreach enhances the study generalisability and provides valuable perspectives into the experiences of caregivers of adolescents living with AA in Australia.

CONCLUSIONS

- AA in adolescents can profoundly affect the entire family.
- While the focus often remains on the patient, the psychosocial and occupational burdens on caregivers receives less attention.
- This first study, conducted in Australia, of the impact on the health-related quality of life of caregivers of adolescents with AA, revealed a substantial psychosocial and occupational burden and an impairment on mental and emotional wellbeing.
- These findings highlight the importance of recognising the disease-related burden that extends beyond the individual patient.

RESULTS

- A total of 53 caregivers of adolescent patients living with AA (43 dyadic and 10 non-dyadic caregivers) participated in the survey (Table 1).
- The caregivers were assigned to sub-groups based on the self-reported extent on adolescents' scalp hair loss per the Scalp Hair Assessment PRO (Less extensive hair loss vs more extensive hair loss).

Table 1. Sociodemographic characteristics of caregivers

	Dyadic Caregivers of Adolescents with			
	Total (N=53)	Less Extensive Hair Loss (n=25)	More Extensive Hair Loss (n=18)	Non-dyadic Caregivers (N=10)
Age, mean (SD), y	43.4 (6.99)	44.7 (6.53)	41.6 (6.38)	43.4 (8.99)
Female (at birth), n (%)	43 (81.13)	22 (88.0)	14 (77.78)	7 (70.0)
Residence location, n (%)				
Metropolitan	43 (81.13)	19 (76.0)	15 (83.33)	9 (90.0)
Regional	10 (18.87)	6 (24.0)	3 (16.67)	1 (10.0)
Rural/remote	-	-	-	-
Aboriginal or Torres Strait Islander origin, n (%)	4 (7.55)	-	4 (22.22)	-
Race, n (%)				
White or Caucasian	47 (88.68)	23 (92.0)	16 (88.89)	8 (80.0)
Asian	3 (5.66)	1 (4.0)	-	2 (20.0)
Multiple races or other	3 (5.66)	1 (4.0)	2 (11.11)	-
Jurisdiction of Australia, n (%)				
New South Wales	15 (28.30)	4 (16.0)	9 (50.0)	2 (20.0)
Victoria	13 (24.53)	10 (40.0)	1 (5.6)	2 (20.0)
Queensland	7 (13.21)	2 (8.0)	3 (16.67)	2 (20.0)
Western Australia	12 (22.64)	8 (32.0)	2 (11.11)	2 (20.0)
South Australia	1 (1.89)	1 (4.0)	-	-
Tasmania	4 (7.55)	-	3 (16.67)	1 (10.0)
Australian Capital Territory	1 (1.89)	-	-	1 (10.0)
Relationship with the dependent adolescent patient with AA, n (%)				
Parent	47 (88.68)	25 (100.0)	12 (66.67)	10 (100.0)
Sibling	2 (3.77)	-	2 (11.11)	-
Other family	2 (3.77)	-	2 (11.11)	-
Legal guardian	2 (3.77)	-	2 (11.11)	-

Medical history of adolescent

	Total (n=53)	Less Extensive Hair Loss (n=25)	More Extensive Hair Loss (n=18)
Time (in years) since first experienced hair loss, mean (SD)	-	5.3 (3.98)	-
Time (in years) since first diagnosed by a HCP, mean (SD)	-	5.3 (4.16)	-

Residence location is classified into three categories: Metropolitan (Major Cities), Regional (Inner and Outer Regional), and Rural/Remote (Remote and Very Remote Australia), as per the Australian Statistical Geography Standard (ASGS) Remoteness Structure. This classification reflects geographic access to services measured by the Accessibility/Remoteness Index of Australia Plus (ARIA+). Less extensive hair loss = Scalp Hair Assessment PRO (SHA PRO) category 0+1+2; More extensive hair loss = SHA PRO category 3+4. Abbreviations: AA = alopecia areata; SD = standard deviation.

The Quality of Life in Child's Chronic Disease Questionnaire (QLCCDQ)

- Mean scores decreased with increasing hair loss, representing an increased burden with increasing hair loss.
- Caregivers reported a total score of 4.8 ± 1.08 (emotions 3.9 ± 1.27 ; symptoms 4.0 ± 1.46 ; roles limitations 3.5 ± 0.89 (family 5.8 ± 1.22 ; social 5.2 ± 1.19 ; occupational 5.3 ± 1.29) (Figure 2).
- Our study reported a numerical difference to an AA cohort previously studied⁴, indicating a reduced quality of life compared to that study.

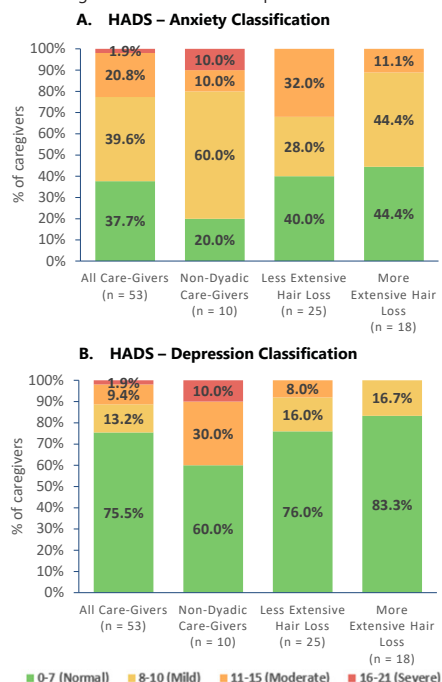
Work Productivity and Activity Impairment (WPAI)

- Most caregivers experienced activity impairment, 50.9%, and did not change with extent of adolescent hair loss (Table 2).
- 49.1% experienced overall work impairment, 45.3% experienced impaired work productivity (presenteeism) and 26.4% experienced work time missed (absenteeism), due to their adolescents' AA.

Hospital Anxiety and Depression Scale (HADS)

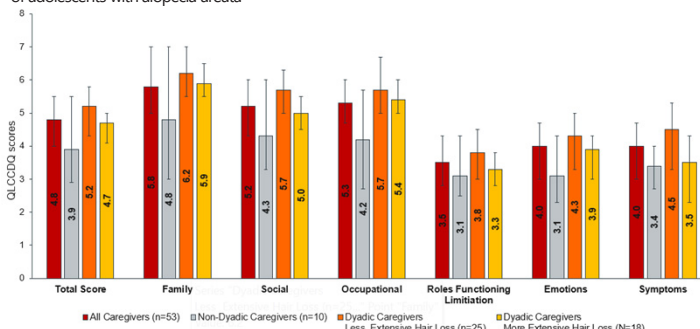
- A total of 62.3% and 24.5% of caregivers reported HADS anxiety and depression levels, respectively, outside the normal ranges (Figure 1).
- The adolescent's extent of hair loss had minimal impact on anxiety and depression amongst the caregivers

Figure 1. Hospital Anxiety and Depression Scale (HADS) scores for caregivers of adolescents with alopecia areata



This 14-item measure, 7 items related to anxiety and 7 related to depression, are scored on a 4-point scale from 0 to 3, describing how often a symptom is experienced. Scores range from 0 to a maximum of 21. Lower scores indicate lower levels of anxiety and depression.

Figure 2. Quality of Life in Child's Chronic Disease Questionnaire (QLCCDQ) scores for caregivers of adolescents with alopecia areata



Individual domain scores are the arithmetic means of items within each domain, with Total Score as the mean of all 15 items. Domain scores for Emotions, Symptoms, and Role Limitations (Family, Social, Occupational). Scores range from 7 (no impairment) to 1 (severely impaired), where lower scores denote higher impairment. A previous study reported QLCCDQ scores from a healthy cohort: emotions=6.2±1.0; symptoms=5.9±1.1; roles limitations=6.5±1.4 (family=6.3±0.9; social=6.6±1.1; occupational=6.4±1.7)

Table 2. Work Productivity and Activity Impairment (WPAI)

	Total (N=53)	Non-dyadic Caregivers (n=10)	Dyadic Caregivers of Adolescents with	
			Less Extensive Hair Loss (n=25)	More Extensive Hair Loss (n=18)
Activity impairment due to adolescent's AA, n (%)	27 (50.9)	7 (70.0)	10 (40.0)	10 (55.6)
Absenteeism due to adolescent's AA, n (%)	14 (26.4)	4 (40.0)	8 (32.0)	2 (11.1)
Presenteeism due to adolescent's AA, n (%)	24 (45.3)	5 (50.0)	10 (40.0)	9 (50.0)
Overall work impairment, n (%)	26 (49.1)	5 (50.0)	11 (44.0)	10 (55.6)

The WPAI assesses four areas expressed as percentages: absenteeism (work time missed), presenteeism (impairment at work/reduced on-the-job effectiveness), overall work impairment (combined effect of absenteeism and presenteeism), and activity impairment (impairment in daily activities other than work) Higher values indicate greater impairment and productivity loss.

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DISCLOSURES

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REFERENCES

- Gilbar A, Ezioni A, Paus R. Alopecia areata. *The New England Journal of Medicine*. 2012; 366:1515-1522.
- Sinclair R, Eisman S, Song W, et al. Incidence and prevalence of alopecia areata in the Australian primary care setting: A retrospective analysis of electronic health record data. *Australasian Journal of Dermatology*. 2023; 64: 330-338.
- Williamson D, Gonzalez M, Finlay AV. The effect of hair loss on quality of life. *Journal of the European Academy of Dermatology and Venereology*. 2001; 15: 137-139.
- Pattinson E, Patel DP, Andrade G, et al. Severity of disease and quality of life in parents of children with alopecia areata, totalis, and universalis: A prospective, cross-sectional study. *Journal of the American Academy of Dermatology*. 2019; 80: 1389-1394.
- Gilding AI, Ho N, Pope E, Sibbald C. The Burden of Disease in Alopecia Areata: Canadian Online Survey of Patients and Caregivers. *JMIR Dermatology*. 2022; 5: e39167.
- Savay Erdogan S, Falay Gur T, Dogan B. Anxiety and depression in pediatric patients with vitiligo and alopecia areata and their parents: A cross-sectional controlled study. *Journal of Cutaneous Medicine and Surgery*. 2021; 20: 2232-2239.
- Famik M, Brozek G, Pierzchala W, et al. Development, evaluation and validation of a new instrument for measurement quality of life in the parents of children with chronic disease. *Health and Quality of Life Outcomes*. 2010; 8: 151.

