

Medical jewellery use in young Australians with adrenal insufficiency

Georgina L Chrisp¹, Maria Quartararo¹, David J Torpy^{2,3}, Henrik Falhammar^{4,5} and R. Louise Rushworth¹

¹School of Medicine, Sydney, The University of Notre Dame Australia, Darlinghurst, NSW, Australia. ²Endocrine and Metabolic Unit, Royal Adelaide Hospital, Adelaide, SA, Australia. ³University of Adelaide, Adelaide, SA, Australia. ⁴Department of Endocrinology, Metabolism and Diabetes, Karolinska University Hospital, Stockholm, Sweden. ⁵Department of Molecular Medicine and Surgery, Karolinska Institutet, Stockholm, Sweden

Abstract

Background: Patients with adrenal insufficiency (AI) are at risk of an adrenal crisis (AC) which is an acute life-threatening episode of AI.¹ Medical jewellery is recommended to AI patients as a non-verbal communication tool for emergencies to prevent delays in diagnosis and management of an AC.^{2,3} In Australia, the major medical identification jewellery provider offers a pay-for-subscription service in which jewellery with a unique identifier and a distinctive emblem can be inscribed with diagnostic and emergency information. Up to date subscriptions are classified as 'active' whereas those with an unpaid annual fee are 'inactive'. In emergencies involving a subscriber with an active subscription only, first responders or medical attendants can utilise a 24 hour telephone response service to access relevant medical information stored on a database according to the subscriber's unique identifier.⁴ Although, use of medical jewellery is considered important and potentially life-saving, its uptake amongst children and young adults with AI is unknown.

Aim: To examine the use of medical jewellery amongst Australians aged 25 years and under with AI.

Methods: Data on the age, sex, region, subscription category (active or inactive) and diagnosis of subscribers to the largest medical jewellery provider in Australia were analysed. Subscription rates were calculated using 2017 Australian population data.⁵ Patient age was categorised into 5 year age groups. Logistic regression models were used to identify predictors of an active subscription. Chi square tests were used to analyse differences between categorical variables and z scores were calculated to determine differences in proportions of subscribers between the highest and lowest age groups or states.

Results: There were 666 patients aged 25 years and under in the database. 358 (53.8%) had an active subscription, corresponding to an active subscription rate of 43.67/million or approximately 14.6% of the estimated patient population with AI. Of these, 238 (66.5%) had primary AI; 82 (22.9%) had secondary AI and the remaining patients (n=38, 10.6%) could not be classified. Congenital adrenal hyperplasia (CAH) was the most frequent specific AI diagnosis (n=153, 42.7%) amongst subscribers, corresponding to a subscription rate of 18.67/ million or 28.9% of the estimated number of patients with CAH. The mean age of active subscribers was 15.9 (SD=5.8) years. Only 18 (5%) of these patients were aged under 5 years. Overall, more females (n=199, 55.9%) than males were active subscribers, with the largest between-sex difference recorded in the 15-19 year age group. Subscription rates also differed significantly by geographic area. Western Australia had the highest subscription rate (82.00/million) and Queensland the lowest (25.41/million). Inactive subscriptions increased with age and were highest in the 20-25 year age group.

Conclusion: Subscription was lower than recommended but increased with age; and was more common in females and varied between geographic areas. Older age was associated with higher levels of inactive subscriptions. Factors leading to low use and discontinuation in young adults should be addressed to help maximise use and reduce the risk of AC-related morbidity and mortality.

Word count: 486

References

1. Rushworth RL, Torpy DJ, Falhammar H. Adrenal Crisis. *New Engl J Med*. 2019 Aug;381:852-61
2. Rushworth RL, Torpy DJ, Stratakis C, Falhammar H. Adrenal crises in childhood: perspectives and research directions. *Horm Res Paediatr*. 2018 Jul;89(5):341-351
3. Bornstein S, Allolio B, Arlt W, Barthel A, Don-Wauchope A, Hammer GD, Husebye ES, Merke DP, Murad MH, Stratakis CA, Torpy DJ. Diagnosis and treatment of primary adrenal insufficiency: an endocrine society clinical practice guideline. *J Clin Endocrinol Metab*. 2016 Feb;101(2):364-389
4. MedicAlert Foundation. "Why become a MedicAlert member". *MedicAlert*, <https://www.medicalert.org.au/benefits-of-membership/>. Accessed 21 Mar. 2021.
5. Australian Bureau of Statistics, "Australian demographic statistics, Jun 2017, estimated resident population by age and sex – at 30 June 2017", Datacube: Excel Spreadsheet, Cat no: 3101.0, 2017