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ORIGINAL RESEARCH

Experiences of Oral Corticosteroid Use and Adverse Effects: A National Cross-Sectional Survey of People with Asthma

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Purpose: Oral corticosteroids (OCS) are an effective treatment for severe uncontrolled asthma or asthma exacerbations, but frequent bursts or long-term use carry serious and sometimes irreversible adverse effects, or complications such as adrenal insufficiency upon discontinuation. Our aim was to survey people with asthma on their experiences of, and attitudes towards, using OCS.

Patients and Methods: This study was a national descriptive cross-sectional survey of people with asthma in Australia. An anonymous survey was hosted online with invitations to participate distributed by national consumer peak bodies. Survey free-text responses were coded to the Theoretical Domains Framework (TDF) to elicit determinants of OCS use.

Results: 1808 people with asthma participated between 3 and 16 May 2022. Most common reasons for using OCS were severe asthma symptoms (40%), doctor prescription (38%) or asthma action plan recommendations (20%). Approximately 55% of people had experienced adverse effects from OCS use. Commonly reported adverse effects were trouble sleeping (69%), weight gain (56%) and mood problems (41%). Of people who had OCS at home or an OCS script, 44% did not have an action plan that described when and how they should take them. People (33%) did not feel well informed about OCS adverse effects from their healthcare team. People had varied awareness (3–65%) of current available strategies to reduce OCS use. 'Knowledge', 'Environmental context and resources' and 'Social influences' were the most coded TDF domains influencing OCS use.

Conclusion: Adverse effects of OCS use are common. People with asthma are not adequately informed about optimal OCS use or strategies to reduce overuse. These findings can help guide the implementation of OCS stewardship initiatives.

Keywords: asthma, corticosteroids, consumer behaviour, attitude, patient participation

Introduction

Asthma is a chronic airway disease that affects approximately 300 million people worldwide.[1] More than 11% of the overall population in Australia and New Zealand report using asthma treatment.[2] Oral corticosteroids (OCS) are prescribed to treat asthma during acute exacerbations (burst therapy) or to manage ongoing uncontrolled symptoms and frequent exacerbations (maintenance treatment).[3] Frequent bursts as well as maintenance OCS therapy are associated with numerous short-term and long-term adverse effects, including insomnia, indigestion, fluid retention, weight gain,

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osteoporosis, hypertension, glucose intolerance and increased risk of infections.[3–10] Adverse outcomes are detectable following one-off OCS use, with risk increasing with repeated use.[11] Discontinuation from high-dosage or long-term use of OCS can also lead to secondary adrenal insufficiency, particularly with abrupt withdrawal of OCS.[12,13] Adrenal insufficiency can present with non-specific signs and symptoms such as, fatigue, weight loss and gastrointestinal upset or life-threatening emergencies such as acute adrenal crisis.[14]

The increased awareness of the adverse effects has led to maintenance OCS becoming a treatment option of last resort in international guidance, but OCS during acute severe asthma exacerbations is considered life-saving and recommended to help avoid hospitalisation and relapse following exacerbation.[15] Accumulating evidence indicates the risk of various long-term adverse effects increases once lifetime exposure to OCS exceeds 1000 mg prednisolone equivalent, a cumulative dose that can be met by only four prescribed courses of prednisolone to treat acute asthma exacerbations.[16] Overuse of OCS therefore places people with asthma at risk of significant adverse effects and irreversible harm.[17] Over a 5-year period, Hew et al[18] estimated that 28% (n = 350,000) of their cohort of Australians with asthma had been dispensed cumulative doses of OCS exceeding 1000 mg prednisolone equivalent. OCS use for the treatment of increased respiratory symptoms in health care settings is too widespread, and not always fully considered.[19,20] This may partly be due to prescriptions based on limited information from brief consultations,[21] or that the decision not to prescribe OCS treatment also carries potential risk.[22] OCS prescriptions for asthma exacerbations (regardless of severity) are common.[23] For example, almost half of the 8000 participants with asthma from 11 countries in the REALISE study cohort reported that they had acute asthma exacerbations treated by OCS in the previous year.[21] There is an urgent need to introduce OCS stewardship approaches, akin to initiatives that achieved success with optimising appropriate antibiotic usage.[24]

A position statement from the Thoracic Society of Australia and New Zealand outlined key principles applicable to the OCS stewardship movement in Australia.[17] The statement provided a strong call for the introduction and application of OCS stewardship programs to minimise the use of OCS, ensuring appropriately targeted OCS use, shortest treatment duration needed to produce clinical benefit and vigilance for emerging adverse effects. Similar calls for action have been produced by international working groups in order to identify potential strategies for implementing OCS stewardship.[25] Together, these calls have set out actionable steps that could be undertaken for OCS stewardship in the future including optimising preventive asthma treatments, addressing modifiable risk factors and comorbidities, education and shared decision making to communicate benefits and risks, timely specialist assessments and use of OCS-sparing biologic and non-biologic add-on therapies, standardised tapering schemes, continuous monitoring of prescriptions and adverse effects, or regulations of OCS prescribing. In this context, understanding the perspectives of people with asthma is key to informing the implementation and translation of any OCS stewardship initiatives. The aim of this study was therefore to undertake the first national survey of people with asthma in Australia on their experiences of, and attitudes towards, using OCS.

Materials and Methods

Design

This study was a national descriptive cross-sectional survey conducted in Australia.

Participant and Recruitment

Adults (aged 18 years or over) living in Australia self-reporting a diagnosis of asthma or care of a child (aged less than 18 years) with asthma were eligible for this study. The survey was hosted online (Qualtrics) by Monash University and was launched on World Asthma Day in 2022 (3rd May 2022). Advertising involved mailing lists, newsletters, webpages and social media channels of key trusted consumer peak bodies in Australia (Asthma Australia; Asthma WA). This included specific promotion by Asthma Australia as part of a campaign to raise awareness on OCS. Each advertisement contained a link to access the survey. The landing page provided brief information about the study and a link to full participant information (Explanatory statement) before proceeding with the survey. People were informed that completion of the survey was considered consent to participation. Participants were made aware by proceeding with the survey they are agreeing to the information provided by the explanatory statement. The survey landing page also clarified that the survey was collecting information regarding OCS and not inhaled medication.

Procedures

The survey was completed anonymously. To understand the reach of the survey, respondents were asked to indicate whether they were answering on behalf of themselves, or a child aged less than 18 years, their state or territory of residence in Australia and the number of years since asthma diagnosis. Respondents were then asked a series of questions (Table 1) which required respondents to select one answer or multiple answers and/or an opportunity to elaborate on their answer using free-text boxes. The full survey template including possible answers to all questions are provided in the Supplementary Material S1.

Sample Size

The online survey was intended to explore the experience of people living with asthma to inform future implementation of OCS stewardship initiatives hence a formal sample size calculation was not performed.

Data Analysis

The survey comprised of categorical and free-text data. Data were exported from Qualtrics and collated in Excel. Categorical data were reported descriptively using numbers and proportions. Any free-text responses that related to OCS use were coded according to a pre-defined framework. Relevance to OCS use was inferred by the survey question or where responses referenced OCS use. The Theoretical Domains Framework (TDF) was used as the coding framework to understand sources of behaviour that prevented or promoted OCS use. As a synthesis of 33 behaviour change theories clustered into 14 domains, the TDF offers a theoretical framework to understand determinants (eg barriers and facilitators) of consumer or health professional behaviour in health care settings and public health.[26] Free-text survey responses were synthesised line-by-line and first mapped to one or more of the 14 domains and then interpreted as to whether it was in the context of preventing or promoting OCS use. The total number of responses coded against each domain and whether the responses related to prevention or promotion of OCS use were collated. Where a response was unclear on prevention or promotion of OCS, the response was counted twice for that domain (ie both as prevention and promotion of OCS use).

Results

Characteristics of Study Participants

The online survey was accessed 2399 times between May 3 and May 18 2022, with a total of 1808 responses (591 did not progress to completion of any questions). Of the 1808 responses, 91% were adults with asthma, with 60% having lived with an asthma diagnosis for more than 15 years. All states and territories of Australia were represented in this national survey. Further breakdown of the survey participants is detailed in Table 2. At least 84% of the survey cohort provided a response to all questions of the survey.

Use of and Access to OCS

Of those who responded to the survey (n = 1808), 39.8% and 37.9%, respectively, use OCS only when they experience severe asthma symptoms (eg to avoid needing to go to hospital) or when their doctor tells them. Others use OCS as recommended by their written asthma action plan (20.2%), as soon as they start to experience worsening asthma

Table 1 Survey Questions on Consumer Experience of OCS Treatment

How do you currently use corticosteroid tablets?
Do you currently have corticosteroid tablets at home?
Do you have a written asthma action plan that describes when and how you should take corticosteroid tablets?
Have you experienced side effects (if yes, please specify)?
Do you think that having more knowledge about the potential side-effects of corticosteroid tablets would have changed the way you used them?
What would you like to have been told about the potential side effects of corticosteroid tablets?
My doctor has discussed the following strategies with me that can reduce corticosteroid tablet use
What other things do you think we could do to reduce overuse of corticosteroid tablets for people with asthma?

Table 2 Characteristics of Survey Participants

Age	**n (%)**
Adult	1644 (90.9)
Child	163 (9.0)
Not declared	1 (0.1)
Asthma diagnosis	
Less than 1 year	25 (1.4)
1 to 5 years	175 (9.7)
6 to 10 years	158 (8.7)
11 to 15 years	134 (7.4)
More than 15 years	1080 (59.7)
Not declared	236 (13.1)
Australian state	
Australian Capital Territory	49 (2.3)
New South Wales	400 (22.1)
Northern Territory	15 (0.8)
Queensland	257 (14.2)
South Australia	187 (10.3)
Tasmania	43 (2.4)
Western Australia	224 (12.4)
Victoria	396 (21.9)
Not declared	237 (13.1)

symptoms (16.2%) or before they start to experience worsening asthma symptoms (3.7%). Some participants reported taking OCS daily (5.5%) whilst others (11.2%) reported never taking them.

With regards to current access to OCS (n = 1800), 12.7% were currently taking them, 54.7% had OCS at home but were not currently taking them, 11.7% had a written prescription to fill when needed, whilst 28.5% had no access to OCS at home. Of people who had OCS at home or an OCS script (n = 1246), 43.7% did not have access to an action plan that described when and how they should take them.

Adverse Effects of OCS

More than half (55%) of participants (n=973/1781) reported experiencing adverse effects when using OCS. The type and number of adverse effects per participant are reported in Figure 1. The number of adverse effects experienced per participant ranged from one to twelve. Of those who reported having experienced adverse effects (n = 973), the most common adverse effects were trouble sleeping (69%), weight gain (56%) and mood problems (41%). Of participants who responded (n = 1603) to whether they felt informed by their health care team about the adverse effects of OCS, 39.8% felt they were, 27.9% only partially whilst 32.4% felt they were not informed. Of participants who responded (n = 1603) to whether more knowledge of adverse effects would have affected previous OCS use, approximately half (50.6%) of participants said "no", 27.8% were unsure and 21.6% responded "yes". Participants (n = 1615) varied in what they would have liked to have been told about the adverse effects of OCS, all of which are reported in Figure 2.

Strategies to Reduce OCS Use

Awareness of strategies to reduce OCS use varied. Of participants who responded with what strategies to reduce OCS use had been discussed with them (n = 1525), there was greatest awareness of use of controller medications (64.9%) and least awareness of specialist treatments such as biologics (13%) and bronchial thermoplasty (3%). All strategies and the proportion of participants that had been informed of are reported in Figure 3A. Of participants who responded to what can be done to reduce overuse of OCS (n = 1540), education of patients (77.1%) and doctors (55.3%) about optimal use

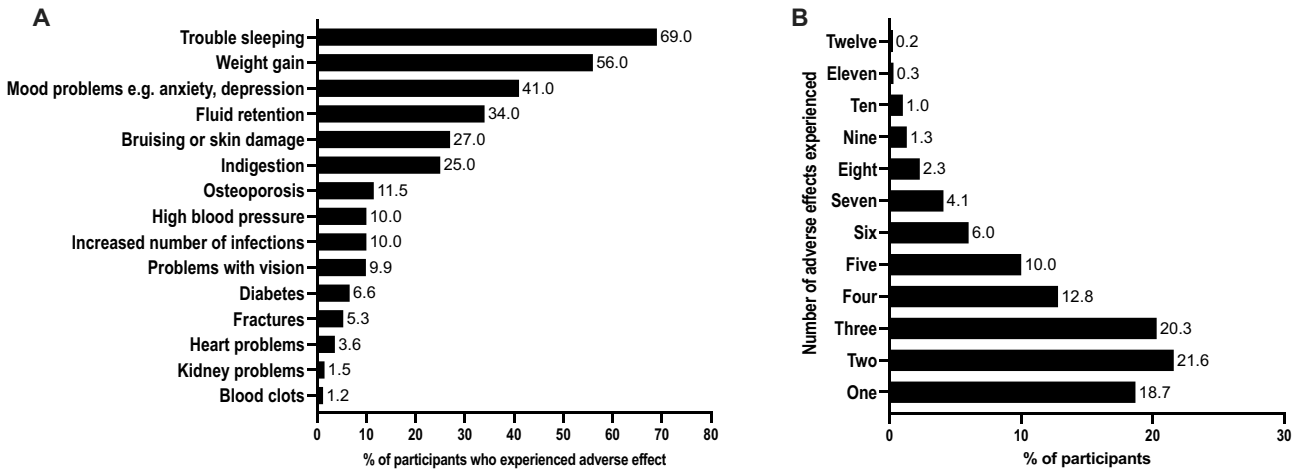

Figure 1 The type (**A**) and number (**B**) of adverse effects of OCS reported by participants (n=973).

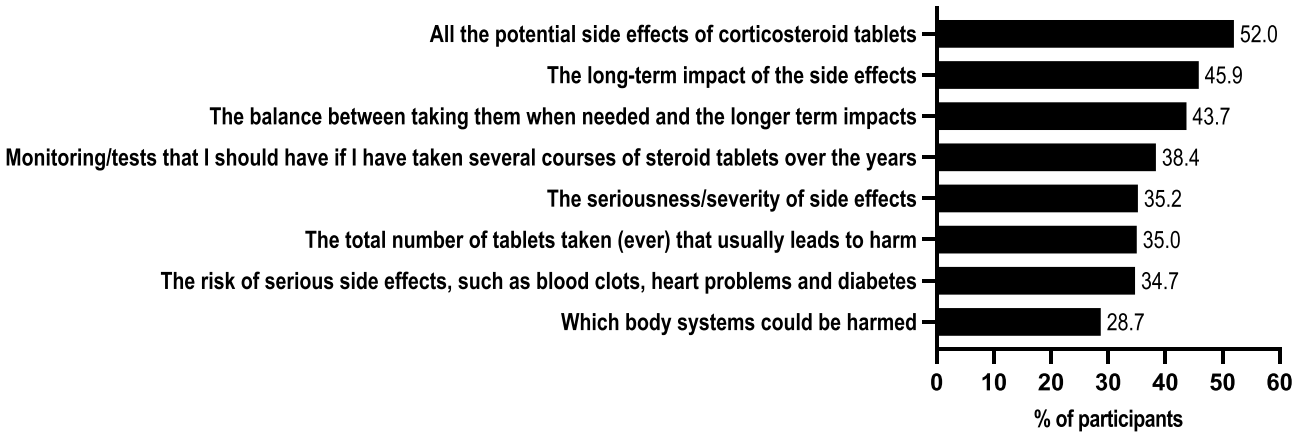

Figure 2 Proportion of participants (n=1615) and information they would have liked to have been told about the adverse effects of OCS.

and potential adverse effects were the most supported. Some respondents supported removing automatic repeats of OCS prescriptions (26%) or reducing the number of tablets dispensed at a time (Figure 3B).

Determinants of OCS Use

Out of a total of 1466 free-text responses across all survey questions, 741 related to OCS use. From these 741 responses, the domains of the TDF were coded 1260 times. All responses and their mapping to the domains of the TDF are available in the Supplementary Material S2. The TDF domains most coded across the free-text survey responses were "Knowledge" (awareness of the existence of something including scientific rationale), "Environmental context and resources" (circumstances of a person's situation influencing behaviour) and "Social influences" (interpersonal processes that change thinking or behaviours) (Table 3). The "Reinforcement" domain was not coded with any free-text responses. The number of times a domain was coded in the context of preventing or promoting OCS use varied (Table 3).

"Beliefs about capabilities", "Beliefs about consequences" and "Goals" were domains more often coded in the promotion of OCS use (Table 3). Participants reported that OCS were a necessary lifesaving treatment when they were very unwell, or OCS allowed them to avoid hospitalisation. Responses reflected a need for OCS when there was loss of control of asthma symptoms or when left with a choice to breathe or not to breathe. Some spoke to OCS as a last resort whilst others reported use being dependent on the increase in symptoms. Participants reflected on the specific severity of asthma attacks (eg admitted to hospital and viral exacerbations) or there being no effective alternatives as circumstances that led to OCS use, all of which underpinned the TDF domain of "Environmental context and resources". Relying on

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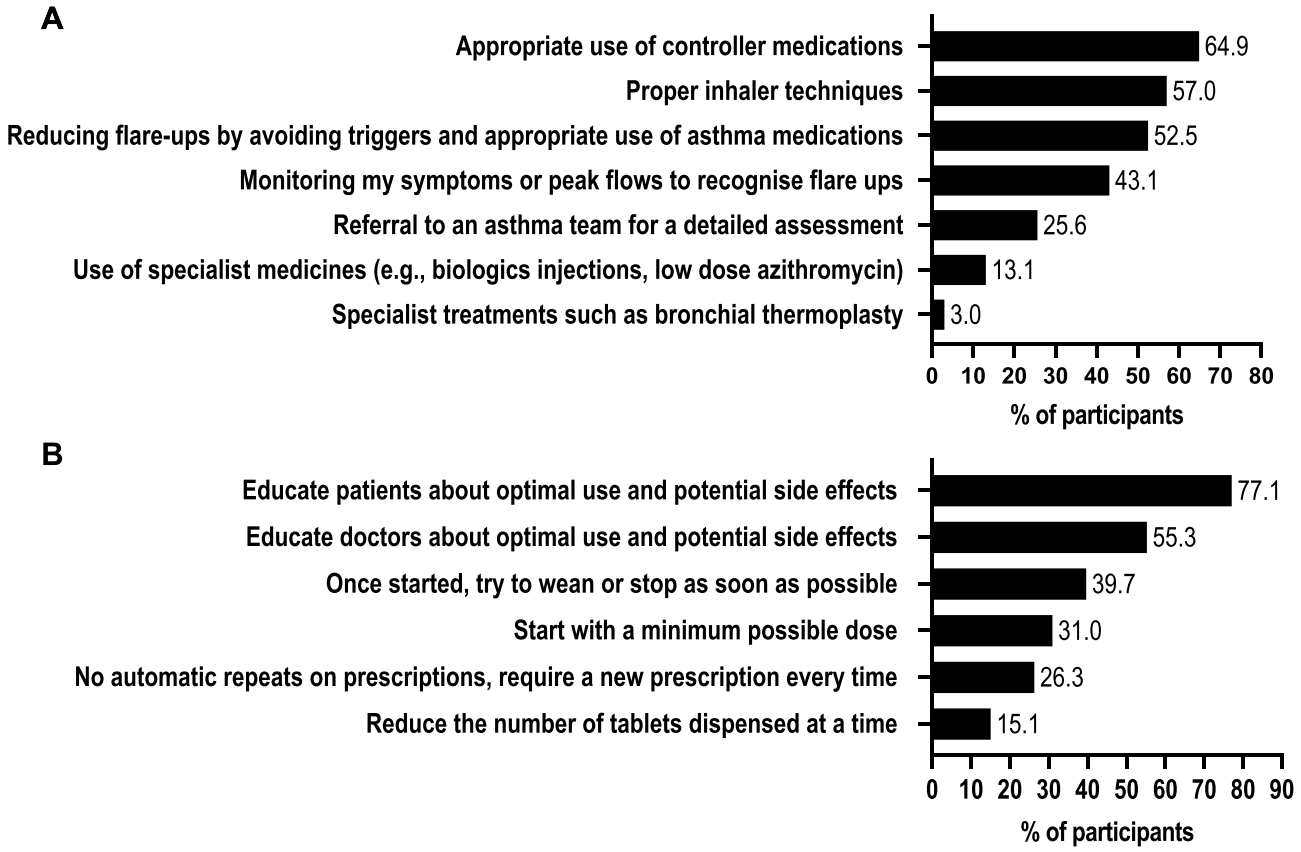

Figure 3 Proportion of participants: (**A**) reporting what strategies to reduce OCS use had been discussed with them (n=1525); (**B**) reporting what other strategies could be used to reduce overuse of OCS (n=1540).

advice from their GP or specialist ("Social Influences") or instructions in the form of action plans ("Behavioural Regulation") were reported by participants as reasons for OCS use. Some demonstrated procedural knowledge of the dosage and duration of OCS use ("Knowledge") or reflected on the number of years of living with asthma ("Skills") or their current/prior employment ("Social and Professional Identity") as acquired experience or practice of knowing when and how to use OCS. For some, the decisions came down to their recall on the balance between the benefits and adverse

Table 3 Determinants of OCS Use Mapped to the Theoretical Domains Framework

TDF domain	Prevent (-) vs promote (+) OCS	Common examples of determinants
Knowledge	(−) 125 (50%) vs 124 (50%) (+)	Knowledge of dosage during asthma attacks; Information from health care team on OCS; Education for health care professionals on broader asthma management
Skills	(−) 22 (54%) vs 19 (46%) (+)	Acquired experience on OCS use following years of living with asthma
Social/Professional Role and Identity	(−) 4 (40%) vs 6 (60%) (+)	Prior employment/experience as a health care professional informs use
Beliefs about Capabilities	(−) 12 (15%) vs 70 (85%) (+)	Lack of choice not to take OCS; Confidence regarding self-control of symptoms
Optimism	(−) 5 (83%) vs 1 (17%) (+)	Confidence there is no overuse of OCS

(*Continued*)

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Table 3 (Continued).

TDF domain	Prevent (-) vs promote (+) OCS	Common examples of determinants
Beliefs about Consequences	31 (17%) vs 147 (83%)	Avoidance of OCS because of adverse effects; OCS is an effective treatment
Intentions	7 (47%) vs 8 (53%)	Sustained commitment or reluctance to use OCS
Goals	1 (20%) vs 4 (80%)	If-then rules according to period of days or increase in symptoms
Memory, Attention and Decision Processes	24 (39%) vs 37 (61%)	Retain information on risk and benefits to decisions where outcome of OCS use may mean life or death
Environmental Context and Resources	141 (49%) vs 150 (51%)	Control of asthma with preventative treatments and avoidance of triggers; Use of biologics; No other effective options for asthma attacks; Use linked to hospitalisation or severe respiratory infections
Social Influences	123 (56%) vs 96 (44%)	Contact GP or specialist before using OCS
Emotion	6 (43%) vs 8 (57%)	Concern or worry about health or child's health
Behavioural Regulation	72 (81%) vs 17 (19%)	Action plans do not include OCS or specific instructions provided for OCS use

Notes: Prevent (-): response where consumer response related to not using OCS or decreasing OCS use; Promote (+): response where consumer response related to use of OCS or increasing OCS use.

effects of OCS and use represented circumstances where benefits outweighed the risks ("Memory, Attention and Decision Processes").

"Behavioural Regulation", "Optimism" and "Social Influences" were more often coded in the prevention of OCS use (Table 3). Participants expressed their asthma action plans do not instruct OCS use whilst some noted their uncertainties on whether OCS are in fact overused. It was apparent that relationships with health care teams helps to prevent OCS use. Participants reported that they would only use OCS following advice from their GP with some noting GP reluctance to prescribe unless absolutely necessary. Respiratory specialists were often mentioned in their influence of discussing or implementing strategies to reduce overuse of OCS. Other health professions were also noted including pharmacists, immunologists and physiotherapists. Prevention of OCS use also presented as existing awareness of the adverse effects of OCS, information from health care team for the need to restrict use or recognition that additional education on broader asthma management was necessary for both people living with asthma and their clinicians ("Knowledge"). Having alternative options to OCS including access to biologics was also reported to prevent OCS use, as were correct use of "preventers" and better control of environmental triggers of symptoms ("Environmental context and resources"). Some participants noted their competence (through experience and practice) or ability to self-manage asthma or having benefited from skill development from others (eg inhaler technique) to help avoid OCS use ("Skills").

Discussion

This study aimed to understand the experiences and attitudes of people with asthma in using OCS. To our knowledge, this study is the largest survey of experiences with OCS in people living with asthma, and the first nationwide study conducted in Australia. Adverse effects were prevalent in people with asthma who had previously used OCS, with trouble sleeping, weight gain and mood problems being the most common. People with asthma had prescriptions for OCS supplies at home, but more than half did not have written action plans to guide use. Many Australians with asthma do not feel adequately informed about OCS, but they want more than information about adverse effects to optimise use. Using a theory-driven approach, we identified key domains that influence consumer behaviour towards the use of OCS including knowledge, environmental context and resources and social influences.

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The current study adds new evidence on the burden of OCS in asthma and through the use of a theoretical implementation science lens has helped understand the key determinants of OCS use. Trouble sleeping, weight gain and mood problems have been reported as either the most perceived, burdensome or important adverse effects of OCS in previous UK-based online surveys of people with and without asthma.[27–29] Interviews with people from an Australian severe asthma registry reported that many were concerned about current and future adverse effects of OCS.[30] At the same time, participants in other qualitative studies have described OCS as a "necessary evil",[31] "best of two evils",[32] or "lesser of two evils".[33] There have been mixed reports in previous interview studies of people with asthma regarding the information they have received about adverse effects of OCS, where some reported a lack of information,[32,33] whilst others reported they were satisfied with the information they were given.[34] Our survey respondents, with a wide range of OCS taking history (current daily use to no past use), perceived education of people living with asthma and health professionals as critical to managing OCS use. Some viewed doctors as the "gatekeepers" but there appears to be insufficient specific instructions or timely decisional support to guide use. Past experiences of OCS use and perceived lack of other options or choice are driving OCS use. Our findings raise concerns that people with asthma in Australia have access to OCS at home but no action plans to guide appropriate use. Taken together, the findings of this study suggest that ensuring that health care professionals provide the right information is an integral step to OCS stewardship, but this alone is unlikely to be sufficient if beliefs about the ongoing role of OCS or a lack of decision support remain unchanged.

The key strength of this study is its provision of the first Australia-wide consumer perspectives on OCS use in asthma. Being able to take less OCS is amongst the most important outcomes for people with severe asthma.[35] Our behavioural analysis of the factors influencing OCS use via the TDF provide a strong foundation for designing corticosteroid stewardship initiatives. Although intervention designers should always consider the most appropriate framework or theories for targeting consumer-related behaviours, our approach to characterising sources of OCS use is congruent with the adoption of the behaviour change wheel to systematically develop interventions.[36] The TDF and behaviour change wheel have been successfully applied to issues of antimicrobial stewardship by optimising the content of existing initiatives and identifying gaps to be addressed by new interventions.[37,38] Analogous to such work in antimicrobial stewardship,[39] future OCS initiatives should ensure co-design with relevant stakeholders to optimise the implementation of behavioural science methods. It is worth noting that our study did not consider clinician perspectives on OCS use. A previous cross-sectional survey in the UK highlighted a clear discordance between clinician perceptions of adverse effects of OCS and the actual burden of adverse effects in people with asthma.[27] These should be explored further due to the social influences (interaction with GP or specialist) domain being a prominent feature in our TDF coding and survey responses identifying clear opportunities for consumers to have more informed conversations to reduce overuse of OCS.

There are some limitations to the current study that should be considered when interpreting the findings. The online sampling method meant that we relied on self-reporting of asthma diagnosis and did not confirm nor assess disease severity or symptom control. However, the range of responses to current use of OCS (eg daily, during severe symptoms, never taken them) suggest we were able to capture a typical and representative asthma population. Given the cross-sectional nature of the survey, we collated consumer perspectives at a point in time during their disease and cannot specify the level of exposure of OCS that led to the perceived adverse effects and would refer readers to the published work of others on prevalence or risk estimates for individual adverse effects according to duration (first use, long-term) and type of exposure (eg intermittent, daily).[11,16] Invitations for the survey were distributed via consumer peak bodies in Australia alongside a mass communication campaign on OCS. This recruitment method was successful in reaching a large number of people with asthma (>1800) during a sampling period of only thirteen days, but a case can be made that survey respondents may not be entirely representative of all people living with asthma in the community. For example, it is reasonable to consider that the participants may have been group of people who are more likely to be engaged in asthma management and/or were attracted to the survey because they had memorable experiences with OCS, or it was a topic that was important to them. This survey documented experiences and perceptions of OCS use amongst people with asthma and was not designed to quantify use or overuse of OCS. It is worth noting that the survey did not specifically ask about any history of avoidance of OCS due to perceived adverse effects but free-text responses suggested that this may occur in people with asthma. Underuse or discouragement of OCS burst during a severe asthma exacerbation, where the

treatment is clinically indicated would be a major concern and again emphasises the importance of stewardship and striking the balance between efficacy and safety for appropriate use of OCS.

Conclusion

In conclusion, people living with asthma commonly experience adverse effects from use of OCS. People with asthma do not feel adequately informed nor does there appear to be optimal use of strategies to reduce overuse of OCS. People are often weighing up the benefits and costs of OCS but existing beliefs, lack of awareness or offer of alternative options shift the decisional balance in favour of using OCS. These findings provide important evidence towards informing the implementation and dissemination of OCS stewardship initiatives. Multiple strategies will be necessary including those that target health care professionals, people living with asthma, and the institutional and structural drivers of OCS use.

Human /Animal Ethics Approval Declaration

This study was performed in accordance with the Declaration of Helsinki. This study was approved by Monash University Human Research Ethics Committee – approval: 32641. All participants provided informed consent to participate in this study.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

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