



Medical identification jewellery use in children and young adults with adrenal insufficiency

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Background

Adrenal insufficiency (AI) results from diseases or conditions of the hypothalamic-pituitary-adrenal axis that impair the biosynthesis of cortisol, with or without aldosterone deficiency. It is typically categorised into primary (PAI) or secondary (SAI) AI, based on the locus of impairment.¹ The estimated prevalence of PAI in Australia is approximately 95 per million.^{2,3} In childhood, the most common form of AI is congenital adrenal hyperplasia (CAH).⁴ All patients with AI are at risk of an adrenal crisis (AC), particularly during acute illness. Infants, young children and young adults may be particularly prone to ACs.⁵ Due to the heterogeneity of presentation and non-specificity of symptoms, AC identification may be difficult.⁶ Delays in diagnosis and initiation of treatment substantially increases the risk of morbidity and mortality. Medical identification jewellery is recommended for all patients with AI. It enables non-verbal communication of an AI diagnosis in an emergency, minimising delays in AI/AC diagnosis and management.⁷ Although the use of medical jewellery by paediatric patients with CAH is low, its uptake in a paediatric and young adult population with AI more broadly is unknown.⁸

Aim

To assess the use of medical jewellery among patients aged 25 years and under with AI in Australia.

Method

Subscription records of all people aged 25 years and under in the database of a large, pay for service Australian medical identification jewellery subscription provider were analysed. Data on age, sex, diagnoses, activity status, and treatment for each eligible subscriber were extracted on 17 September 2018. Subscription rates were calculated using 2017 Australian population data from the Australian Bureau of Statistics.

Results

There were 666 patients with AI included in the study. 358 (53.8%) had an active subscription, corresponding to a rate of 43.7/million and approximately 14.6% of the estimated patient population. The majority (66.5%, n=238) had primary AI; 82 (22.9%) had secondary AI; and 37 (10.6%) patients could not be classified (Table 1).

The mean age of subscribers was 15.9 (SD=5.8) years, with only 18 (5.0%) patients aged under 5 years. Females (n=199, 55.9%) and those in the 15-19 age group had the highest proportion of active subscribers (Figure 1). Subscription rates differed significantly by geographic area (p<0.05) with active rates in Western Australia found to be over three times higher than Queensland (80.9 and 25.4 per million respectively). Inactive (lapsed) subscriptions increased with age and were highest in the 20-25 year age group (Figure 2).

Table 1: Disease characteristics of active subscribers

AI category	N	%	Rate (per million)
All PAI	238	66.5	29.0
CAH only	153	42.7	18.7
PAI (excluding CAH)	85	23.7	10.4
All SAI	73	20.4	8.9
Glucocorticoid induced AI (GCAI) only	9	2.5	1.1
SAI (excluding GCAI)	64	17.8	7.8
AI (undefined)	37	10.3	4.5

Conclusion

Utilisation of a large medical identification jewellery subscription service in patients with AI was low. Uptake increased with age but was associated with higher levels of lapsed subscriptions. Low utilisation rates in younger children suggests that parents/carers elect to maintain close supervision of the child and defer use of medical jewellery until the child is more independent. Overall, females used jewellery more than males. Geographic differences suggest that local factors also influence utilisation. High levels of lapsed subscriptions indicate the need for ongoing reinforcement of AC preventive education, particularly as patients transition from paediatric to adult healthcare.

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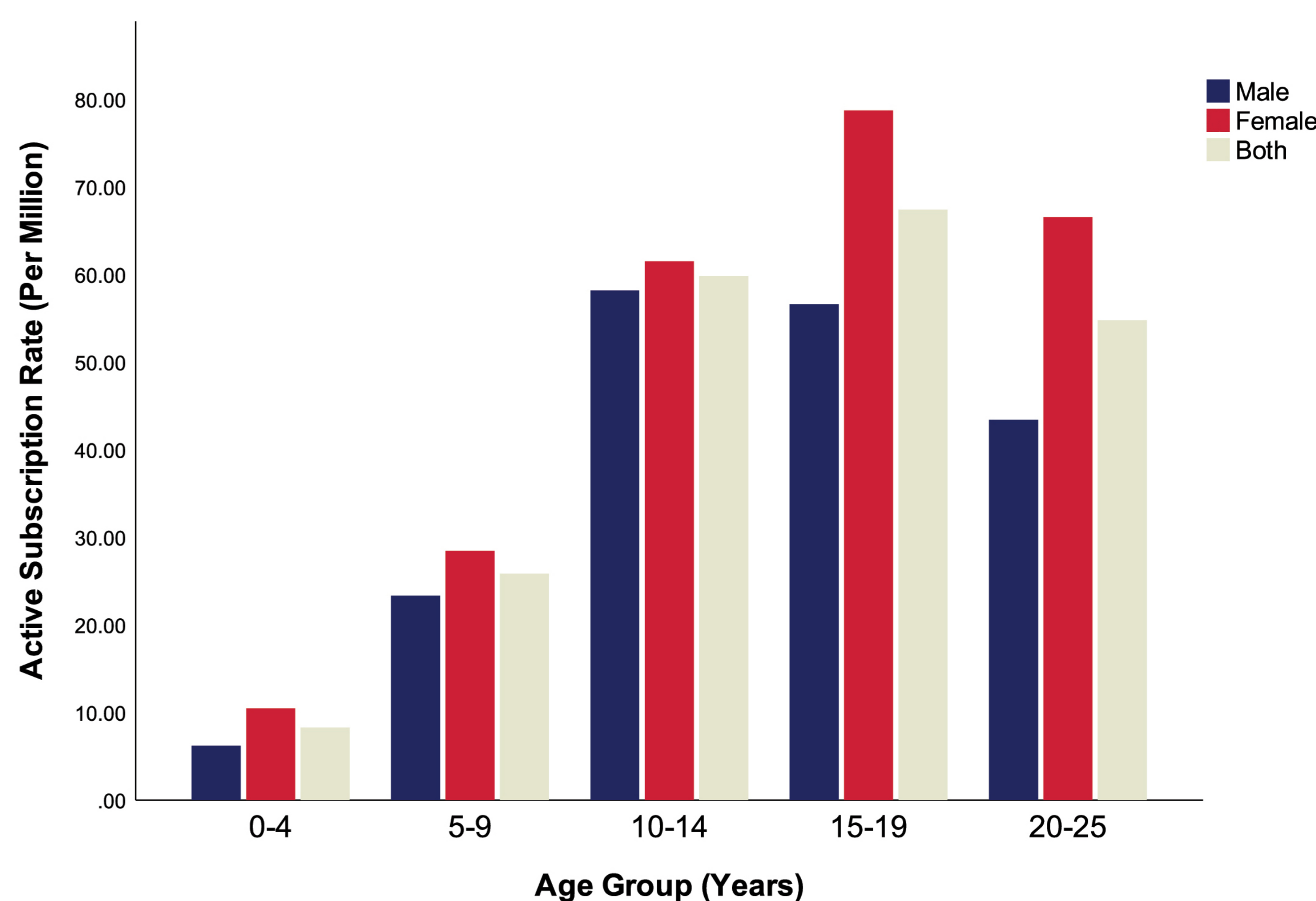


Figure 1: Active Subscription Rates by Sex and Age Group

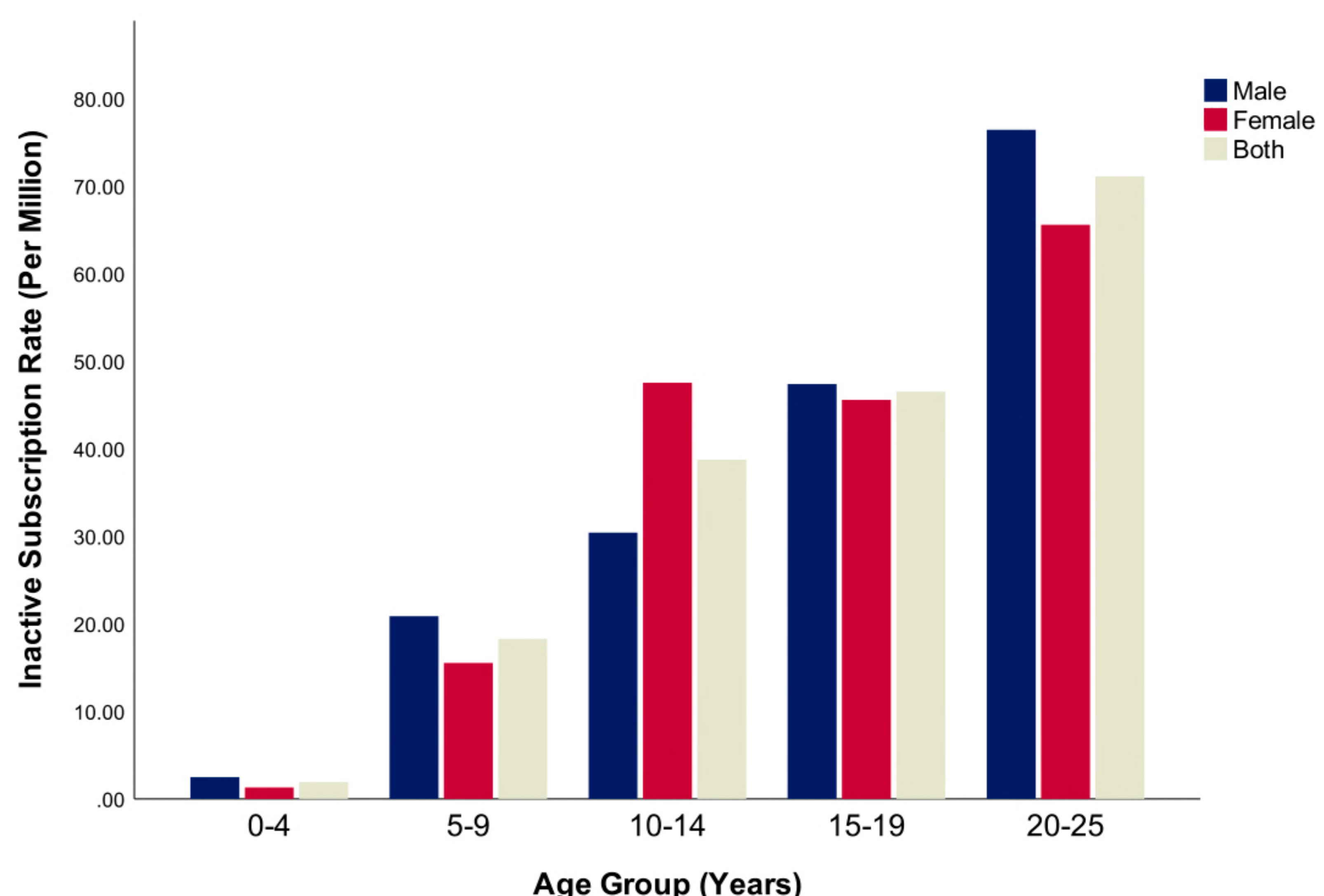


Figure 2: Inactive Subscription Rates by Sex and Age Group

