

DISCIPLINE OF DERMATOLOGY

SYDNEY MEDICAL SCHOOL

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**Paediatric atopic dermatitis and treatment adherence: Exploring factors contributing to
topical corticosteroid phobia as a contributor to poor treatment adherence**

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CANDIDATE DECLARATION

Statement of Originality

‘I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma of the university or other institute of higher learning, except where due acknowledgement is made in the text.

I also declare that the intellectual content of this thesis is the product of my own work, even though I may have received assistance from others on style, presentation and language expression.’

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ABSTRACT

Atopic dermatitis (AD), also known as eczema or atopic eczema, is the most common chronic inflammatory dermatosis (skin condition) affecting paediatric patients in the western world. There continues to be a rapid rise in incidence of this condition worldwide with a doubling of prevalence in children under age five years in the past 30 years. It also remains one of the most treatable with correct management. Topical corticosteroids (TCS), which have a topical anti-inflammatory action, remain central to this management. However, parent and patient poor adherence to prescribed treatment plans often leads to less effective control of their AD.

A review of the literature demonstrated that one of the commonly cited contributing factors to treatment non-adherence in paediatric AD is a fear or anxiety regarding the use of TCS, a condition termed 'TCS phobia' (Chapter 2). Although moderate to severe atopic dermatitis is disabling and highly disruptive for patients and their families, TCS phobia is a significant barrier to effective treatment.

This thesis presents a body of work that aims to identify the sources of information or misinformation about the safety and efficacy of TCS, as well as assessing the impact of this information on parents' and patients' perception on the long term use of TCS to manage their AD.

Previous research has identified that parents of children with AD highlight the role of family and friends, the Internet, pharmacists and general practitioners as key sources of information that contribute to fear and anxiety towards using TCS to manage AD. This can create conflicting information leading to confusion and ultimately poor or non-adherence to

prescribed treatment plans. This is especially the case when the conflicting information comes from different members of the multidisciplinary treatment team. A multidisciplinary treatment team incorporates health care professionals from different disciplines who provide a specific service and associated health information to the patients, and in the setting of AD in Australia includes general practitioners, dermatologists, and pharmacists.

Therefore, it is important to investigate the knowledge and attitudes of these health professionals about the safety and efficacy of TCS that forms the advice provided to parents and patients in paediatric AD. This is because treatment adherence is directly related to risk/benefit of treating a condition as well as the perception of disease severity. If the perceived risks associated with treatment, such as TCS in paediatric AD, outweigh the perceived benefits or perceived disease severity, then there is significant risk of treatment non-adherence.

A consensus statement and systematic review of the adverse effects arising from the use of TCS in children with atopic dermatitis was performed (Chapter 3). The aim of the consensus meeting was to identify the potential and perceived adverse effects and systematically review the literature for each.

Dermatologists play a key role as clinical educators around the use, safety and efficacy of TCS. A cross-sectional survey of all Australian dermatologists was performed to assess their attitudes towards the use and safety of TCS in paediatric AD (Chapter 4). Close to half (44%) of the 455 dermatologists in Australia completed the survey (n=198). Nearly all responders prescribed potent or super-potent TCS in the management of paediatric AD. The most common side-effect cited by over two-thirds of the respondents was peri-orificial dermatitis with only a minority (6%) citing cutaneous atrophy. Most dermatologists stated

that pharmacists were the most common source of misinformation leading to TCS phobia. Of the respondents, 75% strongly agreed that TCS do not cause skin atrophy when used appropriately and under clinical supervision. Furthermore, 77% agreed or strongly agreed that the words ‘use sparingly’ should be removed from pharmacist labels on TCS prescriptions. This study indicates that dermatologists comfortably manage paediatric AD with potent or super-potent TCS and believe that TCS do not cause skin atrophy in paediatric AD. This is in keeping with the current up to date literature on the safety and efficacy of TCS in this setting and represents the baseline against which other healthcare professionals should refer to when providing advice about the treatment of paediatric AD.

Parents and dermatologists commonly cite conflicting information provided by pharmacists on the safety and efficacy of TCS in paediatric AD as contributing to TCS phobia and serving as a major impediment to treatment adherence. Consequently, a study was conducted to assess pharmacists’ beliefs and information on the safety of TCS in paediatric AD treatment (Chapter 5). A cross-sectional survey to assess attitudes and knowledge on the use of TCS in paediatric AD was completed by Australian pharmacists (n=292) who attended a continuing professional development conference. The mean response rate for each question was 86% of the 292 surveyed. Of the responders, 64% recognised that treatment non-adherence was a major reason for treatment failure in paediatric AD. Only a quarter (27%) of the pharmacists would instruct parents/patients to apply TCS until the eczema is clear. Over half (54%) of the responders indicated they would instruct patients to use TCS sparingly. Nearly half (46%) of the responders believed that cutaneous atrophy was the commonest side-effect from use and over half (56%) indicated that side-effects would occur, even if used appropriately. This study demonstrated the existence of significant knowledge gaps about the use and safety of TCS in paediatric AD in Australian pharmacists. Furthermore, their advice to patients

potentially contributes to poor treatment adherence because of this misinformation which can contribute to the fear and anxiety around using TCS.

Parents cite general practitioners and pharmacists as a source of information that contributes to TCS phobia which can in turn affect treatment adherence. The previous study demonstrated the knowledge gap amongst Australian pharmacists. Therefore, a study was conducted to assess general practitioners' beliefs and information on the safety of TCS in paediatric AD treatment (Chapter 6). A cross-sectional survey was performed on Australian general practitioners (n=257) participating in continuing professional development programs. Over a third (40.7%) instruct parents to apply TCS for two weeks or less. Nearly half (47.7%) instruct parents to apply TCS sparingly or with the smallest amount possible. Furthermore, nearly a third (30.2%) reported skin atrophy as the most common TCS side effect. Therefore, this study demonstrates that advice from their general practitioner may carry unintentional risk messages contributing to a fear and anxiety about using TCS and ultimately can lead to treatment non-adherence.

The studies in chapters 4 to 6 demonstrate the potential for conflicting advice from healthcare professionals in a patient's multi-disciplinary treatment team. However, an investigation was needed to assess the actual impact of the advice from healthcare professionals on patients and parents' perception of the safety and efficacy of TCS in AD. Furthermore, it is important to assess the advice provided by pharmacists and general practitioners as related to and reported by patients and parents of patients using TCS on a long-term basis for AD (Chapter 7). A multi-centre cross-sectional survey was performed on a total of 123 adult patients and 78 parents (n=201). Of the total respondents, three quarters (76.6%) reported consistently ("Often" or "Always") receiving one or more message(s) regarding TCS "risk" from a

general practitioner (GP) and/ or pharmacist (n=192). Respondents reported being told to “try natural or complementary and alternative therapies before resorting to the use of TCS” significantly more often by pharmacists than by GPs ($p=0.039$). This study demonstrates that high rates of consistently delivered messages about TCS “risk” from GPs and pharmacists do affect patient/parent understanding about TCS safety. This “risk” messaging can contribute to fear and anxiety about using TCS and may lead to treatment non-adherence.

Chapters 4 to 7 provide evidence that conflicting information from different healthcare professionals in the multi-disciplinary treatment team leads to the delivery of negative risk messaging to parents and patients with AD. This contributes to TCS phobia and can lead to poor treatment outcomes due to non-adherence. However, non-health professional such as parents, family and friends, and the Internet are others sources of knowledge about AD and its treatment. This was also investigated.

The perception of TCS safety in the management of AD is influenced by family/friends of the patient or parent of children with AD. This means these are another potential source of misinformation on TCS which can negatively impact perceptions of TCS safety. A multi-centre cross-sectional survey of patients (aged >18years old) and parents of patients (aged <18years old) with a history of a chronic inflammatory dermatosis was performed to assess information they receive from family/friends and the Internet about TCS use (Chapter 8). A total of 123 patients and 78 parents completed the survey (n=201). Parents/Patients reported that they were more likely to be informed by the Internet “[having] my [child’s] skin condition means that [I/he/she] will need to use topical corticosteroids” ($p < 0.001$) and that “inflamed skin conditions will improve with the topical corticosteroids” ($p = 0.007$). On the other hand, family/friends were more likely to recommend parents/patients “try non-

prescription creams/ointments before resorting to the use of prescription topical corticosteroids” ($p = 0.014$). This study highlights that high rates of messages about TCS ‘risk’ from family/friends and the Internet may affect patient/parent understanding about TCS safety. Furthermore, this may contribute to treatment non-adherence.

Chapters 3 to 8 have demonstrated external influence that can deliver negative biases that contribute to fear and anxiety about TCS use and ultimately lead to non-adherence in the treatment of paediatric AD. However, a parent’s perception of disease severity, representing an ‘internal’ influence bias, can contribute to whether or not they treat their child’s AD. If a parent assesses their child’s AD to be less severe than it actually is, they are much more likely to undertreat and more likely to be non-adherent with the prescribed management plan. A study was performed comparing parent reported disease severity compared to physician assessed disease severity (Chapter 9). A prospective cohort study recruited fifty paediatric patients and their caregivers from an outpatient dermatology clinic. Two clinicians completed ratings on the Eczema Area and Severity Index (EASI) tool and caregivers completed ratings on the Self-Administered EASI (SA-EASI) and Dermatology Quality of Life Index (DLQI) tools. EASI scores between clinicians were compared and there was good inter-clinician reliability ($p = 0.351$). There was a strong, positive statistically significant correlation between EASI and SA-EASI ($r = 0.865$, $p < 0.01$). The EASI score mean was statistically significantly higher than the SA-EASI mean ($p < 0.001$) for a given patient.

This study looked to establish a discrepancy between clinician and caregiver perception of atopic dermatitis severity. It showed that caregivers significantly underestimate the severity of their child’s atopic dermatitis. This provides the clinician with a greater understanding into

poor treatment compliance commonly observed in clinical practice and highlights a need to provide parents with a greater understanding of their child's disease.

By establishing the severity of the eczema to the caregiver, the clinician is empowered to provide education about the expectations surrounding treatment, allowing greater insight into noncompliance. This can facilitate an approach to the fears and misconceptions that caregivers may have.

Overall, the studies in this thesis contribute to an awareness of the sources of negative risk or misinformation about the safety and efficacy of TCS in the setting of paediatric AD.

Furthermore, it demonstrates the direct impact of this information on patients and parents.

These findings provide the basis for education programs to help educate the healthcare professional members of the multi-disciplinary treatment team. It is through consistent positive messaging from these healthcare professionals that patients and parents will be better equipped and supported to combat the negative risk messaging from non-healthcare professional sources such as family, friends and the Internet. Ultimately, this has the capacity to positively impact treatment adherence and outcomes for both the patient with AD and their entire family unit.

PRESENTATION OF THESIS

Atopic dermatitis (AD), also known as eczema, is the most common paediatric dermatology condition. The incidence of AD is increasing across the world. AD is a chronic condition that most of the time will remit or become less severe as the child ages with most children growing out of it. However, it is also a debilitating condition with significant negative biopsychosocial impacts for both the child and their entire family unit. For the majority of children who suffer with AD, it is a condition that can be readily managed with a combination of general skin measures (such as regular emollient and humectants, soap-free wash, and short luke-warm showers or bath oils), environmental modifications to minimise triggers, and topical anti-inflammatory creams or ointments (such as TCS). Unfortunately, compliance is a significant problem when managing AD. This is attributed to a number of factors including a fear of using TCS known in the literature as TCS phobia.

This thesis focuses on identifying the origins and sources of misinformation in the safety and efficacy of TCS which can contribute to ‘TCS phobia’ as well as the impact of this misinformation on the patient and the parents.

This thesis contains 12 chapters.

Chapter 1 gives a broad overview of paediatric AD.

Chapter 2 reports more detailed information from a systematic review about the factors contributing to poor treatment compliance as well as potential strategies to manage these confounders in the setting of paediatric AD. This has been published in the *Australasian*

Journal of Dermatology. Sokolova S and Smith SD. Managing treatment adherence confounders in atopic dermatitis: A review. *Australasian Journal of Dermatology* 56:252-257, 2015.

Chapter 3 outlines a systematic review on the potential and perceived adverse effects from TCS in paediatric AD. This chapter reports the outcome of an Australasian consensus statement with subsequent systematic literature review. It provides the basis of evidence with which dermatologists practice and against which other healthcare professionals and influencers were compared against. This has been published in the *Australasian Journal of Dermatology*. Mooney E, Rademaker M, Dailey R, Daniel BS, Drummond C, Fischer G, Foster R, Grills C, Halbert A, Hill S, King E, Leins E, Morgan V, Phillips RJ, Relic J, Rodrigues M, Scardamaglia L, Smith SD, Su J, Wargon O and Orchard D. Adverse effects of topical corticosteroids in paediatric eczema: Australasian consensus statement. *Australasian Journal of Dermatology* 56:241-251, 2015.

Chapter 4 directs focus on the role that TCS phobia can have in poor treatment adherence as identified in the systemic review. In this setting, it is important to explore the advice that healthcare professionals provide parents of children with AD with respect to the safety and efficacy of TCS. This chapter reports the results of a cross-sectional study investigating the attitudes of Australian dermatologists towards the efficacy and safety of TCS in paediatric AD. This has been published in the *Australasian Journal of Dermatology*. Smith SD, Lee A, Blaszczyński A and Fischer G. Assessing dermatologists' attitudes to efficacy and safety of topical corticosteroids. *Australasian Journal of Dermatology* 57:278-283, 2016.

Chapter 5 examines the first of the two other key members of the multidisciplinary healthcare treatment team who help manage paediatric AD. This chapter reports the results of a cross-sectional study investigating the knowledge and understanding of Australian pharmacists about the safety and efficacy of TCS in paediatric AD. This has been published in the *Australasian Journal of Dermatology*. Smith SD, Lee A, Blaszczyński A and Fischer G. Assessing pharmacist's knowledge and understanding of topical corticosteroid efficacy and safety. *Australasian Journal of Dermatology* 57:199-204, 2016.

Chapter 6 examines the third and final key member of the multidisciplinary healthcare treatment team who help manage paediatric AD. This chapter reports the results of a cross-sectional study investigating the knowledge and attitude of Australian general practitioners towards the safety and efficacy of TCS in paediatric AD. This has been accepted for publication in *Australian Family Physician*. Smith SD, Harris V, Lee A, Blaszczyński A and Fischer G. Assessing general practitioner's attitudes to efficacy and safety of topical corticosteroids. *Australian Family Physician* 46(5): 335-340, 2017.

Chapter 7 builds on the results of chapters 3, 5 and 6 which documented potential differences in education and attitudes towards the safety and efficacy of TCS amongst the healthcare professionals in the multidisciplinary treatment team in paediatric AD. These differences potentially lead to confusion and contribute to misinformation which can lead to TCS phobia. Chapter 7 reports the results of a cross-sectional study investigating the influence that the advice from pharmacists and general practitioners has on the perceptions of adult patients and parents of children with AD on the safety and efficacy of long-term use of TCS. This has been published in *Journal of Dermatological Treatment*. Farrugia L, Lee A, Fischer G, Blaszczyński A, Carter S and Smith SD. Evaluation of the influence of pharmacists and GPs

on patient perceptions of long-term topical corticosteroid use. *Journal of Dermatological Treatment* 28(2):112-118, 2017.

Chapter 8 explores the role that non-healthcare professional sources of information on the safety and efficacy of TCS can have in paediatric AD. This chapter reports the results of cross-sectional study which evaluates the influence family and friends, and the Internet have on perceptions of long-term TCS in adult patients and parents of children with AD. This work has been published in the *Journal of Dermatological Treatment*. Smith SD, Farrugia L, Harris V, Lee A, Blaszczyński A, and Fischer G. Evaluation of the influence of family and friends, and the Internet on patient perceptions of long-term topical corticosteroid use.

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Chapter 9 examines the potential influence parents, as the actual administrators of treatment in paediatric AD, may have on treatment outcome. This chapter reports the results of a cross-sectional study which examined differences in the perception of disease severity in paediatric AD. Parental underassessment of disease severity can be a contributing factor to treatment non-adherence because of decreased perception of the need to treat active paediatric AD. This is an unpublished manuscript.

Chapter 10 presents a summary and discussion, in the form of a systemic review, of the role of healthcare professionals as a source of misinformation on the safety and efficacy of TCS and the potential impact on treatment adherence. This has been published in the *Australian Journal of Pharmacy*. Smith SD and Fischer G. Childhood atopic dermatitis: Exploring the

safety, efficacy and potential misinformation around topical corticosteroids. *Australian Journal of Pharmacy* October Issue 83-88, 2016.

Chapter 11 presents a discussion of the influence of family, friends and the Internet as a source of misinformation about the safety and efficacy of TCS in paediatric AD, and poor disease understanding. These non-healthcare professional influences can contribute to poor treatment adherence. This is an unpublished manuscript.

Chapter 12 presents the conclusions of the research undertaken, and discusses clinical implications, limitations and further research directions.

LIST OF PUBLICATIONS AND PRESENTATIONS

Components of the work presented in this thesis have been published and/or presented in the following forums:

PUBLISHED PAPERS:

Smith SD, Farrugia L, Harris V, Lee A, Blaszczyński A, and Fischer G. Evaluation of the influence of family and friends, and the Internet on patient perceptions of long-term topical corticosteroid use. *Journal of Dermatological Treatment* Published online 28th March 2017 DOI:10.1080/09546634.2017.1306017.

Smith SD, Harris V, Lee A, Blaszczyński A and Fischer G. Assessing general practitioner's attitudes to efficacy and safety of topical corticosteroids. *Australian Family Physician* 46(5): 335-340, 2017.

Smith SD and Fischer G. Childhood atopic dermatitis: Exploring the safety, efficacy and potential misinformation around topical corticosteroids. *Australian Journal of Pharmacy* October Issue 83-88, 2016.

Farrugia L, Lee A, Fischer G, Blaszczyński A, Carter S and **Smith SD**. Evaluation of the influence of pharmacists and GPs on patient perceptions of long-term topical corticosteroid use. *Journal of Dermatological Treatment* 28(2):112-118, 2017.

Smith SD, Lee A, Blaszczyński A and Fischer G. Assessing dermatologists' attitudes to efficacy and safety of topical corticosteroids. *Australasian Journal of Dermatology* 57:278-283, 2016

Smith SD, Lee A, Blaszczyński A and Fischer G. Assessing pharmacist's knowledge and understanding of topical corticosteroid efficacy and safety. *Australasian Journal of Dermatology* 57:199-204, 2016

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Mooney E, Rademaker M, Dailey R, Daniel BS, Drummond C, Fischer G, Foster R, Grills C, Halbert A, Hill S, King E, Leins E, Morgan V, Phillips RJ, Relic J, Rodrigues M, Scardamaglia L, **Smith SD**, Su J, Wargon O and Orchard D. Adverse effects of topical corticosteroids in paediatric eczema: Australasian consensus statement. *Australasian Journal of Dermatology* 56:241-251, 2015

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Stone J, Harris V, Lee A, Dixit A, Fischer G and **Smith SD**. "Comparison between parent versus clinician assessment of disease severity in childhood atopic dermatitis". *Australasian Journal of Dermatology* 58(supp1):88-89, 2017.

Smith SD, Lee A, Blaszczyński A, Fischer G. “An assessment of Australian general practitioners’ knowledge about use of topical corticosteroids in paediatric atopic dermatitis”. *Australasian Journal of Dermatology* 57(supp1):17-18, 2016.

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Smith SD, Lee A, Blaszczyński A, Fischer G. “An assessment and comparison of pharmacists’ and dermatologists’ knowledge about the safety and efficacy of topical corticosteroids in paediatric atopic dermatitis: a source of topical corticosteroid phobia”. *British Journal of Dermatology* 173(supp1):29-30, 2015

Smith SD, Lee A, Blaszczyński A, Fischer G. “Assessment of pharmacists’ knowledge about use of topical of topical corticosteroids in atopic dermatitis: pre- and post-continuing professional development education”. *Australasian Journal of Dermatology* 56(supp2):8, 2015

Mooney E, Rademaker M, Dailey R, Daniel BS, Drummond C, Fischer G, Foster R, Grills C, Halbert A, Hill S, King E, Leins E, Morgan V, Phillips RJ, Relic J, Rodrigues M, Scardamaglia L, **Smith SD**, Su J, Wargon O and Orchard D. “Adverse effects of topical corticosteroids in paediatric eczema: Australasian Consensus Statement”. *Australasian Journal of Dermatology* 56(supp2):8, 2015

Smith SD, Lee A, Blaszczyński A, Fischer G. “Assessment of the attitude of dermatologists to the use of topical corticosteroids in paediatric atopic dermatitis”. *Australasian Journal of Dermatology* 56(supp2):69, 2015

Sokolova A and **Smith SD**. “Managing treatment adherence confounders in paediatric atopic dermatitis”. *Australasian Journal of Dermatology* 55(supp1):21, 2014

CONFERENCE PRESENTATIONS:

L Farrugia, V Harris, A Lee, A Blaszczyński, G Fischer and **SD Smith**. Evaluation of the influence of family and friends, and the Internet on patient perceptions of long-term topical corticosteroid use. Australasian College of Dermatologist Annual Scientific Meeting Poster presentation session May 2017.

J Stone, V Harris, S Dixit, G Fischer and **SD Smith**. Comparison between parent versus clinician assessment of disease severity in childhood atopic dermatitis. Australasian College of Dermatologist Annual Scientific Meeting Poster presentation session May 2017

SD Smith. Influence of advice from General Practitioners and Pharmacists on patient/parents’ knowledge of safety and efficacy of topical corticosteroids in paediatric atopic dermatitis. Australian Medical Association (NSW) Continuing Professional Education Conference 25th July 2016

SD Smith, A Lee, A Blaszczyński and G Fischer. An assessment of Australian General Practitioners' knowledge about use of topical corticosteroids in atopic dermatitis.

Australasian College of Dermatology Annual Scientific Meeting May 2016

SD Smith, L Farrugia, A Lee, S Carter, A Blaszczyński and G Fischer. Evaluation of the influence of pharmacists on patient perceptions of long-term topical corticosteroid use in Sydney, Australia. Australasian College of Dermatology Annual Scientific Meeting May 2016

SD Smith. Atopic Dermatitis and Topical Corticosteroids Phobia. Australian Dermatology Nurses' Association 13th National Conference May 2016.

SD Smith, A Lee, A Blaszczyński and G Fischer. An assessment and comparison of pharmacists' and dermatologist's knowledge about the safety and efficacy of topical corticosteroids in paediatric atopic dermatitis: a source of topical corticosteroid phobia. British Association of Dermatologists 95th Annual Meeting 7th July 2015.

SD Smith. Rethinking management of atopic dermatitis – topical corticosteroid phobia. General Practitioner Conference and Exhibition (GPCE) Sydney 24th May 2015

SD Smith, A Lee, A Blaszczyński and G Fischer. An assessment pharmacists' knowledge about the safety and efficacy of topical corticosteroids in paediatric atopic dermatitis: before and after education intervention. Australasian College of Dermatologists Annual Scientific Meeting May 2015.

SD Smith, A Lee, A Blaszczyński and G Fischer. An assessment of dermatologist's attitude to the safety and efficacy of topical corticosteroids in paediatric atopic dermatitis.

Australasian College of Dermatologists Annual Scientific Meeting Poster session May 2015.

SD Smith. Impact of topical corticosteroids on treatment adherence in paediatric atopic dermatitis. Australian Medical Association (NSW) Continuing Professional Education Seminar 14th June 2014.

SD Smith. Managing treatment adherence in paediatric atopic dermatitis. Australasian College of Dermatology Annual Scientific Meeting 18th May 2014

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LIST OF ABBREVIATIONS

AD = Atopic Dermatitis

CAM = Complementary and Alternative Medicine

GP = General Practitioner

MDT = Multidisciplinary Team

TCS = Topical Corticosteroids

CHAPTER 1

General Introduction

ATOPIC DERMATITIS

Atopic dermatitis (AD), or eczema, is the most common dermatological condition in children worldwide. Mild to moderate AD is also one of the most treatable dermatological conditions when correct management is instituted. The use of topical corticosteroids (TCS) remain a key criterion standard in the care of all AD. Although AD, especially in moderate to severe cases, can be disabling and highly disruptive for patients and their entire family unit, fear and anxiety with respect to the use of TCS can be a significant barrier to effective treatment [1-7]. The literature often refers to this fear and anxiety relating to TCS use as ‘corticosteroid phobia’.

Previous published research has demonstrated a link between ‘corticosteroid phobia’ with a preference for ‘natural therapies’ [7]. Furthermore, patients and their parents often have a poor understanding of the pathophysiology of AD which has a predominantly genetic basis. This often leads patients and parents to pursue perceived ‘cures’ for their disease and often focus on a search for offending specific allergens in the environment or food that can be eliminated [7]. The abandonment of evidence-based medical therapy can have potentially detrimental outcomes for the paediatric patient [8-11]. Furthermore, in extreme examples of this abandonment it can lead to legal neglect and even death of the patient [12].

Parents frequently cite ‘skin thinning’, or cutaneous atrophy, as the side effect they fear the most [7]. Concern about this specific perceived or potential side effect of TCS is entrenched

in parents in Australia, and is also seen around the world [4,5,13]. Cutaneous atrophy is a documented side effect of TCS. However, it is not seen in the setting of paediatric AD when TCS are used appropriately with supervision [14]. In the clinical circumstances that it can occur, it is usually when potent products are used inappropriately, such as under plastic occlusion or on macerated skin of the flexures for extended periods of time [15]. The fear of causing cutaneous atrophy by using TCS has become pronounced in members of the healthcare professional multi-disciplinary team and in general communities so that many patients and parents receive grossly exaggerated risk warnings. In particular, 88% of parents with children who suffer from paediatric AD report friends and family (50%), with pharmacists (44%) and GPs (25%) as sources of information characterising TCS as dangerous [7]. This can result in a confusion in patients and parents about the safety and efficacy of TCS to manage their AD and leads to poor treatment adherence [8,9]. Education of patients and parents whose children have AD helps to deconstruct this complex issue and dramatically increases treatment adherence.

HEALTH BURDEN OF ATOPIC DERMATITIS

The prevalence of symptoms of AD in children under 5 years of age in Australia is approximately 20%, which has more than doubled over the past three decades [16,17]. This increase in prevalence has been seen in other western countries such as the USA [18]. The reason for this continued increase in disease prevalence is not currently well understood. However, environmental and socioeconomic factors appear to play an important role in disease prevalence [19]. AD can be managed well in most patients and usually remits with age with most children growing out of their AD. However, AD places a significant burden on patients and their family unit. In fact, it has previously been shown that a child with AD

has a higher biopsychosocial impact on the entire family unit than having a child with diabetes because of the problems with itching, sleep loss, problems at school and mood and behavioural changes [2,3,5,20].

The financial and social burden of eczema in children is significant. A previous Australian study calculated conservative estimates of annual personal costs for managing atopic dermatitis [20]. For each child with mild eczema, the cumulative costs of direct medical, hospital and treatment as well as the indirect costs such as time off work for caregivers have been estimated to be AUD 1100 per year. For a child with severe eczema, these costs increase to over AUD 6000. This study also found that this financial cost incurred in the management of AD was greater than that for the management of asthma. There are also other practical difficulties that occur when caring for a child with AD which impact and restrict a family's lifestyle including skin care, feeding, shopping, washing and cleaning, psychological pressure, and physical exhaustion [21].

TREATING ATOPIC DERMATITIS

Generally, AD is a condition that can be well managed. This involves a combination of environmental modification, infection control, identification and management of triggers and, in some children, investigation of allergies. A key component of the pathophysiology of AD is an associated mutation in a gene coding for a protein called filaggrin [21]. AD sufferers who have this mutation results in a poorer keratinocyte adhesion and decreased natural moisturising factors [23]. Therefore, treatment of AD necessitates the restoration of epidermal barrier function with emollients. Emollients are the basis of management and should be used even when the skin is clear [24]. When there is active AD characterised by

inflammation of the skin, TCS are the mainstay of medical therapy because of their anti-inflammatory effect.

TREATMENT NON-ADHERENCE

Treatment non-adherence occurs when patients/caregivers change or do not follow the management plan prescribed to them. It may arise from intentional conscious decision making by the patient or by unintentional effects [25].

There are a variety of reasons why patients become intentionally non-adherent to treatment including health beliefs [12,25] or a desire to pursue complementary and alternative medicine therapies [7]. Intentional treatment non-adherence also occurs when patients or their caregivers hold fears about treatment due to a perceived risk of adverse effects. This may lead patients/caregivers to change the treatment plan independently of the doctor's original guidance [26]. This may include alteration of their dosage, increase or decrease, or even cessation of therapy completely without the direct involvement of their treating physician.

Alternatively, patients/caregivers can become unintentionally non-adherent to treatment. The most common reasons are forgetfulness or lack of knowledge about the disease and its treatments [26]. Poor knowledge about the amount and frequency of application, whether by poor instructions or conflicting information from members of the healthcare professional team have been identified as another potential cause of unintentional non-adherence [27].

Irrespective of whether treatment non-adherence is intentional or unintentional, poorer treatment outcomes can occur from the divergence from physician directed management plan [26].

AIMS OF THE THESIS

To date, there has been a discussion in the literature about the role of TCS phobia, characterised by a fear and/or anxiety about the use of TCS in treatment non-adherence. Previous research in which I participated has demonstrated the safety profile of TCS in the setting of paediatric atopic dermatitis (Appendix I). Furthermore, other previous published research in which I have participated has indicated that information received from family/friends, the Internet, pharmacists and general practitioners can all contribute as sources of misinformation leading to TCS phobia (Appendix II). Furthermore, other previous research has demonstrated that there is a paucity in the literature around the detailed examination of these healthcare professional and non-healthcare sources of information and their impact on patient/parent's perception about the safety and efficacy of TCS. This thesis presents several studies addressing this important gap in the medical literature.

The aims of these studies were to:

- 1) Systematically review the literature on factors which contribute to poor treatment adherence in AD and determine the importance of TCS phobia as a key contributing factor to poor treatment adherence (Chapter 2).
- 2) Systemically review the safety and efficacy of TCS in paediatric AD (Chapter 3)
- 3) Investigate the knowledge and attitudes of Australian dermatologists to the use of TCS in paediatric AD (Chapter 4).
- 4) Investigate the knowledge and attitudes of Australian pharmacists to the use of TCS in paediatric AD (Chapter 5).
- 5) Investigate the knowledge and attitudes of Australian general practitioners to the use of TCS in paediatric AD (Chapter 6).

- 6) Investigate the impact of advice from pharmacists and general practitioners about the use of TCS as reported by patients and parents (Chapter 7).
- 7) Investigate the impact of information from family/friends and the Internet about the use of TCS as reported by patients and parents (Chapter 8).
- 8) Investigate the potential differences between in parental reported assessment of disease severity and clinician assessed disease severity in paediatric AD as a potential contributor to treatment non-adherence (Chapter 9).

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CHAPTER 2

Factors contributing to poor treatment outcomes in childhood atopic dermatitis: A review.

This chapter contains the systematic review, “Factors contributing to poor treatment outcomes in childhood atopic dermatitis: A review,” published in the *Australasian Journal of Dermatology* 2015;56:252-257.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

As co-author of the paper:

Sokolova A and **Smith SD**. Managing treatment adherence confounders in atopic dermatitis: A review. *Australasian Journal of Dermatology* 56:552-257, **2015**

I confirm that Saxon D Smith has made a major contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

Signed: _____


Name: _____ Dr Anna Sokolova _____

Date: _____ 7/7/17 _____

REVIEW ARTICLE

Factors contributing to poor treatment outcomes in childhood atopic dermatitis

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ABSTRACT

Atopic dermatitis (AD) is a chronic relapsing inflammatory disease of the skin and is the most common paediatric dermatological condition. While no cure is available, it can be treated effectively if adherence to a therapeutic plan is maintained. Poor adherence to treatment is common in AD and can lead to treatment failure, which has significant impacts on the patient, family and society. A comprehensive literature search was conducted to identify factors that contribute to poor treatment adherence in childhood AD and to identify possible strategies to remedy these. Identified factors leading to poor treatment adherence include: complexity of treatment regimen, lack of knowledge, impaired quality of life, dissatisfaction with treatment strategies, infrequent follow up, corticosteroid phobia and the use of complementary and alternative medicine. Effective strategies to increase treatment adherence include: caregiver education and utilisation of education adjuncts, optimisation of the patient/caregiver–clinician relationship, early and frequent follow up and improvement of patient and caregiver quality of life.

Key words: adherence, atopic dermatitis, compliance, eczema, management, treatment.

INTRODUCTION

Atopic dermatitis (AD) is a common inflammatory disease of the skin with a chronic relapsing course.^{1,2} Treatment regi-

mens are often complex, consisting of the daily application of emollients and long-term topical corticosteroid (TCS) or the use of calcineurin inhibitors. Further strategies include environmental modification, avoidance of triggers, phototherapy and the management of complications such as secondary infections. Oral anti-inflammatory medications and immunomodulators may be required in severe cases. The available treatment strategies are effective.^{3,4} However, poor treatment adherence is common, and only 32% of patients have been found to be adherent to topical therapy in AD when measured with electronic monitoring,⁵ leading to poor treatment outcomes. This highlights the fact that non-adherence to treatment is an important cause of treatment failure.⁵

Implications of poor treatment adherence in AD

Poor treatment outcomes have significant consequences for patients and their families.⁶ Children with AD suffer from sleep disturbance, are more irritable, require greater attention^{7–9} and are at increased risk of mental health problems by the age of ten.¹⁰ This has substantial psychosocial implications for their caregivers and families.¹¹ The ability of parents to work, complete household duties and engage in social activities is impaired^{6,12–14} and parents also experience significant psychological strain from self-blame, guilt and sadness.⁷ The personal economic burden of AD is also significant; with one Australian study quantifying the direct mean costs to families of AU\$330, AU\$818 and AU\$1255 annually for mild, moderate and severe AD, respectively, with further indirect costs including the loss of income from time taken off work, travel and the cessation of employment.¹⁴ In addition, the economic burden to society is considerable, with significant costs resulting from primary care and emergency department presentations, hospital

Abbreviations:

AD	atopic dermatitis
CAM	complementary and alternative medicine
CS	corticosteroid
HRQoL	health-related quality of life
TCS	topical corticosteroid
TPE	therapeutic patient education

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Table 1 Levels of evidence and associated grade of recommendation. Modified from the Oxford Centre for Evidence-based Medicine Levels of Evidence²²

Grade of recommendation	Level of evidence	Description
A	1a	Systematic review of RCT
	1b	Individual RCT with narrow confidence interval
	1c	All or none
B	2a	Systematic review of cohort studies
	2b	Individual cohort study (including low quality RCT, e.g., < 80% follow up)
	3a	Systematic review of case-control studies
C	3b	Individual case-control study
	4	Case series and poor quality cohort and case-control studies
D	5	Expert opinion without explicit critical appraisal, or based on physiology, bench research or first principles

RCT, randomised controlled trial.

admissions, speciality consultations, prescription medications, procedures and laboratory costs,¹⁵ with estimates of direct financial costs in the USA of between US\$364 million to US\$5.8 billion annually.^{15–17} Treatment may be escalated inappropriately if poor treatment outcomes are interpreted as ineffectiveness of the treatment rather than poor adherence to treatment,¹⁸ which may result in significant systemic side-effects for the individual,¹ additional psychosocial burden on families and further financial costs to society.

Limitations of assessing treatment adherence

It is difficult to gauge treatment adherence in the clinical setting. Self-reports by patients and caregivers may overestimate treatment adherence, though diary and questionnaire measures may be more accurate than interview-based self-reports.¹⁹ Non-self-report measures include pill counts, canister weights, pharmacy claims and electronic monitoring. However, all these measures reflect presumed adherence rather than providing an absolute measure of medication applied or ingested.²⁰ Despite these difficulties, findings from studies of treatment adherence suggest that non-adherence is extremely common in patients with chronic disease²¹ and this has significant implications for treatment outcomes.

Objectives

The purpose of this review article is to identify the major causes of poor treatment adherence in childhood AD and to suggest mitigating strategies to improve adherence.

METHODS

A comprehensive literature search was conducted using PubMed/MEDLINE, Embase, the Cochrane Database of Systematic Reviews and the Cochrane Central Register of Controlled Trials in October and November 2013. The following search terms were used: 'atopic dermatitis' or 'atopic eczema' or 'eczema' and 'adherence' or 'compliance'. Published studies up to November 2013 were included. The search was limited to English language studies. The highest level of evidence and grade of recommendation was noted

for each suggested mitigating strategy, using a modified version of the Oxford Centre for Evidence-based Medicine levels of evidence table (Table 1).²²

RESULTS

Factors contributing to poor treatment outcomes

Complexity of treatment regimens

Treatment regimens are perceived to be complex and burdensome as a result of the prescription of multiple medications, frequent dosing schedules and the cumbersome application of topical preparations.²³ The requirement for long-term therapy is also often problematic. Adherence to even a twice-daily application of topical therapy drops by 60% a few days after the commencement of treatment.⁵ Parents and caregivers admit that taking shortcuts, such as the reduced frequency of topical therapy application, is necessary to simplify treatment regimens.²⁵

Lack of knowledge

Lack of understanding of the disease pathogenesis and prescribed treatments is common in AD.^{24,25} Nearly half the parents and caregivers, when questioned, cannot correctly identify the potency of commonly prescribed TCS or the nature of the antimicrobial components correctly.²⁵ Such lack of understanding may result in the incorrect application of topical therapy and confusion about the escalation of treatment, leading to poor treatment adherence and outcomes.

Impaired quality of life

To be successful, complex treatment regimens in the context of chronic disease require ongoing commitment from patients and caregivers. Emollients are applied even when there is no evidence of active disease on the skin, giving little respite from caregiver duties. Health-related quality of life (HRQoL) is significantly impaired in children with AD and their caregivers,⁶ which has direct negative implications for treatment adherence.^{26,27}

Patient dissatisfaction

Patient satisfaction is a determinant of treatment adherence.^{28,29} A cross-sectional survey in Japan reported that a satisfactory patient/caregiver–clinician relationship was the most important factor driving treatment adherence in their population.⁵⁰ However, a survey of the UK National Eczema Society showed that only 19% of initial consultations with a dermatologist met patients' expectations and only 40% of patients were satisfied with the treatment given.¹² Acknowledging patients' preference is an important component of patient satisfaction. Recommendations for topical therapies should take patient/caregiver vehicle preference into account,⁵¹ including the type of preparation³² and the frequency of application.²⁵ Treatment plans designed without the patient/caregiver preferences in mind are likely to lead to treatment failure.²⁴

Frequency of follow up

Adherence to topical therapy in AD increases significantly around the time of follow-up appointments.⁵ This finding, termed 'white coat compliance',⁵⁵ has also been reported in psoriasis⁵⁴ and hand dermatitis.⁵⁵ The timing of follow-up appointments also seems to be important, with earlier follow up resulting in higher rates of treatment adherence.⁵⁶

Corticosteroid phobia

Corticosteroid (CS) phobia is a common phenomenon in parents caring for children with AD,^{57,58} with over 80% fearing potential local and systemic side effects associated with regular CS application.⁵⁹ Fears include irreversible skin atrophy, immune suppression and growth failure with long-term steroid application,^{57,40} frequently resulting in treatment failure due to non-adherence.⁵⁹

Use of complementary and alternative medicine

Despite the lack of evidence for complementary and alternative medicine (CAM) in the management of AD,⁴¹ CAM continues to be a popular adjunct to treatment. Common strategies include homeopathy, the use of botanical extracts and Chinese herbal medicine.⁴¹ More than half of AD patients may include a form of CAM in their management.⁴² CAM is more likely to be used, usually upon recommendation by friends or family, by patients with a long duration of disease and if they perceived that orthodox treatment strategies have failed.⁴² Side-effects, medication interactions and the worsening of AD symptoms with the use of some CAM have been reported,^{45–46} confounding treatment outcomes.⁴⁷ Further, the inappropriate sole use of CAM to manage AD can have catastrophic consequences.⁴⁶

Improving treatment adherence

Optimisation of the patient/caregiver–clinician relationship

A satisfactory relationship between the physician and patient/caregiver is one that involves good verbal and non-

verbal communication, effective listening and collaborative decision-making.⁴⁸ Physicians who appear to show a genuine interest in their patients, who are able to foster understanding and enquire about psychosocial issues are likely to achieve greater patient satisfaction.^{49,50} As clinicians we can embrace our role of health educator to provide disease and treatment specific information to meet the parents' needs and simplify the complexity of treatment to aid their understanding. The use of topical combination formulations has been shown to increase treatment adherence and improve clinical outcomes in acne management.⁵¹

Grade of recommendation: B (level 2b evidence)

Patient education Patient education is a key strategy to improving treatment adherence, as the lack of understanding of the prescribed treatment and fear of medication side-effects are significant adherence confounders in the management of AD. Educational approaches range from the medical practitioner giving simple information and advice to offering comprehensive multidisciplinary strategies. Systematic reviews examining the utility of patient education in AD have been difficult to interpret due to the diversity of educational approaches used, small sample sizes and variability in treatment end-points.^{41,52,53} However, the quality of education is important as longer, more structured sessions improve patient satisfaction⁵⁴ and disease outcomes.⁵⁵ Accordingly, the addition of nurse-led education sessions to standard dermatological consultations has been shown to result in improved patient satisfaction, quality of life and disease outcomes,^{56,57} although large-scale prospective studies are lacking.

Given the proposed benefit of comprehensive education in AD management, guidelines for therapeutic patient education (TPE) have recently been developed,⁵⁸ which will allow for the standardised delivery of a multidisciplinary educational strategy in AD. TPE aims to empower patients with the relevant skills and knowledge required to manage their chronic disease while maintaining their quality of life.⁵⁸ It is a multimodal, patient-centred approach, combining structured teaching with skill transference and psychosocial support and requires input from a number of health professionals, including doctors, nurses and clinical psychologists. It comprises a thorough initial consultation with a doctor and nurse team and the identification of educational objectives to allow targeted delivery of information using a variety of educational resources. Collective teaching sessions can also be incorporated into the model using either lecture or workshop formats. Standardisation of the educational model will allow for a more rigorous investigation into its usefulness in improving treatment adherence in AD.

Grade of recommendation: A (level 1b evidence)

Written eczema action plans Written action plans have been proposed as useful educational adjuncts to verbal instruction in AD.⁵⁹ Two studies, including a small randomised controlled trial⁶⁰ and a quality improvement

study,⁶¹ have shown beneficial outcomes following the addition of eczema action plans to simple verbal instruction during patient consultations. Benefits included increased patient understanding as well as decreased anxiety about self-management in AD, which may increase patient satisfaction, improve their quality of life and result in better treatment adherence.

Grade of recommendation: B (level 2b evidence)

Other education adjuncts Additional education adjuncts have been suggested to promote treatment adherence but have not been rigorously studied. The accuracy of topical agent application by adults with AD was improved when fluorescent cream was used as a teaching aid⁶² and the regularity of topical agent application may be increased with positive reinforcement strategies in children, such as sticker charts⁶³ and with memory aids such as regular text messages in adolescents.⁶⁴

Grade of recommendation: C (level 4 evidence)

Targeted education regarding TCS Educating caregivers about the important role of TCS in AD management is critical at the time of treatment prescription to overcome the potential impact of CS phobia. Side-effects from TCS are extremely rare and are usually secondary to an inappropriate prescription of highly potent formulations or incorrect application of the TCS.⁶⁵⁻⁶⁷ Correctly applied TCS are well tolerated, even with prolonged use,⁶⁸ with most side-effects being reversible if they are diagnosed early.⁶⁹ Counselling patients and parents about the role of TCS in AD treatment, as well the method of application, leads to decreased parental anxiety and a higher acceptance of CS treatment.⁷⁰

Grade of recommendation: B (level 2b evidence)

Early and frequent follow up Regular follow up may reduce the perceived burden of treatment, maintain patients' motivation and convey the physician's interest in patient adherence.⁴⁸ More frequent follow ups may facilitate treatment adherence.⁵¹ Further, as treatment adherence declines rapidly following the initial consultation, earlier follow ups may lead to increased adherence,⁵⁶ although a small randomised controlled trial was unable to confirm this.⁷¹

Grade of recommendation: B (level 2b evidence)

Improving quality of life A number of studies have underlined the importance of maintaining quality of life of both patients and caregivers in AD management as impaired HRQoL has negative implications for the use of topical therapy.²⁸ The number and severity of AD flares are directly correlated with reduced HRQoL,¹¹ suggesting that strategies that aim to improve disease outcomes through better treatment adherence should lead to an improvement in the patients' quality of life. Better disease control may then serve as positive reinforcement for ongoing treatment

adherence and may potentially reduce caregiver's willingness to try adjunct strategies such as CAM due to perceived futility of orthodox treatments.

Grade of recommendation: D (level 5 evidence)

Future research Poor treatment adherence is common in childhood AD, with significant implications for the individuals concerned, their family and society. While a number of prospective trials have been conducted to investigate strategies that are effective in improving treatment adherence, more research is needed. Educational interventions can now be studied more rigorously with the publication of standardised guidelines for TPE in AD. While the regularity of follow up is important, further research into the exact frequency and mode of follow up is warranted. The caregiver burden may be improved and the perceived complexity of treatment strategies can be rendered less daunting with the development of new vehicles that reflect patient/caregiver preferences. It is also essential to define the sources and impact of misinformation on the use and safety of TCS to better support the patient/caregiver and improve treatment adherence.

CONCLUSION

Identifying the major factors that lead to poor treatment adherence is of particular importance in childhood AD, where a common cause of treatment failure is poor adherence rather than disease severity or the ineffectiveness of treatment. A prescribed treatment plan can lead to significant improvements in disease and psychosocial outcomes. However, poor adherence is very prevalent for a variety of reasons. Building a strong patient/caregiver-clinician relationship, simplifying treatment regimens, implementing comprehensive education sessions and increasing the frequency of follow up are important mitigating strategies against poor treatment adherence in childhood AD. Future research will better define the most effective ways of implementing these strategies in the clinical setting, improving both disease outcomes and the quality of life of patients and caregivers.

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CHAPTER 3

Review on the safety of topical corticosteroids in paediatric atopic dermatitis

This chapter contains the systematic review, “Adverse effects of topical corticosteroids in paediatric eczema: Australasian consensus statement.” published in the Australasian Journal of Dermatology 2015;56:241-251.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

As first author of the consensus statement paper and on behalf of the consensus statement group:

Mooney E, Rademaker R, Dailey R, Daniel B, Drummond C, Fischer G, Foster R, Grills C, Halbert A, Hill S, King E, Leins E, Morgan V, Phillips R, Relic J, Rodrigues M, Scardamaglia L, **Smith S**, Su J, Wargon O and Orchard D. Adverse effects of topical corticosteroids in paediatric eczema: Australasian consensus statement. *Australasian Journal of Dermatology* 56:241-551, **2015**.

I confirm that Saxon D Smith has made a contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

Signed: 

Name: Dr Emma Mooney

Date: 7/7/17

REVIEW ARTICLE

Adverse effects of topical corticosteroids in paediatric eczema: Australasian consensus statement

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ABSTRACT

Atopic eczema is a chronic inflammatory disease affecting about 30% of Australian and New Zealand children. Severe eczema costs over AUD 6000/year per child in direct medical, hospital and treatment costs as well as time off work for caregivers and untold distress for the family unit. In addition, it has a negative impact on a child's sleep, education, development and self-esteem. The treatment of atopic eczema is complex and multifaceted but a core component of therapy is to manage the inflammation with topical corticosteroids (TCS). Despite this, TCS are often underutilised by

many parents due to corticosteroid phobia and unfounded concerns about their adverse effects. This has led to extended and unnecessary exacerbations of eczema for children. Contrary to popular perceptions, (TCS) use in paediatric eczema does not cause atrophy, hypopigmentation, hypertrichosis, osteoporosis, purpura or telangiectasia when used appropriately as per guidelines. In rare cases, prolonged and excessive use of potent TCS has contributed to striae, short-term hypothalamic-pituitary-adrenal axis alteration and ophthalmological disease. TCS use can also exacerbate periorificial rosacea. TCS are very effective treatments for eczema. When they are used to treat active eczema and stopped once the active inflammation has resolved, adverse effects are minimal. TCS should be the cornerstone treatment of atopic eczema in children.

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Abbreviations:

BMD	bone mineral density
HPA	hypothalamic-pituitary-adrenal
TCA	topical corticosteroids

INTRODUCTION

Atopic dermatitis or eczema is a chronic inflammatory disease of the skin with a relapsing course. It affects 20% of children aged 3–11 years,¹ with a higher incidence in cities in developed countries. The prevalence of eczema in young children in Australia has increased from 10 to 30% over the last 15 years.^{2,3}

The financial and social burden of eczema in children is significant. For each child with mild eczema, the direct medical, hospital and treatment costs and the indirect costs such as time off work for caregivers have been estimated to be AUD 1100 per year. For a child with severe eczema, these costs increase to over AUD 6000.⁴ The psychological toll on the children and their families is at least as great as that seen in children with diabetes.⁵ Therefore, for financial, developmental and emotional reasons, it is of the considerable importance to have an effective and safe treatment.

Fortunately, such a treatment exists. It was developed in the 1950s as compound F, the first topical corticosteroid (TCS) preparation.⁶ The potential value and importance of TCS cannot be overstated, but steroid phobia due to misinformation among the general community, pharmacists and prescribing physicians, has led to its underutilisation. We have therefore reviewed the relevant medical literature and have developed a position statement on the safe use of TCS in children with atopic eczema, with a particular focus on adverse effects.

METHODS

An Australian and New Zealand panel of physicians with an interest in managing paediatric eczema was constituted to review the use of TCS in children with atopic eczema. The aim of the consensus meeting was to identify and address misconceptions on corticosteroid treatment of eczema, using published evidence combined with over 430 person-years of clinical practice in paediatric dermatology. The panel included practicing paediatric dermatologists from Australia and New Zealand, paediatricians, dermatology nurses and advanced dermatology trainees. Each reported TCS side-effect was reviewed in the context of a paediatric eczema population and key practice points agreed upon. These are listed at the end of this review.

RESULTS

There was universal agreement that the underutilisation of TCS due to the widespread fear of side-effects leads to worse outcomes for children with eczema in both the short and long term.

Corticosteroid efficacy and potency

Glucocorticosteroids have anti-inflammatory, immunosuppressive, anti-proliferative and vasoconstrictive effects.⁷ In the target cell, glucocorticoids bind to receptors in the cytoplasm before traversing the nuclear envelope and binding, either directly or indirectly, to DNA. Gene regulation and

transcription of various mRNA follows, resulting in both the beneficial and potentially deleterious effects of steroids.⁷ TCS reduce protein synthesis and cellular mitosis as well as inhibiting the proliferation, migration and chemotaxis of fibroblasts. The secretion of certain interleukins is inhibited and the vasoconstrictive effects of adrenaline promoted. TCS also reduce the inflammatory action of histamine and bradykinin.

The potency of TCS depends on the inherent characteristics of the particular steroid molecule and the amount of the molecule that reaches the target cell. Only 1% of hydrocortisone cream is absorbed in the forearm skin of a normal individual.⁸ In a single application study using radiolabelled hydrocortisone, absorption varied from 0.25 to 3%.⁸ Factors that influence absorption of TCSs through the skin include:

Penetration

How the TCS is formulated will influence its penetration through the skin. In a comparison of a cream, ointment, gel and foam formulation of betamethasone, the foam produced the highest vasoconstrictor activity (a measure of potency) and the cream the least.⁹ In a similar comparison of cream, gel and ointment preparations of fluocinolone acetonide, the cream formulation was more potent than the ointment preparation, with the gel having an intermediate activity.¹⁰ Occlusion has been reported to cause increased absorption in 96-h studies, but not in 24-h.

Concentration

A number of experimental (animal and human) studies from the 1970s and 1980s show little or no correlation between the vasoconstrictor test results and the concentration of topical steroid applied.

Saturation

Within three applications a steroid reservoir develops in the dermis (once it has been absorbed through the epidermis), which influences the rate of subsequent absorption. Doubling the number of hydrocortisone molecules on the skin from a 1–2% hydrocortisone cream increases absorption in a linear fashion with the first application, but absorption falls once dermal saturation occurs, thereby negating the concentration effect.¹¹

Elimination

The elimination of steroids from the dermis affects subsequent absorption. This occurs either by transport into the circulation or via its metabolism.

The most important factor, however, in determining the potency of a TCS is how well the active agent binds to corticosteroid receptors (i.e., the inherent potency of the steroid molecule) (Table 1). TCS potency is measured by the cutaneous vasoconstrictor assay.^{9,12–14} This measures the degree of pallor of the skin caused by both

Table 1 Potency ranking of selected topical corticosteroid preparations

	Usual concentration (%)
Class I: mild	
hydrocortisone	0.5–1.0
hydrocortisone acetate	0.5–1.0
Class II: moderate	
clobetasone butyrate	0.05
hydrocortisone butyrate	0.1
betamethasone valerate	0.02
betamethasone valerate	0.05
triamcinolone acetonide	0.02
methylprednisolone aceponate	0.1
triamcinolone acetonide	0.05
Class III: potent	
betamethasone dipropionate	0.05
betamethasone valerate	0.05–0.1
mometasone furoate	0.1
Class IV: very potent	
betamethasone dipropionate in optimised vehicle	0.05
clobetasol propionate	0.05

an augmentation of the vasoconstrictive response to adrenaline/noradrenaline and via occupancy of classical glucocorticoid receptors.^{7,15}

Steroid concentration

There is very little clinical difference in the potency of 0.5%, 1% and 2% hydrocortisone. Diluting a strong steroid by mixing it in a moisturiser base will not make it significantly less potent. If you wish to reduce potency, use a less potent steroid molecule.

Frequency of application

Putting a steroid on thrice daily adds very little to a once-daily application, particularly after several days of use. Apply steroids once or twice daily as directed.

Use liberally

The recommendation ‘use sparingly’ is nonsensical and has no value. Moreover, it unfortunately promotes inadequate use of the drug. In focus groups of parents, significant concern was generated by the instruction to use sparingly. Parents felt this created the impression that cortisone should be used only when eczema was severe and that this contributed to the underutilisation of TCS.¹⁶ It is better to recommend that the steroid is applied liberally and then carefully rubbed or massaged into inflamed skin. A very thick application is, however, wasteful. Use the fingertip unit as a guide to the quantities that should be used (Appendix 1).^{17,18}

Atrophy

The most frequent fear and misunderstanding about TCS use is clinically relevant skin thinning. In a survey of 276

pharmacists (Dr S. Smith, pers. comm., 2014), 46% stated that atrophy of the skin is the most common side-effect of TCS use. Two-thirds (67%) reported telling patients not to use TCS for a period longer than 2 weeks at a time.

This fear is not well founded. Much of the early literature on the side-effects resulting from TCS use comes from 1960–1980s.^{19–22} In these articles, cutaneous atrophy is highlighted as a potential side-effect of TCS use. However, these studies were generally of low quality, with small numbers of patients, and methods that are not consistent with the manner or nature of steroid use today (i.e., prolonged continuous application under occlusion in flexural areas).^{20,21}

At the biological level, atrophy refers to a decrease in dermal connective tissue and is characterised by the loss of elasticity and thinning. Histologically, there is a reduction in size of the corneocyte in the epidermis as well as thinning of the dermis.²³ The initial reduction in size of the keratinocytes reflects a reduction in metabolic activity. With prolonged exposure to high-potency steroids the number of cell layers is reduced, with the disappearance of the stratum granulosum and the thinning of the stratum corneum.^{22,24,25} In a study of three cases, there was significant resorption of mucopolysaccharide ground substance after 6 weeks of very potent steroid application (clobetasol propionate under occlusion in Duhring chambers).²² This rapidly reversed on discontinuation.^{22,25,26}

However, these observations have little clinical relevance. A recent Australian cross-sectional study²⁷ stressed that routine, long-term use of TCS in children with eczema does not cause skin atrophy. In total, 70 children were initially treated with a potent TCS (betamethasone dipropionate ointment 0.05% or methylprednisolone aceponate) before changing to a less potent TCS (betamethasone valerate). The mean amount of potent topical steroid per month used was 79 g, medium potency TCS was 128 g and weak potency TCS was 34 g. A validated dermoscopic technique was used to determine skin atrophy at 210 TCS sites and 70 control sites.^{28,29} None of the treatment or control sites demonstrated atrophy (all scored 0). Seven sites did show grade 1 telangiectasia, all in the cubital fossa; however, the same degree of telangiectasia was observed in the control group (3.2% *vs* 3.1%), suggesting that having some telangiectasia in the cubital fossa is a normal variation in the paediatric population.

A randomised controlled trial in adults with active eczema treated with 2 weeks of daily potent TCS (fluticasone 0.0005% ointment) followed by 16 weeks of twice weekly application showed no evidence of atrophy in the serial skin biopsies compared to placebo.³⁰ In a study of 174 children with atopic eczema treated with a 3-day bursts of a potent TCS (0.1% betamethasone valerate) showed no difference in skin thinning.³¹ Using ultrasonography the baseline thickness was measured at 0.91 mm thick. At the end of the 18-week study there was only 0.01 mm difference compared with baseline.

In the combined experience of the panel members no cases of steroid atrophy has been observed if TCS were used for the treatment of atopic eczema and if it were discontinued once the acute inflammation had settled. The cases of

steroid atrophy seen in children by the panel members were in the setting of 'off label use' to areas of hyperpigmentation or hypopigmentation for prolonged periods of time (months), particularly in higher absorption sites such as the axillae, flexures and groin. Occlusion, particularly with plastic wraps, has also been observed to increase the risk in these sites. It is, however, very important to recognise that parents and non-dermatologists often incorrectly ascribe the changes of active atopic eczema to be evidence of 'skin thinning'.

Summary

What is commonly referred to as skin thinning by parents and non-dermatologists is usually a misrepresentation of active eczema; (ii) irreversible skin thinning does not occur when TCS, used for eczema in children, is stopped on resolution of the dermatosis.

Striae/rubra distensae

Striae are visible, linear scars forming in areas of dermal damage produced by the stretching of the skin. Initially there may be inflammation and oedema of the dermis, followed by the deposition of dermal collagen along the lines of mechanical stress. Histologically, striae are characterised by the thinning of the overlying epidermis, with fine dermal collagen bundles arranged in straight lines parallel to the surface.⁵² Striae represent scar tissue and therefore, once they have developed, are permanent. They occur most commonly in association with rapid vertical growth (i.e., the back of young teenagers, excessive weight gain or loss and in association with pregnancy (striae gravidarum).

The evidence that TCS lead to striae is mostly low level, and includes five case reports, two small case series, one randomised controlled trial and three review articles. In total, striae were observed in 15 of 312 patients. In a head to head comparison of pimecrolimus and TCS (0.1% triamcinolone acetonide to the trunk or limbs and 1% hydrocortisone to the face, neck or intertriginous areas) for 1 year in 658 adults, only three patients developed striae.⁵³ However, in a specific study of TCS (moderate and potent) used in children over a mean of 10.8 months, in 210 test sites and 70 controls no striae were observed.²⁷

In over 430 person-years of paediatric dermatology practice, the panel recalls only one case of striae in a child using TCS for eczema. In contrast most of the panel members had seen striae, albeit very rarely, when used for non-eczematous conditions, particularly in overdose and under occlusion for extended periods of time.

Although concern is occasionally expressed over the possibility of delayed striae formation due to childhood use of TCS, there is no evidence to support this, even when TCS have been used inappropriately. Striae do occur commonly in children and teenagers during rapid growth phases with an estimated incidence of 25–35%,⁵⁴ but TCS do not produce striae in children using standard TCS treatment for eczema.

Summary

TCS do not induce striae when used to treat atopic eczema in children unless used inappropriately or in overdose and only then at certain sites (i.e. the axillae and groin).

HPA axis suppression

HPA axis suppression can occur following use of any exogenous steroid. Physiological adrenal suppression has been defined as a 'cortisol level below the normal range but with the capacity for prompt recovery' while pathological adrenal suppression is described as 'a state of adrenal insufficiency, adrenal crisis or persistent laboratory evidence of adrenal suppression without prompt recovery'.⁵⁵ Following exposure to exogenous corticosteroid, the body adjusts the HPA axis through the physiological suppression of endogenous cortisol. Following weeks to months of persistent exogenous corticosteroid exposure, the adrenal glands may become atrophic and are temporarily unable to produce adequate glucocorticoids to meet the body's requirements. In this situation, the adrenal suppression becomes pathological and an adrenal crisis may occur.

Following TCS use, temporary physiological adrenal suppression may be apparent within 2–4 weeks but is quickly reversible and the patient recovers fully.^{55–58} We are unaware of any reports of pathological adrenal suppression during the use of TCS that is discontinued on resolution of the active eczema.

In a review of 16 TCS trials that recorded HPA suppression, only one reported pathological adrenal suppression: five adult psoriasis patients who used more than 100 g clobetasol propionate a week for between 10 weeks to 18 months developed features of Cushing's syndrome. On withdrawal they suffered symptoms of adrenocortical insufficiency; and in addition they developed pustular psoriasis.⁵⁵

There are 25 paediatric case reports in the literature of HPA axis suppression. These children had mostly used super-potent topical steroids (clobetasol propionate) for 1–17 months for diaper eczema.^{59–67} There have been two reports of death due to sepsis in association with marked overuse of TCS in very young infants.^{48,49}

It is clear that physiological HPA axis suppression can occur for the duration of treatment with potent TCS. When used for routine eczema management in children, pathological HPA suppression has not been reported.

Summary

Physiological HPA axis suppression can occur with widespread and prolonged, or occlusive use, of potent/super-potent TCS. Clinically significant or pathological adrenal suppression is very rare in the treatment of paediatric eczema with topical agents.

Infected or excoriated skin

Most children with eczema are colonised with *Staphylococcus aureus*^{50,51} and many will develop secondary bacterial or

viral infections, such as *Herpes simplex* or *Molluscum*. Conversely, children's eczema will often flare following primary skin infection.⁵² There is, however, little evidence that treatment with TCS worsens any outcomes associated with infection. Indeed, adequate treatment of the eczematous skin with TCS generally restores the barrier function of the skin and greatly aids control of any associated infection, without the need for antibiotic or antiviral treatment.^{55,54} In children with significant secondarily infected eczema, TCS use should be combined with oral antibiotics or antivirals as clinically indicated. Topical antibiotics should generally be avoided to minimise the development of antibiotic resistance.

Children with atopic eczema often have areas of excoriated or weeping skin, or both. Corticosteroids have the potential to slow the healing of ulcerated skin, through reduced epidermal DNA synthesis and morphological changes in fibroblasts.¹⁹ When applied daily to incised pig-skin, triamcinolone acetonide was found to reduce the rate of wound healing in the pigs by 62% by day 7.¹⁹ However, the control of inflammation of atopic eczema by using TCS far outweighs the slight reduction in the rate of wound healing. There is little evidence to contraindicate the use of TCS on excoriated atopic eczema.

The members of the panel recommend moderate to potent strength TCS for children with atopic eczema with superimposed bacterial or viral infection, provided they are also receiving appropriate antiseptic, antibacterial or antiviral treatment if clinically indicated.

Summary

TCS should be the first-line treatment for excoriated or infected eczematous skin. Concurrent infection (e.g. *S. aureus*, *H. simplex*, *Molluscum*) should be treated if clinically significant. There is no evidence that putting TCS on excoriated or infected eczema is deleterious.

Allergic contact dermatitis to TCS

TCS allergy is a delayed hypersensitivity reaction whose reported prevalence is increasing.^{55,56} The low molecular weight of corticosteroid molecules should prevent it from becoming immunogenic but the degradation of the C17 side chain allows it to bind to amino acids to generate a hapten-protein complex, which can act as an allergen.⁵⁷

There is significant geographical variability in the reported prevalence of TCS allergy in both adults and children. This is due, in part, to regional differences in patch-test methodology and the prescribing habits of different countries.⁵⁸⁻⁶⁰ A meta-analysis by Dooms-Goossens and colleagues showed that approximately 1% of children patch-tested demonstrate allergy to TCS, although the relevance was not always clear.⁶¹ In children who do not respond to, or are made worse by topical steroid use, the incidence of steroid allergy was found to be 25%, although the overall incidence was not reported;⁶² 85% of those with positive patch test had multiple allergies.⁶⁵

Summary

Allergy to TCS is uncommon in children with atopic eczema but should be considered in those children who demonstrate a poor response to appropriate-strength TCS.

Osteopaenia/osteoporosis

Osteopenia or osteoporosis with resulting bone fractures is a well-known side-effect following the chronic use of oral corticosteroids in adults and children alike.⁶⁴⁻⁶⁶ The quality of evidence that TCS has any effect on bone mineral density (BMD) manifesting as osteopenia or osteoporosis, is relatively low. In one case-control study of 45 children with eczema using TCS, only children also on oral cyclosporin were found to have lower BMD and bone mineral apparent density) in the lumbar spine.⁶⁷ However, when the six patients with cyclosporin were excluded there was no significant difference found between those treated with TCS and the controls. There was no correlation between corticosteroid variables (eczema severity scoring system, dose of TCS, years of TCS usage, affected body surface area) and bone density at any site. The body location of eczema, vitamin D intake and the use of occlusion with TCS were not examined as potential confounders. Cyclosporin itself is thought to activate osteoclasts and suppress osteoblasts and bone formation,⁶⁸ and is known to be associated with an increase in osteocalcin levels, pointing to a secondary process of bone loss.⁶⁹

The limited research available to date suggests the risk of bone thinning in children with moderate to severe atopic eczema does not appear to differ from the expected prevalence of low BMD in the general population.⁷⁰

Summary

Reduced BMD is unlikely to occur in children with eczema treated with TCS. The panel has not identified any children with atopic eczema using only TCS who have developed osteopenia or osteoporosis.

Ocular effects

Potential adverse effects of systemic corticosteroids on the eyes include changes to intraocular pressure (glaucoma), cataract formation and infection. There is medium quality evidence that the prolonged application of corticosteroid eyedrops for ophthalmological conditions can result in ocular complications such as cataracts, glaucoma and ocular infections.⁷¹ There is, however, only level 4 and 5 evidence on the ocular side-effects of corticosteroid used topically near the eye.

Intraocular side-effects are rare when TCS is used appropriately in the periocular region (i.e., one week of moderate or potent TCS use, followed by mild potency TCS or calcineurin inhibitors for maintenance). A recent study assessed 88 patients with atopic eczema who utilised topical steroids to the eyelids and periocular region, with no increased risk of glaucoma observed.⁷² However, there are a

few case reports of adverse effects, which are primarily based around medication errors.^{75–75} In most of these cases there has been prolonged use of potent or very potent TCS for months to years. In many instances the TCS was originally prescribed for use in non-facial areas or for another patient altogether.

In the setting of atopic eczema, cataracts can develop through one of two distinct pathways. The more common is related to the disease itself; persistent itching and rubbing of the eyelids may induce traumatic cataracts. Systemic steroids (> 15 mg prednisone/day for over 12 months) can also induce posterior subcapsular cataracts.⁷⁶ Lower doses of systemic corticosteroids in combination with TCS use in the periocular region, subconjunctival and nasal steroid sprays has also been associated with posterior subcapsular cataracts, with seven cases reported in a 5-year period to 2001.⁷⁷

In a study of 37 atopic eczema patients who used moderate potency TCS periorbitally for an average of 6 months/year over 5 years, seven were found to have cataracts.⁷² Two of these patients were also using oral steroids, four of the seven were found to have age-related cataracts and one patient was found to have cataracts secondary to rubbing, in the setting of atopic eczema. None was directly related to TCS use.

It is currently unclear as to whether there is a threshold of TCS use which can induce cataract or glaucoma. It is possible that susceptible individuals, such as those with a personal or family history of cataracts, glaucoma, diabetes, myopia or previous eye problems have a lower threshold.

Summary

In predisposed individuals, the prolonged use of potent TCS in the periorbital area has been rarely associated with cataract and glaucoma. However, there is little evidence that less potent TCS used on the eyelids and periorbital area, even if used for a long duration, cause ocular sequelae. TCS use elsewhere on the face or body has not been shown to cause ocular sequelae. If potent TCS are to be used for prolonged periods in high-risk patients it may be advisable to obtain a baseline ophthalmology review and consider using a topical calcineurin inhibitor instead.

Hypertrichosis

Hypertrichosis may be generalised or localised, congenital or acquired. It must be differentiated from hirsutism. There is no high-quality evidence to support an association between TCS use and hypertrichosis. While various texts report an association between the two, each references a statement in a previous article or textbook, with no actual cases clearly documented. However, nine members of the consensus group report having seen localised hypertrichosis in children with a discoid pattern of atopic eczema (with or without prurigo nodularis), in the skin immediately surrounding the discoid patches or nodules. The localised hypertrichosis resolved on discontinuation of the potent

TCS (and the eczema). It is unknown whether this reported localised hypertrichosis is an epiphenomenon due to lichenification, traumatic rubbing or itching, the underlying discoid pattern of atopic eczema or an adverse effect of TCS use.

Summary

TCS do not cause permanent hypertrichosis. Transient hypertrichosis has been seen in discoid eczema and prurigo nodularis treated with potent TCS.

Periorificial dermatitis/rosacea

The pathogenesis of perioral dermatitis or rosacea is not completely understood. Fluorinated TCS, tacrolimus, inhaled steroids, *Demodex* mites, tartar control toothpastes, cosmetics, hormonal influences, occlusive moisturisers, cosmetics and amalgam fillings have all been implicated at one time or another.^{78–82} TCS are commonly prescribed in children for mild perinasal, periocular or perioral erythema, which initially are often effective. However, continued use or discontinuation, or both, can induce perioral dermatitis. In a study of 79 children with periorificial rashes, two-thirds (66%) were reported to be using TCS at the time of the initial evaluation.⁷⁹ However, it was not clear whether the periorificial rash had occurred prior to use of the TCS or following treatment. All cleared with the cessation of the topical steroid and use of topical metronidazole.

A number of studies have reported a rosacea-like eruption occurring in patients using tacrolimus.^{80–82} One study of 16 children with periorificial dermatitis compared those using topical tacrolimus with those using TCS.⁸⁰ The clinical presentation was similar, with a significant colonisation of *Demodex* mites occurring in both groups. All patients cleared on stopping the topical agents and treatment with topical metronidazole. There have been reports of inhaled steroids inducing perioral rosacea.⁸³

The consensus group believes that perioral dermatitis or rosacea can be induced in predisposed children, even by simple emollients or mild over-the-counter TCS (e.g. 1% hydrocortisone). The presence of a perioral, perinasal or periocular rash should raise suspicion of possible perioral dermatitis or rosacea. TCS should not be used to treat rosacea, as they typically lead to a cycle of dependence with flare on treatment withdrawal.

Perioral dermatitis or rosacea is generally easy to manage by avoiding all topical preparation (TCS, thick emollients, sunscreens, cosmetics, etc.). If treatment is required, consider 6 weeks of systemic antibiotics (e.g., erythromycin or tetracycline if the patient is over 12 years of age). If systemic treatment is inappropriate, consider topical metronidazole or azelaic acid. Patients should be warned to expect a flare following the cessation of treatment, and counselled about the importance of avoiding topical preparations, including TCS on the central portion of the face.

Summary

TCS may aggravate a tendency for perioral dermatitis/rosacea in predisposed individuals. Physicians who prescribe TCS for facial eczema should be aware of this complication.

Red face

The presentation of patients with a red face, often with the headlight sign (large areas of facial erythema with sparing of the nose and upper lip), has been described in adults using potent TCS, mostly for seborrhoeic dermatitis.⁸⁴ Nitric oxide is suggested to be a mediator of the rebound vasodilation reported in these cases. These patients are often described as being steroid dependent or addicts. Treating this involves cessation of all topical steroids and other skin-care products but it may take many months of discomfort to achieve this. Systemic therapy with anti-inflammatory antibiotics is often necessary (e.g., tetracyclines). The red face has not been reported as occurring in children, but should be kept in mind in teenagers whose inflammatory dermatosis deteriorates despite increasing steroid potency use.

Summary

The red face has not been described in children with eczema but should be kept in mind in teenagers who continue to deteriorate despite increasing steroid potency.

Tachyphylaxis

Tachyphylaxis refers to a progressive reduction in efficacy of an agent with its continued use and is often reported by patients and their families following TCS usage. The evidence for tachyphylaxis is, however, weak and is confounded by issues of non-compliance, and other reasons for failure to respond to treatment (e.g., acute flare due to secondary infection or exposure to irritants). In a mouse model TCS cause the inhibition of DNA synthesis and mitosis in the epidermis. With ongoing treatment DNA synthesis and mitosis recover and the tissue becomes insensitive to further stimulation.⁸⁵

A study of adolescents and adults⁸⁶ used either fluticasone 0.05% cream or ointment, or the equivalent base. Following clearance, patients entered a 16-week follow-up study. All patients applied an emollient once daily; half the patients then applied a TCS twice weekly, while the control group applied the base twice weekly. Those patients using twice weekly TCS had a median time to relapse of more than 16 weeks as opposed to 6 weeks for the base only. Most patients who applied a potent TCS twice weekly had not relapsed at 4 months.

In a 12-week study, none of the 32 patients being treated for psoriasis with TCS exhibited detectable signs of tachyphylaxis.⁸⁷ In another review there was no evidence that the clinical efficacy of glucocorticoids had diminished significantly in long-term continuous use in inflammatory

skin diseases.⁸⁸ However, in 10 volunteers with normal skin, a histamine-induced wheal was suppressed following 14 days of daily fluocinolone acetonide 0.01% applied under occlusion to the flexor aspect of the forearm. Maximal wheal suppression occurred on day 8, but by day 14 the study reported almost total tolerance to the TCS.⁸⁹

Non-compliance with treatment or the inadequate use of TCS is often a more common explanation for loss of response to TCS. Lack of adherence results from many factors: the chronic nature of eczema, the need for the ongoing application of creams, the prohibitive costs of topical agents and complexities in coordinating school, work and family plans. A study of adherence to topical treatment of eczema revealed only a 32% adherence in 8 weeks of treatment.⁹⁰ Non-compliance is particularly affected by steroid phobia. In one study 73% of dermatology outpatients reported being worried about using TCS and 33% confessed to non-compliance.⁹¹

Summary

There is no evidence to show that tachyphylaxis occurs in children with eczema treated with TCS. While there are some animal studies showing tachyphylaxis with TCS use, clinical studies have generally failed to confirm this.

Purpura

Purpura is not uncommon in individuals with significant sun damage, particular if they have also received prolonged courses of systemic or topical steroids. Purpura develops secondary to the loss of the supporting architecture of the local vasculature and is precipitated by shearing stress. It is usually asymptomatic.^{92,95} Although it is commonly listed as an adverse effect, the evidence for TCS-induced purpura without significant phototrophy, is poor.

A small study of six patients reported atrophy, telangiectasia and purpura related to TCS use.⁹⁴ One patient had used flurandrenolide 0.05% under occlusion for 5 years and experienced easy bruising. A second patient had used the same agent four times daily for 10 months. Two other patients used very potent TCS up to four times a day for 18 months and 5 years, respectively. All had continued to use the potent TCS long after the initial dermatosis had settled, i.e., they were being applied to non-diseased skin.

Purpura is a theoretical risk with TCS use but the literature does not support its presence in children nor in any individual using TCS to treat active eczema and ceasing on the resolution of disease activity. In addition, none of the consensus group had experience of TCS-related purpura in children. Summary Purpura does not occur in children with eczema being treated with TCS when they are stopped on the resolution of the active dermatosis.

Hypopigmentation

TCS produce vasoconstriction, which can be confused with hypopigmentation. It is mediated via occupancy of classical

glucocorticoid receptors.¹⁵ The time profile of vasoconstriction is dependent on the agent used, with carbon-11-chlorosteroid being the quickest.⁹⁵ The vehicle used also seems to contribute to the blanching profile, with betamethasone dipropionate ointment having a different profile to the same chemical in a cream base.⁹⁵

Although there are very few reports in the literature of TCS causing hypopigmentation, this side-effect continues to be widely reported. The literature includes two case reports⁹⁶ of hypopigmentation following the use of intralesional steroids, and one case of hypopigmentation localised to sites of use of flurandrenolide impregnated tape.⁹⁷ Fortunately, the hypopigmentation resolved within 7 days on cessation of use.

Hypopigmentation in the context of treating eczema in children is very common. This is largely due to the underlying disease (e.g., pityriasis alba).^{98–99} In the experience of the review group, only two children have been observed to develop localised hypopigmentation; both occurred in Fitzpatrick skin types IV–V and both had been using potent or very potent TCS. Fortunately, the hypopigmentation occurred only at the treated site, and in each case the pigmentary change was transient and resolved completely over a period of a few weeks to months following cessation of the TCS.

Summary

The hypopigmentation seen in patients with eczema is usually secondary to the eczema (e.g., pityriasis alba). It resolves with appropriate treatment of the eczema, particularly after exposure to UV light. TCS do cause short-term vasoconstriction, which may be mistaken as hypopigmentation. Very potent TCS have been used inappropriately as a skin lightening agent.

Telangiectasia

There is some evidence from animal studies that triamcinolone acetonide and fluocinolone acetonide can induce telangiectasia in rats.¹⁰⁰ It is notable that the studies used excessive quantities of TCS. While telangiectasia have been reported with prolonged, excessive and occlusive use of TCS,^{100–105} there is little evidence that telangiectasia occur when used to treat active childhood eczema when treatment is stopped on resolution of the dermatosis.

In a recent study, 92 Australian children treated using mild to potent TCS or emollients as per their eczema severity were followed over a mean of 10.6 months.²⁷ Mild grade 1 telangiectasia was seen in 3% of the cases, all of which involved the antecubital fossa. However, this was similar to the control group (3%).

In another study investigators undertook a right-left comparison in the same individual using between hydrocortisone 1% cream and pimecrolimus 1% cream. This was an 8-week single centre study of the uninvolved forehead skin of 20 patients with atopic eczema.⁵⁵ Following a twice-daily application for 2 months, no dermal thinning or telangiectasia was demonstrated, as measured by ultrasound or dermoscopic photography.

Alclometasone dipropionate 0.05% was compared with hydrocortisone 1% in a randomised double blind manner in 32 children with eczema, looking for evidence of atrophy or telangiectasia following its twice-daily application for 3 weeks. There was no evidence of telangiectasia or sign of cutaneous atrophy in any child.¹⁰²

It is the panels' opinion that telangiectasia can develop after the prolonged use of very potent TCS, but is very unlikely in children when TCS are used appropriately for active eczema. Care should be taken with prolonged and excessive use of very potent topical steroids, particularly when used in combination with inhaled, intranasal and systemic steroids.

Summary

Routine use of TCS in children with eczema should not cause telangiectasia.

CONCLUSION

TCS remain the mainstay of the management of active atopic eczema in combination with the regular use of emollients, the management of triggers and the treatment of concurrent infection. The safety profile of TCS remains robust when it is used appropriately. Appropriate use is defined as 1–2 generous applications per day to all the inflamed skin until the active eczema is controlled as per guidelines (Appendix 1). The advice given by dermatologists to parents of children with eczema regarding the use of TCS is unfortunately frequently undermined by other health professionals. There is a pressing need for the re-education of these health professionals on the excellent safety record of these medications.

Key Points

There is little difference in the clinical effect between 0.5, 1 and 2% hydrocortisone.

Diluting a strong steroid with moisturiser does not reduce its clinical effect. Potency reduction is achieved by using a less potent steroid molecule.

Most topical steroids can be applied once daily, preferably in the evening or at night.

The recommendation 'use sparingly' is nonsensical and has no value. Use the fingertip unit as a guide.

What is commonly referred to as skin thinning by parents and non-dermatologists is usually a misinterpretation of active eczema.

When TCS used for eczema in children are stopped on resolution of the dermatosis, irreversible skin thinning does not occur.

TCS do not induce striae when used to treat atopic eczema in children, unless used inappropriately, or in overdose and only then at certain sites (i.e., axillae and groin).

Physiological HPA suppression can occur with very widespread and prolonged, or occlusive use of potent/super-potent TCS. This recovers quickly.

Clinically significant/pathological adrenal suppression is very rare in the treatment of paediatric eczema with TCS.

There is no evidence that applying TCS on excoriated or infected eczema is deleterious.

TCS should be the first-line treatment for atopic eczema, regardless of whether the skin is excoriated or infected.

Clinically significant concurrent infection (e.g., *S. aureus*, *H. simplex*, *Molluscum*) should be treated.

Allergy to TCS is rare in children with atopic eczema, but should be considered in those children who demonstrate a poor response to appropriate strength TCS.

Reduced bone mineral density is very unlikely to occur in children with eczema treated with TCS.

Prolonged use of potent TCS in the periorbital area has rarely been associated with cataract and glaucoma.

TCS use away from the eyes has not been shown to cause ocular sequelae.

Transient hypertrichosis has been seen in discoid eczema and prurigo nodularis treated with potent TCS.

TCS may aggravate a tendency for periorificial/perioral dermatitis, in predisposed individuals.

The red face has not been described in children with eczema, but should be kept in mind in teenagers who continue to deteriorate despite increasing steroid potency.

There is no evidence to show that tachyphylaxis occurs in children with eczema treated with TCS.

TCS do not induce purpura in children with atopic eczema.

The hypopigmentation seen in patients treated with TCS, as their eczema clears, is caused by the eczema (as in pityriasis alba), not the treatment.

TCS do cause short-term vasoconstriction, which can be mistaken as hypopigmentation.

Routine use of TCS in children with eczema should not cause telangiectasia.

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APPENDIX I

Appendix 1. Guidelines for the practical use of TCS

When to apply

Apply 1–2 applications per day as per the product information, to all the inflamed skin until eczema is cleared. There is no requirement for intervals without therapy.

How much to apply

There is no requirement to use sparingly. Please refer to the following table of application volume recommendation.

Table A1 Fingertip unit^{17,18}

Patient's age	Face and neck	Arm and hand	Leg and foot	Anterior chest and abdomen	Back and buttocks
3–12 months	1	1	1½	1	1½
1–3 years	1½	1½	2	2	3
3–6 years	1½	2	3	3	3½
6–10 years	2	2½	4½	3½	5
>10 years	2 ½	4	8	7	7

CHAPTER 4

Assessment of dermatologists' attitudes to efficacy and safety of topical corticosteroids

This chapter contains the original research, “Assessing dermatologists’ attitudes to efficacy and safety of topical corticosteroids,” published in the Australasian Journal of Dermatology 2016;57:278-283.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

As co-author(s) of the paper:

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We confirm that Saxon D Smith has made a major contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

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Name: Dr Andrew Lee

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ORIGINAL RESEARCH

Attitudes of Australian dermatologists to the use and safety of topical corticosteroids in paediatric atopic dermatitis

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ABSTRACT

Background: Atopic dermatitis is a common paediatric dermatological condition. Topical corticosteroids (TCS) are central to treatment, but non-adherence leads to poor outcomes and treatment failure. Parents commonly cite TCS phobia as an obstacle to treatment adherence. Dermatologists play a key role as clinician educators around the use, safety and efficacy of TCS.

Objectives: To assess dermatologists' attitudes towards and experiences of the use and safety of TCS in managing paediatric atopic dermatitis (pAD).

Methods: All 455 practicing Australasian College of Dermatologists fellows in Australia were surveyed either when attending the May 2014 annual scientific meeting or via two subsequent emails. The survey assessed their attitudes towards the use and safety of TCS in treating pAD.

Results: Of 198 completed surveys, nearly all responders prescribed potent or super-potent TCS to treat pAD. The most common TCS side-effect cited by over two-thirds of respondents was peri-orificial dermatitis. Most stated that pharmacists were the most common source of misinformation leading to TCS phobia. Of the respondents, 75% strongly agreed that

TCS do not cause skin atrophy when used appropriately and under clinical supervision. Furthermore, 77% agreed or strongly agreed that the words 'use sparingly' should be removed from pharmacist labels on TCS prescriptions.

Conclusions: Dermatologists manage pAD with potent or super-potent TCS. Pharmacists are cited as the main contributor of misinformation leading to TCS phobia, supporting the removal of the words 'use sparingly' from prescription TCS. Most dermatologists believe TCS do not cause skin atrophy when used appropriately in pAD.

Key words: atopic dermatitis, attitudes, corticosteroid phobia, dermatologists, efficacy, paediatrics, safety, topical corticosteroids.

INTRODUCTION

Atopic dermatitis (AD) is the most common paediatric dermatological condition in the world.¹ With correct management it is also one of the most treatable. Topical corticosteroids (TCS) are accepted as the gold standard of treatment of active disease. However, inadequate adherence to medical therapy frequently results in unsatisfactory treatment outcomes.^{1–3} Poor adherence often stems from corticosteroid phobia. That is, although paediatric atopic

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Abbreviations:

ACD	Australasian College of Dermatologists
AD	atopic dermatitis
ASM	annual scientific meeting
CAM	complementary and alternative medicine
pAD	paediatric atopic dermatitis
TCS	topical corticosteroids

dermatitis (pAD) can be disabling and disruptive of patients and their families, anxiety over the use of TCS leads to poor adherence to topical treatment regimens.^{2,5-8}

Corticosteroid phobia is a major cause of non-compliance and treatment failure in pAD.⁹⁻¹² This fear of using TCS is also seen by paediatricians attempting to manage asthma with inhaled corticosteroids.⁸⁻¹¹ Whilst the use of the term phobia may be a relative misnomer, the resultant fear and its impact on treatment adherence is very real. Parents are often warned of the dangers of TCS, not only by their friends, relatives and the media, but also by traditionally trusted sources, including their family doctor and pharmacists.⁸ Often when advice and information is offered by family and friends, it is unsolicited by the parents of children with pAD and contributes to the creation of a negative cultural environment as parents contend with the demands of managing their child's illness.

Treatment of AD with TCS results in very few side-effects when correctly used and a recent consensus statement from a group of Australian paediatric dermatologists has stated this categorically.¹³ However, it is a common belief among Australian parents that medical treatment for pAD with TCS is dangerous and that 'natural' therapy is safe and therefore preferable.⁸ The most common danger associated with the use of TCS that parents cite is that it will 'thin the skin' irreversibly.⁸ Parents also voice concerns about immune suppression and growth failure.

Fear of TCS has also been linked to a preference for natural therapies promoted by complementary and alternative medicine (CAM) practitioners.⁸ Parents, who often have a poor understanding of the predominantly genetic basis of pAD, frequently pursue the 'cures' that CAM purports to provide.⁸ This can result in parental abandonment of evidence-based medical therapy, resulting in potentially serious, detrimental outcomes for their children. In the extreme case this has resulted in the death of a child from sepsis secondary to untreated atopic dermatitis.¹⁴

Parents of children with pAD seek advice and support from their treating dermatologist. In particular, this trusted relationship is critical to treatment adherence in the face of the sea of misinformation that parents frequently have to negotiate. It is important for dermatologists to recognise their key role as health educators in relation to the use, safety and efficacy of TCS in pAD.

OBJECTIVES

To assess current attitudes and experience of practicing dermatologists about the use and safety of TCS in managing pAD.

MATERIALS AND METHODS

A survey of all 455 Australian-based practicing fellows of the Australasian College of Dermatologists (ACD) was performed. Initially surveys were distributed at the ACD May 2014 annual scientific meeting (ASM). Two subsequent follow-up emails were sent to all Fellows, inviting those who had not already completed the initial survey at the ASM

to complete an electronic version of the survey. The survey assessed as to their attitude towards the use and safety of TCS in treatment pAD (Table 1).

RESULTS

Data were collected and analysed from 198 (44%) completed surveys from a total of 455 dermatologists. A small number of responses (1%) were excluded since they provided either nil or multiple answers. Of the sample, 118 (60%) participants completed the paper-based survey while 80 (41%) did so through a web-based format. The 1% of errors occurred in the paper-based versions of the survey.

Participants' characteristics (Table 2)

There was a relatively even representation from respondents with a different duration of experience as practising dermatologists. There was more representation by those who had been practising for more than 20 years (36%) and by those who had been practicing for fewer than 5 years (21%; Table 2). However, this variation in the spread of experience closely reflects the composition, by years of practice, of current Fellows of the college (pers. com., ACD, 25 February 2015).

TCS prescribing behaviour (Table 3)

More than half (52%) of the dermatologists reported prescribing between six and 10 topical corticosteroids prescriptions on an average working day for any condition; 7% reported prescribing more than 16 scripts a day, and 24% reported prescribing five or fewer a day. Nearly all respondents (98%) reported using a potent or super-potent TCS in AD when required. A minority (2%) reported that the strongest class of TCS they would use was moderate. No dermatologist reported that the strongest TCS they would use was a weak TCS.

TCS side-effects and source of phobia (Table 4)

Most dermatologists (69%) reported that the most common side-effect they encountered with TCS use was peri-orificial dermatitis, with 16% reporting bruising. Only 6% reported that the most common side-effect seen was cutaneous atrophy.

Two-thirds (64%) indicated that pharmacists were the most common source of TCS phobia, followed by 23% who believed it resulted from the influence of family and friends.

Instructions given when prescribing TCS (Table 5)

Two-thirds of the dermatologists surveyed (67%) reported informing their patients that TCS may thin their skin. In this there was no difference related to the number of years they had practiced. Instructions to use TCS sparingly were given by 21% of dermatologists. This instruction was increasingly

Table 1 Assessing dermatologists' attitude to and use of topical corticosteroids

I have been a consultant dermatologist for

a. 0–5 years

b. 6–10 years

c. 11–15 years

d. 16–20 years

e. >20 years

1. On an average day in my rooms I write scripts for topical corticosteroids

a. 1–5 times

b. 6–10 times

c. 11–15 times

d. 15–20 times

e. >20 times

2. The strongest topical corticosteroid I prescribe is

a. Weak

b. Moderate

c. Potent

d. Superpotent

e. I avoid topical corticosteroids in preference for other topical medications

3. The commonest side-effect I see from topical steroid use is

a. Cutaneous atrophy

b. Striae

c. Telangiectasia

d. Bruising

e. Peri-orificial dermatitis

4. Patients are often concerned about topical corticosteroid use. What do you think is the most common source of this fear?

a. Pharmacist warnings

b. GP warnings

c. Naturopaths or other complementary and alternative medicine provider

d. The internet

e. Influence from friends and family

5. When prescribing topical corticosteroids I do the following

Warn that the medication may thin their skin Yes ☐ No ☐

Instruct them to use the medication sparingly Yes ☐ No ☐

Give patients a time limit on how long they can use their treatment Yes ☐ No ☐

Tell patients to use their treatment until their skin has normalised regardless of how long this takes Yes ☐ No ☐

6. On a scale of 1 (strongly disagree) to 5 (strongly agree) indicate to what extent you agree with the following statement:

If used as directed at an appropriate dose and time for skin site and severity of disease, topical corticosteroids are very unlikely to cause cutaneous atrophy

	1	2	3	4	5
	Strongly disagree			Strongly agree	

7. On a scale of 1 (strongly disagree) to 5 (strongly agree) indicate to what extent you agree with the following statement:

The term sparingly should NOT be written on the label of prescribed tubes of topical corticosteroid

	1	2	3	4	5
	Strongly disagree			Strongly agree	

Table 2 Surveyed dermatologists' duration of practice

	Respondents, <i>n</i> (%)
Total	198
Duration of practice (years)	
0–5	41 (21)
6–10	28 (14)
11–15	31 (16)
16–20	27 (14)
> 20	71 (36)
Missing	0

likely as the number of years practiced increased ($P < 0.001$). Of the group of dermatologists who had been practising the shortest period (fewer than 5 years), 3/41 (7%) instructed patients to use TCS sparingly, compared to

Table 3 Average number of topical corticosteroids (TCS) prescriptions written daily by dermatologists

	Respondents <i>n</i> (%)
Number of TCS scripts daily	
0–5	47 (24)
6–10	103 (52)
11–15	35 (18)
16–20	7 (4)
20 +	6 (3)
Missing	0
Strongest TCS used	
Weak	0 (0)
Moderate	3 (2)
Potent	35 (18)
Super-potent	159 (80)
Avoid	1 (1)
Missing	0

Table 4 Most commonly seen side-effects of topical corticosteroids (TCS) and most common source of TCS phobia, according to dermatologists

	Respondents <i>n</i> (%)
Most common side-effect of TCS	
Cutaneous atrophy	11 (6)
Striae	3 (2)
Telangiectasia	15 (8)
Bruising	31 (16)
Peri-oral dermatitis	155 (69)
Missing	3
Source of TCS phobia	
Pharmacist	120 (64)
General practitioner	8 (4)
Naturopaths or complementary and alternative medicine provider	8 (4)
The internet	8 (4)
Influence of family and friends	43 (23)
Missing	11

Table 5 Instructions given by dermatologists when prescribing topical corticosteroids (TCS)

	Respondents <i>n</i> (%)
Warn that TCS may thin skin	
Yes	152 (67)
No	64 (33)
Missing	2
Use TCS sparingly	
Yes	41 (21)
No	155 (79)
Missing	2
Time limit on TCS use	
Yes	119 (61)
No	76 (39)
Missing	3
Use TCS until skin has normalised regardless of how long this takes	
Yes	108 (56)
No	86 (44)
Missing	4

23/70 (33%) of dermatologists who had been practising for more than 20 years.

Most dermatologists (61%) gave patients a time limit for how long TCS could be used. However, 56% also instructed patients to use their treatment until their skin had normalised, regardless of how long it took with TCS use.

Dermatologists' beliefs on TCS atrophy and labelling of TCS (Table 6)

Most (93%) of the dermatologists either agreed (17%) or strongly agreed (76%) that TCS, if used as directed at an appropriate dose and duration in accordance with disease severity, are unlikely to cause cutaneous atrophy. Furthermore, 77% of the dermatologists either agreed (27%) or strongly agreed (51%) that the term 'sparingly' should not

Table 6 Dermatologists' beliefs on topical corticosteroids (TCS) causing atrophy and labelling of TCS

TCS, if used at an appropriate dose and duration, are unlikely to cause cutaneous atrophy	Respondents <i>n</i> (%)
Strongly disagree	6 (3)
Disagree	1 (1)
Ambivalent	8 (4)
Agree	35 (17)
Strongly agree	150 (76)
Missing	0
The term 'sparingly' should not be written on the label of prescribed tubes of TCS	
Strongly disagree	11 (6)
Disagree	11 (6)
Ambivalent	25 (12)
Agree	55 (27)
Strongly agree	100 (51)
Missing	0

be written on the label of prescribed tubes of TCS. A further 12% were ambivalent on this issue while a minority (11%) disagreed with this statement.

DISCUSSION

Australian parents commonly believe that TCS used in the treatment of pAD are dangerous and that natural therapy is safe and therefore preferable.⁸ In fact, Charman and colleagues⁹ found that 73% of people were anxious about using TCS on their own or their child's skin. Typically, parents were most anxious that TCS would cause skin thinning (35%), and 10% were concerned about systemic absorption, resulting in the retardation of growth and development.

These fears surrounding TCS are common. TCS phobia is expressed by up to 73% of dermatology patients and parents.^{9,15-17} This phenomenon is also encountered by paediatricians attempting to manage asthma with inhaled corticosteroids.^{8,10-12} However, the fear associated with using TCS is not a true phobia. It is the result of misinformation on the dangers of TCS propagated not only by friends, relatives and the media but also by traditionally trusted sources, including their family doctor and, in particular, pharmacists.⁸

Our study shows that dermatologists at all levels of clinical experience prescribe potent or super-potent TCS where clinically appropriate in pAD. This is in contrast to the fear expressed by parents and even general practitioners of using even the weakest TCS (1% hydrocortisone) in the treatment of pAD. While this was not directly assessed in the survey, it is not unreasonable to assume that the willingness of dermatologists to prescribe TCS relates to their level of specific knowledge about the safety and efficacy of TCS and their general experience of using TCS to manage a spectrum of skin conditions.

It was interesting to find that most dermatologists surveyed (64%) believe that pharmacists are the main contributor to misinformation. A further 23% suggest that the

influence of family and friends is the main contributor. This is in contrast to a previously reported study of parents in which friends (88%) and family (50%) were reported to be a greater influence than pharmacists (44%).⁸ Nevertheless, both dermatologists and parents cite these groups as being very influential in their attitude to TCS, and thus any TCS safety and education programme needs to target both these groups.

The most common side-effect seen by dermatologists in the use of TCS in pAD is peri-oral dermatitis (69%) and only a minority cite cutaneous atrophy (6%) as a side-effect. However, it has previously been shown that when used under appropriate supervision with careful instructions from the dermatologist, cutaneous atrophy does not occur in TCS-treated pAD.¹⁸ Despite these facts there is a disconnect between the 67% of dermatologists who still specifically warn parents about TCS as a side-effect while the majority (79%) do not suggest that TCS should be applied sparingly. However, this disconnect may be explained by respondents perhaps answering 'yes' to warning about atrophy, when in fact they were simply mentioning it and explaining that if TCS is used correctly atrophy should not occur, and thus addressing patients' fears about it. For this reason, the true number of dermatologists reinforcing the warning that TCS may cause cutaneous atrophy is likely to be lower.

Nonetheless, in the current climate of widespread TCS phobia, such warnings may reinforce the existing misinformation that prevents patients' adherence to treatment. This has implications for the education of dermatologists on their own influence on patients' behaviour.

Dermatologists who had been practising for longer periods were more likely to advise patients to use TCS sparingly. This could either reflect out-of-date information or the fact that dermatologists who had practised for longer periods had seen more cutaneous atrophy as an adverse event across all the conditions they treat. Furthermore, it could represent the impact of earlier reports exploring side-effects of TCS.^{19,20} In light of the finding from this study that 93% of dermatologists believe that TCS was unlikely to cause cutaneous atrophy and were comfortable with the safety and efficacy of TCS, it more likely represents practice methods that do not reflect current evidence.

Another finding from this survey was that there relabelling TCS prescriptions should be considered. Specifically, the common recommendation on TCS tubes to use it sparingly should be removed, as this has the potential of affecting compliance rates and therefore interfere with the medical advice given to patients who require TCS for their treatment. This warning, in fact, directly contravenes most medical advice from dermatologists and has the potential to confuse and influence patients to use inadequate amounts of TCS, leading to the poor management of pAD. A large number of dermatologists (77%) in this survey believed that the term 'sparingly' should be removed from TCS labels. The warning also contravenes the pharmacists' code of ethics, which specifically states that pharmacists should label medications only in accordance with what is written on the prescription by the doctor.²¹

The lack of need for phrase 'use sparingly' of TCS labelling is further supported by the fact that a significant portion of dermatologists treating pAD advise patients that there is no strict time limit on the duration of TCS use, and that it should be used until the condition is normalised regardless of how long it takes.

CONCLUSION

Dermatologists in Australia commonly utilise potent or super-potent TCS for the treatment of pAD. Most report that skin atrophy is rare and that side-effects are uncommon when TCS are used appropriately. Despite the known facts on the safety of TCS a substantial number of dermatologists still advise their patients that cutaneous atrophy is a risk of this treatment, which, in the current climate, may contribute to TCS phobia. Dermatologists believe that the effective management of pAD is affected by TCS phobia, for which pharmacists are cited as the main contributor. Most dermatologists support removing the phrase 'use sparingly' from TCS labelling.

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CHAPTER 5

Assessment of pharmacist's knowledge and understanding of topical corticosteroid efficacy and safety.

This chapter contains the original research, "Assessing pharmacist's knowledge and understanding of topical corticosteroid efficacy and safety," published in the Australasian Journal of Dermatology 2016;57:199-204.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

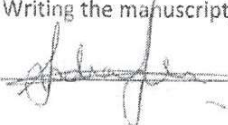
As co-author(s) of the paper:

Smith SD, Lee A, Blaszczyński A and Fischer G. Assessing pharmacist's knowledge and understanding of topical corticosteroid efficacy and safety. *Australasian Journal of Dermatology* 57:199-204, 2016.

We confirm that Saxon D Smith has made a major contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

Signed:

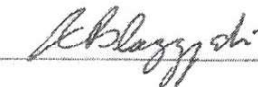


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ORIGINAL RESEARCH

Pharmacists' knowledge about use of topical corticosteroids in atopic dermatitis: Pre and post continuing professional development education

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ABSTRACT

Background/Objectives: Topical corticosteroids (TCS) are the standard of care in paediatric atopic dermatitis (pAD). Parents commonly cite TCS phobia as a major impediment to treatment adherence. Misinformation on TCS side-effects can impact on perceptions of TCS safety. We aimed to assess pharmacists' beliefs and information on the safety of TCS in pAD treatment and determine whether their beliefs could be modified.

Methods: Australian pharmacists attending a continuing professional development conference were assessed before and after an evidence-based lecture on the use of TCS in pAD. Responses were recorded in real time on electronic keypads.

Results: The mean response rate was 86% of the 292 surveyed. Of responders, 64% recognised that treatment non-adherence was a major reason for treatment failure in pAD. The post-education session assessment demonstrated a major attitude shift compared to the pre-education assessment. After education, pharmacists would instruct parents/patients to apply TCS until the eczema is clear (27 vs 92% pre and post-education, $P < 0.0001$). The proportion that would instruct patients to use TCS sparingly dropped

from 54 to 8% ($P < 0.0001$). The belief that cutaneous atrophy was the commonest side-effect dropped from 46 to 7% ($P < 0.0001$). The belief that side-effects from TCS would occur, even if used appropriately, dropped from 56 to 11% post-education ($P < 0.0001$).

Conclusions: The significant knowledge gaps about the use and safety of TCS in pAD in Australian pharmacists and their advice to patients potentially contributes to poor treatment concordance. These attitudes appear modifiable through targeted, evidence-based education delivered by a dermatologist.

Key words: adherence, corticosteroid phobia, knowledge, pharmacist, topical corticosteroid.

INTRODUCTION

Paediatric atopic dermatitis (pAD) is the commonest paediatric dermatological condition worldwide and, when managed using topical corticosteroids (TCS), also one of the most treatable. However, inadequate compliance with medical therapy frequently results in unsatisfactory treatment outcomes.^{1–5} Poor concordance often stems from so-called corticosteroid phobia. That is, although severe pAD is disabling and disruptive to patients and their families, anxiety over the use of TCS leads to poor adherence to topical treatment regimens and subsequent poor responses to treatment.^{1,4–7}

Corticosteroid phobia is a major cause of non-concordance and treatment failure in pAD.^{8–11} This

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Conflict of interest: none

Dr S Smith, Dr A Lee, Professor A Blaszczyński and Associate Professor G Fischer contributed equally to this review article.

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Abbreviations:

AD	atopic dermatitis
TCS	topical corticosteroids
pAD	paediatric atopic dermatitis

phenomenon is also seen by paediatricians attempting to manage asthma with inhaled corticosteroids.^{7–10} The amount of misinformation current on TCS means that this concern is widespread.

Treatment of pAD with TCS is accepted as the standard of care in dermatology. Furthermore, it has very few side-effects if correctly used.¹² However, it is a common belief among Australian parents that medical treatment for pAD with TCS is dangerous and that 'natural' therapy is safe and therefore preferable.⁷ The most common belief that parents offer regarding perceived risks associated with the use of TCS is that it will thin the skin irreversibly. Many parents also voice concerns about immune suppression and growth failure.⁷

Fear of TCS appears to be linked to a preference for the so-called natural therapies promoted by complementary and alternative medicine (CAM) practitioners.⁷ Parents, who often have a poor understanding of and guilt-driven emotional resistance to the predominantly genetic basis of pAD, frequently pursue the cures that CAM purports to provide and also focus on allergy as a cause of atopic dermatitis (AD).⁷ This can result in parents' abandoning evidence-based medical therapy with potentially serious, detrimental outcomes for children.¹²

The objective of this study was to assess pharmacists' beliefs and sources of information on the safety of TCS in treatment of pAD and to determine whether their beliefs can be modified by re-education.

MATERIALS AND METHODS

Pharmacists attending a plenary continuing professional development conference were assessed on their sources of education and knowledge of the use of TCS in the treatment of pAD. All attendees at the conference were able to attend an evidence-based education session conducted by a paediatric dermatologist presenting data on TCS safety and TCS phobias, previously published in peer-reviewed journals.^{7,12,15} Pre and post-education session assessments were performed with responses recorded on an electronic keypad in real time. The questions were developed with the assistance of a psychologist (author AB) and were piloted with pharmacists prior to the session.

The Northern Sydney Local Health District Human Research and Ethics Committee indicated that no formal ethics approval was required due to the voluntary attendance by participants at a conference session where their attendance formed part of personal professional development. Participants gave implied consent by their voluntary participation in the questions.

A cross-sectional survey was performed at a continuing professional development conference for pharmacists in Australia held on the Gold Coast, Queensland, in February 2014. The participants were pharmacists practicing in Australia in a range of clinical settings. Participants were attending an education session delivered by dermatologists on the management of skin diseases. The participants were asked a series of multi-choice questions before to a session specifically dealing with the use and safety of TCS in the

treatment of pAD. They had 15 seconds to respond to each question. The responses were collected via an individual de-identified electronic keypad and for each question were shown to participants in the form of aggregated anonymous results after the time to respond had expired. The initial 14 questions covered information of the participants' characteristics, their primary sources of education of TCS during their pharmacy degree and continuing education, and their attitudes and knowledge on the use and safety of TCS in treatment of pAD.

After the education session the final six questions focusing on pharmacist behaviour in dispensing TCS were repeated to assess any change in their attitudes or future behaviour as a direct result of the education intervention. Descriptive statistics were used to characterise question responses. McNemara's test was used to compare proportions of correct responses pre and post-education. All analyses were conducted using SPSS 20.0 (SPSS, IBM, Armonk, NY).

RESULTS

The total number of pharmacists surveyed was 292. The average number of response per question was 250 of 292 (86%) with the spread of actual response rate of 94 to 276 per question. The median response rate was 261/292 (89%).

Respondents' characteristics

There was a relatively even spread of pharmacists across all age groups, with a slight, expected decline in representation as the age increased. The proportions seen in those surveyed were similar (<30-year-olds, 32 *vs* 29%; 30–40-year-olds, 23 *vs* 31%; 40–50-year-olds, 16 *vs* 17%; 50–60-year-olds 22 *vs* 13%; >60-year-olds, 8 *vs* 15%) to national averages.¹⁴ Of those surveyed, 43% had been practising for less than 10 years and 59% for more than 20 years (Table 1).

Half of those present (49%) indicated that their primary source of continuing information about TCS was from pharmacy journals, 8% from dermatology journals and 21% from the internet. The majority (64%) received their undergraduate education about TCS from a pharmacist and 10% received it from a dermatologist (Table 2).

Pre-education responses (Table 3)

TCS advice

Just under half (46%) of the respondents stated that they spent time informing the patient about TCS use even when prescribed by a dermatologist.

A large portion of pharmacists surveyed did not recommend the use of the TCS in line with the prescription advice. Of responders, 6% reported that they would suggest an alternative frequency of application and a further 5% would advise twice a day regardless of formulation. Furthermore, 67% of pharmacists advised that the maximum duration that TCS could be used was 2 weeks or less. When directing the amount of TCS to be applied, 54% reported informing

Table 1 Respondents' characteristics

	Respondents, n (%)
Total	292
Age (years)	
<30	77 (32)
30–40	54 (23)
40–50	38 (16)
50–60	52 (22)
>60	19 (8)
Missing	52
Years of practice	
<5	95 (36)
5–9	18 (7)
10–14	26 (10)
15–19	21 (8)
>20	105 (39)
Missing	29
Average number of patients who are prescribed TCS daily	
<1	6 (6)
1–5	41 (44)
6–10	22 (25)
11–15	8 (9)
>15	17 (18)
Missing	198

Table 2 Education of pharmacists

	Respondents, n (%)
Primary source of information about prescription of TCS:	
Pharmacy journals	131 (49)
Clinical dermatology journals	20 (8)
Internet-based sources	57 (21)
Pharmaceutical representatives	35 (13)
Pharmacy meetings	24 (9)
Missing	25
Primary source of education on TCS at university received from:	
A lecturer who was a pharmacist	165 (64)
A lecturer who was a dermatologist	25 (10)
A lecturer who was a non-dermatologist	18 (7)
A pharmacologist	41 (16)
Other source	11 (4)
Missing	32
When dispensing TCS, time spent informing patient/ parent about their use:	
Rarely	10 (4)
Only when purchased over the counter	31 (12)
Even when prescribed by a general practitioner	78 (30)
Even when prescribed by a non-dermatologist specialist	22 (8)
Even when prescribed by a dermatologist	120 (46)
Missing	31
TCS, topical corticosteroids	

the patient that TCS should be used sparingly, while 41% reported advising patients to use TCS either generously or based on fingertip unit guidelines. Pharmacists under 40 years of age and those who had been practising for less than 10 years were more likely to recommend TCS use for a short

duration. Only 14 out of 95 who had been practising for less than 10 years (15%) recommended that TCS be used until the eczema was clear.

Knowledge

Almost half (46%) of pharmacists believed that skin atrophy was the most common side effect of TCS. Pharmacists who had been practising for less than 10 years were more likely to incorrectly understand this side effect of TCS than those who had been practising more than 10 years.

Of those surveyed, 64% believed that poor TCS compliance was a major reason why patients with AD fail to get better. The survey did not explore the source of this information and it was therefore not clear if this was because of patients are not following pharmacist advice or medical advice. However, it was clear that most are aware of this problem.

Counselling behaviour

Almost 60% of pharmacists asked patients about the location and reasons of their TCS use, and held discussions in front of other patients. Pharmacists who had been practising for fewer than 10 years or pharmacists aged under 40 and were more likely to ask questions in a non-private setting about patients' TCS use.

Internet education

Pharmacists whose primary source of TCS information was stated as being from internet sources (21%) were the most likely to give incorrect answers before the education session. In general, this subgroup was twice as likely to give the incorrect answer to every question (except those about counselling) compared to those who had received their primary education about TCS from pharmacy and clinical dermatology journals.

Post-education responses (Table 3)

After the education session, the likelihood of well-informed responses significantly improved in all seven questions regarding correct TCS advice, knowledge and counselling behaviour. More pharmacists now stated they would dispense TCS only as indicated on the prescription (52 vs 88%, $P < 0.0001$). Of those surveyed, 92% stated they would advise TCS be used until the eczema is clear, compared to 27% prior to education ($P < 0.0001$). Most pharmacists stated they would now instruct the patient to apply TCS generously or according to fingertip guidelines (41 vs 72%, $P < 0.0001$). Nearly all pharmacists acknowledged that side-effects do not occur with TCS when they are used appropriately (43 vs 89%, $P < 0.0001$) and 88% stated they would now counsel patients about TCS out of earshot of others or in a private setting, compared to 41% pre-education ($P < 0.0001$).

DISCUSSION

Poor compliance with treatment is common in pAD and can lead to treatment failure. Treatment failure has significant

Table 3 Pre and post-education responses of pharmacists

	Pre-education, <i>n</i> (%)	Post-education, <i>n</i> (%)	Respondents for both questions, <i>P</i> -value
When dispensing TCS I recommend it should be applied:			
Once a day regardless of formulation	2 (0.8)	4 (2)	<i>n</i> = 235
Twice a day regardless of formulation	12 (5)	4 (2)	<i>P</i> < 0.0001
Once/twice a day depending on formulation	99 (37)	11 (4)	
†Only as indicated on the prescription supplied	137 (52)	220 (88)	
I suggest alternative frequency of application	16 (6)	10 (4)	
Missing	26	43	
When dispensing TCS I recommend the be used for:			
Maximum of 3 days	6 (2)	12 (5)	<i>n</i> = 247
Maximum of 1 week	100 (37)	4 (2)	<i>P</i> < 0.0001
Maximum of 2 weeks	74 (28)	3 (1)	
Maximum of 1 month	16 (6)	1 (0)	
†Until the eczema is clear	73 (27)	241 (92)	
Missing	25	31	
When dispensing TCS I instruct the patient/parent to apply:			
Only the smallest amount possible	9 (3)	9 (34)	<i>n</i> = 246
Sparingly	145 (54)	21 (8)	<i>P</i> < 0.0001
As the patient/parent feels appropriate	6 (2)	41 (16)	
†Generously	19 (7)	120 (47)	
†Based on fingertip unit guidelines	92 (34)	66 (26)	
Missing	21	55	
The most common side effect from regular use of TCS is:			
Stinging/itching	17 (6)	2 (1)	<i>n</i> = 251
Hypo or hyper-pigmentation of the skin (discolouration)	9 (3)	0 (0)	<i>P</i> < 0.0001
Thinning of the skin (Skin atrophy)	126 (46)	19 (7)	
Growth retardation	4 (1)	7 (3)	
†None of the above when used appropriately	120 (44)	233 (89)	
Missing	16	31	
Compliance/adherence with the use of TCS in the treatment of skin conditions:			
An insignificant problem as patients with eczema use their medication	17 (7)	9 (4)	<i>n</i> = 207
Impossible to prevent	25 (10)	10 (4)	<i>P</i> = 0.002
†A major reason patients with eczema fail to get better	155 (64)	189 (79)	
A more significant problem with oral agents	25 (10)	6 (3)	
A poor excuse for ineffective drug treatment	19 (8)	25 (11)	
Missing	51	53	
When I counsel patients about using TCS, I:			
†Take them to a separate room	1 (0)	24 (10)	<i>n</i> = 240
†Take them aside so that other patients are out of earshot	109 (41)	197 (78)	<i>P</i> < 0.0001
Talk to them in front of other patients	45 (17)	18 (7)	
Ask them why they are using their treatment	48 (18)	1 (0)	
Ask them where they will applying their treatment	64 (24)	12 (5)	
Missing	25	40	

†Correct response, TCS, topical corticosteroids.

impacts on the patient, family and society.⁵ A previous study has shown that patients commenced on topical therapies for dermatological conditions frequently fail to comply with their treatment instructions.¹⁵ One of the significant contributing factors affecting treatment adherence in pAD is corticosteroid phobia. In fact, corticosteroid phobia is expressed by between 40 and 75% of dermatology patients and parents.^{8,16–18}

Parents often say that they have been warned of the dangers of TCS not only by friends, relatives and the media but also by traditionally trusted sources, including their general practitioner and pharmacist.⁷ This helps to create a negative cultural environment for parents of children with pAD, which they contend with as well as managing the treatment demands of their child's illness.

A recent Australian focus group study showed that parents commonly believe that medical treatment for pAD with TCS is dangerous and they prefer 'natural' therapy, which they believe is safer.⁷ Charman and colleagues found that 72.5% of people worried about using TCS on their own or their child's skin. Although skin thinning remains the most prevalent fear (35%), 10% of patients were concerned about systemic absorption resulting in the retardation of growth and development. Hydrocortisone 1% was the most commonly used TCS and one-third of the patients using this classified it as being either strong or very strong, or were unsure of its potency. This highlights the need for evidence-based health literacy education to improve patient education regarding the safety, potency and appropriate use of TCS.⁸ It is important that the education provided to parents

of children suffering with pAD acknowledges the impact of the pAD and pays particular attention to addressing carers' treatment beliefs.¹⁹

Community pharmacists play a role in educating patients about the management of dermatology conditions.^{20,21} The pharmacists' code of ethics requires that they offer information on the use of medications but that this information should never conflict with the prescriber's recommendation.²²

However, research from our group shows that misinformation offered by pharmacists in Australia has a major impact on the perceptions of TCS safety and also reveals that pharmacists are the most influential group contributing to TCS phobia in the general public.⁷ Anecdotally, many dermatologists have had the experience of patients failing to respond to treatment due to the modifications imposed by the pharmacist from whom they obtained their prescription medication. Reports by patients to dermatologists cite verbal advice and changes to the labelling on the medication, particularly the addition of the word sparingly, which sends a message that the medication is inherently dangerous. There is also evidence from a previous French study that showed that more than 50% of patients reported that they had been warned about the use of TCS by pharmacists.²⁵ This research confirmed that this is also happening commonly in the community in Australia, with 88% of pharmacists stating that they would change instructions indicated on a prescription. Although this dropped to 52% after the education session, this indicates that this behaviour is difficult to modify. That 46% of pharmacists reported that skin atrophy was a common side-effect of the use of TCS also highlighted the need for further education to pharmacists about TCS safety. A previous study has called for the removal of the words use sparingly from the label on prescribed TCS.²⁴ In Australia this is printed automatically by pharmacy software. It is possible that this influences not only patients but pharmacists as well.

The data in this study also demonstrate that pharmacists' sources of information may not be optimal or evidence-based, and it would appear that this has been amplified in the last decade, as evidenced by the responses of younger pharmacists, who are more conservative than older ones.

The data do, however, demonstrate that evidence-based information may have a prompt impact on beliefs which were, in the majority, obviously not always firmly held and were amenable to re-education. The attitude that it is acceptable to change the content of the label on the medication from the prescription written by the doctor requires further exploration, as the reasons for this are likely to be complex.

A secondary finding that became evident in the data from this study was that pharmacists not only contradict medical advice on TCS but engage patients publicly within earshot of other patients. Again anecdotally, many dermatologists have heard this from their patients who may find it embarrassing and intrusive. Further, this behaviour breaches Australian privacy legislation. It would appear that pharmacists need to become more aware of their impact on patients and indeed, their vulnerability to patients' complaints over

privacy. The results from our demographic data are also a reasonably good representation of the general pharmacist population, making our results even more applicable.

The responses from the pharmacists in this study also ironically demonstrate that, despite the fact that they themselves realise that poor concordance is a major factor in poor treatment response, they are unwittingly part of the problem. The source of their knowledge of poor concordance was not explored by this study as this finding was not anticipated.

A limitation of our study was that the phrasing of some questions may have resulted in ambiguity and potentially reduced validity in some of the responses elicited, and also contributed to some of the missing responses. A question that could have been improved included 'when I dispense TCS I spend time informing the patient/parent about using them.' We also acknowledge that our question on counselling on TCS use, the questions could have been split into two separate components such that the first three responses were separate from the last two options, in order to improve the validity of the question. The limitations imposed by the keypads which allowed only one correct answer were not anticipated.

A further limitation of the study was that we were unable to assess whether short-term changes in attitudes evidenced during the session would translate into long-term behavioural change. However, most pharmacists receive information from other pharmacists rather than clinicians, and this implies that their own health beliefs are subject to misinformation generated within their own group, without the involvement of actual stakeholders. Education of pharmacists by dermatologists on the use of TCS would appear to be critical to changing the information given to patients.

Poor concordance with TCS treatment is costly to the community and to patients, disruptive to the family unit, frustrating to treating doctors and not based on evidence. The generation of more evidence of their safety should be a priority for researchers and every attempt should be made to disseminate this information to the pharmacy community both at undergraduate and postgraduate level. Dermatologists, who have the most confidence in and experience with the use of TCS, have a critical role in potentially changing the way pharmacists influence patients in the Australian community through pharmacy journals, conferences and at undergraduate level in pharmacy schools at Australian universities. Removal of the use sparingly instruction on medication labels should also be a priority.

CONCLUSION

It is evident that there are wide education gaps in Australian pharmacists' knowledge of the use and safety of TCS in pAD. This ultimately contributes to the misinformation parents and patients receive about the use and safety of TCS, which in turn directly affects the compliance that is the key to good treatment outcomes. Targeted education, especially in pharmacy journals and at undergraduate level, preferably delivered by a dermatologist, is needed to

improve pharmacist's knowledge and eliminate misconceptions. Our data indicate that their attitudes may be modified by evidence-based, clinically centred re-education.

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CHAPTER 6

Assessment of general practitioners' attitudes to efficacy and safety of topical corticosteroids.

This chapter contains the original research, "Assessing general practitioners' attitudes to efficacy and safety of topical corticosteroids," published in the Australian Family Physician 2017;46:355-340.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

As co-author(s) of the paper:

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We confirm that Saxon D Smith has made a major contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

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General practitioners' knowledge about use of topical corticosteroids in paediatric atopic dermatitis in Australia

Saxon D Smith, Victoria Harris, Andrew Lee, Alex Blaszczyński, Gayle Fischer

Background and objective

Topical corticosteroids are the standard of care in paediatric atopic dermatitis (pAD). However, messages that overstress possible side effects can have a negative impact on perceptions of safety and contribute to treatment non-adherence. The aim of this study was to assess general practitioners' (GPs') perception of the safety of topical corticosteroids in pAD treatment.

Methods

Australian GPs participating in continuing professional development programs were assessed before an education session on pAD. Responses were recorded via an electronic survey.

Results

A total of 257 GPs were surveyed. More than one-third (40.7%) of the GPs instructed parents to apply topical corticosteroids for two weeks or less. Nearly half (47.7%) instructed parents to apply topical corticosteroids sparingly or with the smallest amount possible. Furthermore, nearly one-third (30.2%) reported skin atrophy as the most common side effect of topical corticosteroids.

Discussion

Advice to patients given by Australian GPs may carry unintentional risk messages contributing to treatment non-adherence. Evidence-based information on the safety of topical corticosteroids is needed to empower GPs to improve treatment outcomes in pAD.

Paediatric atopic dermatitis (pAD) is the most common paediatric dermatological condition, affecting >20% of children aged five years or younger.¹ All cases of pAD require environmental modification, identification and avoidance of the triggers that cause flares, but in virtually all except mild cases, topical corticosteroids are an essential part of management. Poorly controlled pAD has a significantly negative impact on the quality of life of affected children, as well as their entire family.^{2,3} Frequently, unsatisfactory outcomes occur because of poor adherence with medical therapy⁴⁻⁸ and this can stem from multiple sources.⁹ In particular, 'corticosteroid phobia' has been identified as a major cause of non-adherence and treatment failure.¹⁰⁻¹³ Despite the burden of pAD to patients and families, anxiety regarding the use of topical corticosteroids poses a dilemma for parents, where unnecessary fear of using a safe and effective treatment paralyses their ability to help their child.^{4,7,8,14,15} This phenomenon is also seen by paediatricians when managing asthma with inhaled corticosteroids.^{10-12,15}

Topical corticosteroids are the standard of care in the treatment of pAD. When used appropriately they have very few side effects.¹⁶ However, there is a common belief among Australian parents that topical corticosteroids can be dangerous, and they prefer 'safe', 'natural' therapy.¹⁵ Parents believe irreversible skin thinning (atrophy) to be the most common perceived risk. This is also a common belief among Australian pharmacists.¹⁷ However, dermatologists as a group do not see skin atrophy as a common complication,¹⁸ and there is a lack of evidence from current clinical research for such complications when topical corticosteroids are used appropriately.¹⁹ The subject of general practitioners' (GPs') attitudes to the safety of topical corticosteroids has not been specifically examined.

Parents' attitudes can result in abandonment of evidence-based medical therapy, with potentially detrimental outcomes.²⁰ Furthermore, inadequately applied topical corticosteroids results in poor outcomes, such as rapid rebound

flare of pAD from prematurely ceased treatment. This creates the impression of treatment failure. The objective of this study was to assess Australian GPs' beliefs and sources of information on topical corticosteroid safety.

Methods

A survey was administered to Australian GPs participating in continuing professional development (CPD) programs. Participants were invited to complete a survey, which assessed sources of education and knowledge of topical corticosteroids in the treatment of pAD. Three separate CPD events were used: a web-based education module and two separate face-to-face CPD conferences. Each program was approved by The Royal Australian College of General Practitioners (RACGP) or Australian College of Rural

and Remote Medicine (ACRRM) for CPD accreditation.

An evidence-based education session was conducted by a dermatologist on the management of pAD. Surveys were completed prior to participating in CPD education events. Responses were recorded using a web-based module with inbuilt data collection and an online survey tool (SurveyMonkey) for face-to-face conference attendees. Questions were developed with the assistance of a psychologist (author AB) and piloted with GPs prior to the events.

The Northern Sydney Local Health District Human Research and Ethics Committee indicated that no formal ethics approval was required because of voluntary attendance by participants at a conference session where their attendance formed part of personal professional development. Participants gave implied consent by their voluntary participation in the questions.

Chi-squared test was used to analyse question responses using SPSS 20.0 (SPSS Inc, Chicago, IL).

Results

A total of 257 GPs were surveyed. Of these, 109 (42.4%) completed the survey prior to the web-based module and 148 (57.6%) participated in two separate face-to-face CPD events. Of those who participated in the face-to-face events, 108 (42.0%) were located in Brisbane and 40 (15.6%) in Perth.

Demographic data

There was an even spread of GPs across all age groups, with the exception of those aged <30 years of age (Table 1). This broadly compares with national averages for the age of practising GPs in Australia (<35 years: 13.4%; 35–44 years: 24.9%; 45–54 years: 24.9%; 55–64 years: 23.1%; 65–74 years: 11.2%; ≥75 years: 2.5%).²¹ Of those surveyed, 16.2% had been practising for <10 years and 58.1% >20 years.

Source of education

Table 2 shows the sources of education about topical corticosteroids. More than

Table 1. Demographic data

Topics	Respondents, n (%)
Total	257
Age (years)	
<30	11 (4.3)
30–39	57 (22.1)
40–49	60 (23.3)
50–59	78 (30.2)
>60	51 (19.8)
Missing	0
Years of practice	
<5	16 (6.2)
5–9	38 (14.7)
10–14	32 (12.4)
15–19	40 (15.5)
≥20	131 (50.8)
Missing	0
Average number of patients who are prescribed topical corticosteroids daily	
<1	69 (26.7)
1–5	171 (66.3)
6–10	9 (3.5)
11–15	3 (1.2)
>15	5 (1.9)
Missing	0

Table 2. Education of general practitioners about topical corticosteroids

	Respondents, n (%)
Primary source of information about prescription:	
• General practice journals	106 (41.1)
• Dermatology journals	14 (5.4)
• Internet-based sources	39 (15.1)
• Pharmaceutical representatives	20 (7.8)
• Clinical meetings	78 (30.2)
Missing	0
Primary source of education at university received from:	
• lecturer who was a pharmacist	19 (7.4)
• lecturer who was a dermatologist	162 (62.8)
• lecturer who was a non-dermatologist specialist	22 (8.5)
• lecturer who was a general practitioner	20 (7.8)
• other source	34 (13.2)
Missing	0
Primary source of education during general practice training:	
• lecturer who was a pharmacist	4 (1.6)
• lecturer who was a dermatologist	99 (38.4)
• lecturer who was a non-dermatologist specialist	18 (7.0)
• lecturer who was a general practitioner	81 (31.4)
• other source	55 (21.3)
Missing	0

one-third of participants (38.5%) indicated that their primary source of continuing information about topical corticosteroids was from general practice journals, 34.5% from clinical meetings/conferences, 12.8% from the internet and 4.0% from dermatology journals. The majority (57.4%) received undergraduate education about topical corticosteroids from a dermatologist. However, during postgraduate general practice training, nearly as many received their education on topical corticosteroids from a GP (31.4%) as from a dermatologist (38.2%).

Topical corticosteroid advice

Responses to questions about prescribing and advice given to parents are shown in Table 3. The majority of responders indicated that they vary the strength of topical corticosteroids on the basis of disease severity (69.0%) and site (63.2%). Twice as many GPs indicated that the maximum strength of topical corticosteroids they would prescribe was potent (36.8%), compared with those who would prescribe moderate potency (15.1%) or weak potency (16.9%). Furthermore, only 3.9% indicated they avoid topical corticosteroids.

Less than half (46.9%) of the GPs indicated they would recommend applying a topical corticosteroid until active disease clears and, 40.7% responded that they instructed parents to apply topical corticosteroids for only two weeks or less. There was a trend across the group based on age and years of experience. GPs younger than 39 years of age were more likely to instruct application for two weeks or less, whereas GPs aged 50 years or older were more likely to instruct application until pAD was cleared. Similarly, GPs with more than 20 years' experience were more likely to instruct application of topical corticosteroids until pAD cleared.

When directing the amount of topical corticosteroids to be applied, nearly equal numbers of GPs reported instructing parents to apply 'sparingly' (37.6%) or the smallest amount possible (10.1%)

as compared with those who instructed an amount based on fingertip guidelines (39.1%) or 'generously' (7.4%). Only a minority (5.4%) instructed parents to apply as they felt appropriate. There was no discernible trend across age or years of practice.

Knowledge

More than half (58.1%) of GPs believe that when topical corticosteroids are used appropriately, side effects are unlikely to occur, yet nearly one-third (30.2%) indicated that skin atrophy was the most common side effect from regular use (Table 3). Across all ages and years of practice, if a GP indicated they instruct

parents to apply topical corticosteroids sparingly or thinly, they were statistically more likely to select skin atrophy as the most common side effect ($P = 0.002$).

Treatment adherence

Of those surveyed, the majority either strongly disagreed (17.1%) or disagreed (48.8%) that topical corticosteroid adherence was an insignificant problem because parents/patients use their medications. Furthermore, the majority either strongly disagreed (14.3%) or disagreed (50%) that poor treatment adherence was impossible to prevent. However, the majority either strongly agreed (8.9%) or agreed (57.4%) that

Table 3. General practitioners' knowledge responses

	n (%)
When I prescribe topical corticosteroids the maximum strength I use is:	
• I avoid topical corticosteroids	10 (3.9)
• Weak	42 (16.9)
• Moderate	39 (15.1)
• Potent	95 (36.8)
• Based on severity	178 (69.0)
• Based on site	163 (63.2)
When I prescribe I recommend they be used for:	
• Maximum of 3 days	5 (1.9)
• Maximum of 1 week	28 (10.9)
• Maximum of 2 weeks	72 (27.9)
• Maximum of 1 month	31 (12.0)
• Until the eczema is clear [†]	121 (46.9)
• Missing	0
When I prescribe topical corticosteroids I instruct the patient/parent to apply:	
• Only the smallest amount possible	26 (10.1)
• Sparingly	97 (37.6)
• As the patient/parent feels appropriate	14 (5.4)
• Generously [†]	19 (7.4)
• Based on fingertip unit guidelines [†]	101 (39.1)
• Missing	0
The most common side effect from regular use of topical corticosteroids is:	
• Stinging/itching	13 (5.0)
• Hypo or hyper-pigmentation of the skin (discolouration)	14 (5.4)
• Thinning of the skin (Skin atrophy)	78 (30.2)
• Growth retardation	1 (0.4)
• None of the above when used appropriately [†]	150 (58.1)
• Missing	1

[†]Multiple responses possible

[†]Correct response

poor treatment adherence was the major reason patients with pAD fail to get better. Interestingly, there were essentially equal numbers of respondents who indicated they disagreed (33.7%), were neutral (34.1%), or agreed (23.3%) that treatment adherence issues were a more significant problem with oral agents than topical agents (Table 4).

Discussion

Paediatric atopic dermatitis is a common condition. If managed appropriately, mild-to-moderate cases respond readily to treatment. This involves using topical corticosteroids of adequate potency matched to the severity of pAD, in amounts that cover all involved areas daily until the skin is a normal colour and texture, and without a specified time limit. Despite this, children with pAD and their families continue to experience disruption to health and sleep because of parental reluctance to undertake safe and effective therapy. Children who could be effectively treated in general practice find their way to a dermatologist, with resultant cost to themselves and the community. This survey did not explore the information source(s) that may contribute to poor treatment adherence, but it was clear that the majority of GPs are aware of this problem.

The role of dermatologists in this multidisciplinary team is to increase confidence in treatment and educate parents on the best use of topical corticosteroids. This can involve de-briefing anxious and disbelieving parents regarding previous treatment advice.

One of the most significant contributing factors affecting treatment adherence in pAD is corticosteroid phobia, which is expressed by 40–73% of dermatology patients and parents.^{10,22–24} Previous research shows some parents state one source of treatment information leading to this fear comes from their GP.¹⁵ This study sought to explore this further.

A 2006 Australian study found that moderate-to-severe pAD caused maternal stress equivalent to that associated

with the care of children with severe developmental and physical problems such as Rett syndrome.²⁵ More recently, an Australian focus group study showed parental concerns about the safety of topical corticosteroids come from many sources, not only pharmacists, family, complementary and alternative medicine (CAM) practitioners and online information, but also their GPs.¹⁵ Interestingly, this study showed a possible link between a fear of using topical corticosteroids and a preference for CAM. Parents, who often have a poor understanding of, and guilt-driven emotional resistance to, the genetic basis of pAD, frequently pursue 'cures' that CAM purports to provide. Furthermore, this research revealed that parents sometimes experienced difficulty in convincing their GPs to refer their child to a dermatologist.

GPs are aware that poor adherence is a cause of treatment failure. However, when GPs instruct parents on short time limits and minimal volume application of topical corticosteroids in this chronic skin disease, or warn about skin atrophy, they may unintentionally convey a risk message about side effects that confirms parents' misunderstanding of the nature and treatment of chronic skin disease.²⁶

Our group has shown that the word 'sparingly', routinely printed on topical corticosteroid labels by pharmacists even when not written on prescriptions, has a negative impact on patients' perceptions of topical corticosteroid safety.²⁶ In this study, the concept of sparing application was also embraced by a substantial number of GPs. Negative risk messages have a greater impact and are more powerfully recalled than positive ones, and a warning that is casually mentioned by a GP may have a profound effect on a parent, particularly when this is reinforced by misinformation found on the internet.²⁶

In the crowded undergraduate curriculum of medical schools, dermatology education tends to be kept to a minimum. In general practice, at least 10% of daily consultations relate to the skin. GPs receive further

training at the postgraduate level, but less than half of this is delivered by dermatologists, who have hands-on experience and confidence in using topical corticosteroids. It is interesting that younger GPs in our cohort are more cautious than older ones. This may

Table 4. General practitioners' non-compliance responses

	n (%)
An insignificant problem as patients with eczema use their medication:	
• Strongly disagree	44 (17.1)
• Disagree	126 (48.8)
• Neutral	41 (15.9)
• Agree	40 (15.5)
• Strongly agree	6 (2.3)
• Missing	0
Impossible to prevent:	
• Strongly disagree	37 (14.3)
• Disagree	129 (50.0)
• Neutral	56 (21.7)
• Agree	32 (12.4)
• Strongly agree	3 (1.2)
• Missing	0
A major reason patients with atopic dermatitis fail to get better:	
• Strongly disagree	8 (3.1)
• Disagree	35 (13.6)
• Neutral	43 (16.7)
• Agree	148 (57.4)
• Strongly agree	23 (8.9)
• Missing	0
A more significant problem with oral agents:	
• Strongly disagree	13 (5.0)
• Disagree	87 (33.7)
• Neutral	88 (34.1)
• Agree	60 (23.3)
• Strongly agree	9 (3.5)
• Missing	0
A poor excuse for ineffective drug treatment:	
• Strongly disagree	13 (5.0)
• Disagree	68 (26.4)
• Neutral	78 (30.2)
• Agree	81 (31.4)
• Strongly agree	17 (6.6)
• Missing	0

reflect changes in medical teaching and lack of personal experience.

Research from our group shows that misinformation offered by pharmacists in Australia has a major impact on perceptions of topical corticosteroid safety and also reveals that pharmacists are the most influential group contributing to topical corticosteroid phobia.¹⁵ This study presents further investigations indicating that GPs can have a similar, if somewhat less negative, attitude to the use of topical corticosteroids. Ultimately, this suggests that it is important that both groups require an evidence-based update on this subject to ensure the best outcomes for patients. With a view to clarify the safety and efficacy of topical corticosteroids, a consensus statement by Fellows of the Australasian College of Dermatologists regarding the side effects of topical corticosteroids has recently been published.¹⁶

Evidence shows appropriate use of topical corticosteroids in treatment of pAD does not result in skin atrophy.¹⁹ In terms of treatment duration, it is important that GPs recognise that inflammatory skin diseases, which are usually chronic, require ongoing topical corticosteroid treatment that cannot be time-limited. Currently, pharmacists and GPs appear to be unwittingly contributing to topical corticosteroid phobia, which in turn results in treatment failure. In terms of health economics, increased confidence at the GP level in the appropriate use of topical corticosteroids would relieve the burden on dermatology services and empower GPs to successfully manage pAD.

There are potential limitations to this study, given this is a sample of GPs who were participating in CPD activities. This may mean that the participant GPs were attempting to upskill in an area in which they felt deficient, which might mean the results overstate the issue at hand. Conversely, the results may understate the issue at hand with GPs who do not actively participate in regular CPD activities in the area of dermatology. Another limitation is the practical nature of survey-based

research, which limits a broader diversity of potential answers. A further potential limitation is that while this study explored the management of pAD, it is possible that a child's age (in addition to the site and severity of the atopic dermatitis) may also affect the maximum strength of a topical corticosteroid that a GP will prescribe.

Implications for general practice

There may be education gaps in Australian GPs' knowledge of the use and safety profile of topical corticosteroids in pAD. This may contribute to exaggerated risk messaging that reinforces misinformation parents/patients currently receive about use and safety of topical corticosteroids from numerous sources. In turn, this can directly affect treatment adherence, which is the key to good outcomes. Targeted education, especially in general practice journals and CPD conferences, is needed to enable successful management of pAD in general practice.

For further reading about the clinical management of pAD, please refer to an article by Page, Weston and Loh, published in *Australian Family Physician*.²⁷

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CHAPTER 7

Evaluation of the influence of pharmacists and GPs on patient perceptions of long-term topical corticosteroid use

This chapter contains the original research, “Evaluation of the influence of pharmacists and GPs on patient perceptions of long-term topical corticosteroid use,” published in the Journal of Dermatological Treatment 2017;28:112-118.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

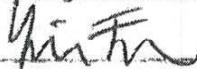
As co-author(s) of the paper:

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We confirm that Saxon D Smith has made a major contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

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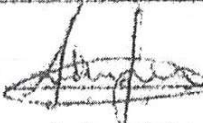


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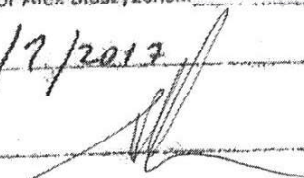


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ORIGINAL ARTICLE

Evaluation of the influence of pharmacists and GPs on patient perceptions of long-term topical corticosteroid use

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ABSTRACT

Purpose: To assess pharmacist and general practitioner (GP) advice and behaviors, as related to and reported by patients and parents of patients using topical corticosteroids (TCS) on a long-term basis.

Materials and methods: Multicenter cross-sectional survey of patients (aged 18+) and parents of pediatric patients (aged <18) with a history of long-term (≥ 1 month) TCS use, assessing: TCS treatment adherence and reasons for non-adherence; beliefs regarding TCS use and safety; messages regarding TCS received from community pharmacists, GPs, family/friends and the Internet; and experiences of GP and pharmacist counseling regarding TCS use.

Results: A total of 123 patients and 78 parents completed the survey ($n = 201$). 76.6% of respondents reported consistently ("Often" or "Always") receiving one or more message(s) regarding TCS "risk" from a GP and/or pharmacist ($n = 192$). Respondents reported being told to "try natural or complementary and alternative therapies before resorting to the use of TCS" significantly more often by pharmacists than by GPs ($p = 0.039$).

Conclusions: High rates of consistently delivered messages about TCS "risk" from GPs and pharmacists affect patient/parent understanding about TCS safety and may lead to treatment non-adherence. This indicates a need for reeducation of these groups on the safety of TCS use.

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Introduction

Topical corticosteroids (TCS) have been a mainstay in the treatment of inflammatory dermatoses for decades, and there is ample evidence to support their long-term efficacy and safety. Clinical dermatologists generally agree that with appropriate use, the benefits of topical corticosteroid therapy continue to outweigh their putative risks and side effects (1–3).

Despite this expert consensus, TCS treatment adherence tends to be suboptimal in dermatological patients (4–6). The consequences of non-adherence in inflammatory skin conditions vary based upon the severity of the patient's disease, the condition's responsiveness to TCS and the extent of non-adherence. Ramifications range from unnecessary symptomatology to disability, with death at the extreme end of the spectrum (7).

"Corticosteroid phobia" is a significant contributing factor to TCS treatment non-adherence (8–11). This "phobia" can be attributed to irrational fear or a lay misunderstanding of the word "steroid" either due to confusion around the difference between systemic and topical usage, or between anabolic steroid abuse and appropriate corticosteroid medication. However, derivation and propagation of this "phobia" appear to be due to messages disseminated in the media, on the Internet, amongst friends and family, and, most troublingly, from conventionally trusted health professionals such as general practitioners (GPs) and pharmacists (8,9,12).

Significant knowledge gaps exist amongst pharmacists with regard to TCS use in atopic eczema (13), and both pharmacists and GPs continue to verbally warn patients about the presumed

"risks" of appropriate long-term TCS use (9,12). Calls to remove the words "sparingly," "thinly" and other warnings that may fuel corticosteroid phobia from TCS packaging (14) have been only sporadically heeded in community pharmacies. These observations suggest that the use of warnings against long-term TCS usage is deeply ingrained into pharmacy and GP professional cultures. Thus, further investigation and intervention are required.

Community pharmacists and GPs are well placed to identify and intervene in patient non-adherence since they see a given patient more often than dermatologists do and may observe the patient's prescription refill patterns (15–18). Pharmacist and GP interventions have been associated with improvements in treatment adherence (19,20), but there is concern that messaging inconsistent with dermatologist advice correlates with poorer adherence (13,21). Hence, it is imperative that dermatologists, GPs and pharmacists send consistent messages to dermatological patients regarding the safety of long-term TCS use.

Materials and methods

Survey development

A cross-sectional survey was designed to assess pharmacist and GP advice and behaviors, as related to and reported by patients and parents of patients using TCS on a long-term basis.

The following information was collected:

- Demographics
- Rates of TCS treatment adherence
- Reasons for non-adherence

- Beliefs regarding TCS concerns, necessity and self-efficacy
- Beliefs regarding consistency and reliability of information sources
- Frequency of messages received from community pharmacists, GPs, family/friends and the Internet regarding TCS-related risks and benefits
- Experiences of TCS-use counseling with GPs and pharmacists

TCS treatment adherence was evaluated using the five-item medication adherence report scale (MARS), a validated tool which asks about unintentional (one item) and intentional (four items) non-adherent behaviors (22,23). Respondents reported the frequencies of these non-adherent behaviors on a five-point Likert-type scale, from “Never” to “Always”.

The survey was piloted with patients and parents prior to the commencement of data collection. The respondents’ pilot survey responses and verbal feedback were utilized to optimize survey design. Piloting and feedback incorporation were iterated until no further changes were required.

Within questions, statements were ordered randomly so that related statements were not clustered together and positive and negative statements were interspersed. Questions were without jargon or abbreviations. Adult and pediatric versions of the survey differed in phrasing but not in content, except for one question pertaining only to the pediatric population (“I worry that TCS may reduce my child’s growth”).

A pharmacist (author SC) and a psychologist (author AB) were involved with survey development.

The study protocol was approved by the Health Research Ethics Committee of the Northern Sydney Local Health District at Royal North Shore Hospital, and by the North Shore Private Hospital Ethics Committee, as a low/negligible risk study.

Study participants and administration

The study participants included dermatological patients (aged 18+) and parents of pediatric dermatological patients (aged <18) with a history of long-term (≥ 1 month) TCS use. Participants were recruited in the waiting rooms of three dermatology outpatient clinical sites within Greater Sydney: public clinics at Royal North Shore Hospital, private pediatric and vulvovaginal clinics at North Shore Private Hospital and a private clinic in Gosford. Both adult patients and parents of pediatric patients were recruited at each site. All qualifying participants with English language literacy were invited to participate in the study.

All study participants were informed about the objectives of the study prior to enrollment, and were given an information sheet about the safety of TCS upon completion and submission of their survey. Survey responses were anonymous, and participant consent was granted implicitly. Respondents were allowed to skip questions or mark them as “not applicable” if the topic was not relevant to their personal experiences to date. The participants did not receive compensation for their time.

Statistical analysis

Survey responses were analyzed using descriptive statistics. Each MARS item was analyzed separately (rather than using a combined numerical score, which risks over-simplification of the results). All ordinal analyses of five-item Likert-type scales were executed on three composite categories (negative, neutral/equivocal and positive):

- *Adherence and Messages:* Never/Rarely, Sometimes, Often/Always

- *Experiences:* Strongly Disagree/Disagree, Neutral, Agree/Strongly Agree

Wilcoxon signed-rank tests were used for paired comparisons between pharmacists and GPs. Friedman tests were used for comparisons between messages received from pharmacists, GPs, family/friends, and the Internet; messages with significant results were followed up with post-hoc pairwise comparisons between each unique pair of message sources to identify differences underlying the result. All statistical analyses were performed with SPSS version 23.0 (SPSS Inc., Chicago, IL).

Two surveys were excluded from the final results due to incompleteness.

Results

A total of 201 completed surveys were collected between January 2015 and February 2016, with 61.2% from adult patients ($n = 123$) and 38.8% from parents of pediatric patients ($n = 78$). Each study site contributed surveys to this total, with 40.8% ($n = 82$) from North Shore Private Hospital, 39.3% ($n = 79$) from Royal North Shore Hospital and 19.9% ($n = 40$) surveys from the private clinic in Gosford.

Respondent and patient characteristics

Characteristics of the survey respondents (adult patient or parent of the pediatric patient) and the patients are given in Table 1.

Of the patients, 52.8% were aware of the concept of a “fingertip unit” (104 out of 197 respondents) (24). Of those aware, reported sources of information on the concept were (respondents could select multiple sources if applicable): dermatologist (54.8%, $n = 57$), GP (25.0%, $n = 26$), pharmacist (16.3%, $n = 17$) and other (e.g. another type of specialist, the Internet, or written materials) (30.8%, $n = 32$).

Adherence

Responses to the five-item MARS are presented in Table 2. Non-adherence rates, defined as reporting to engage in non-adherent

Table 1. Respondent and patient characteristics.

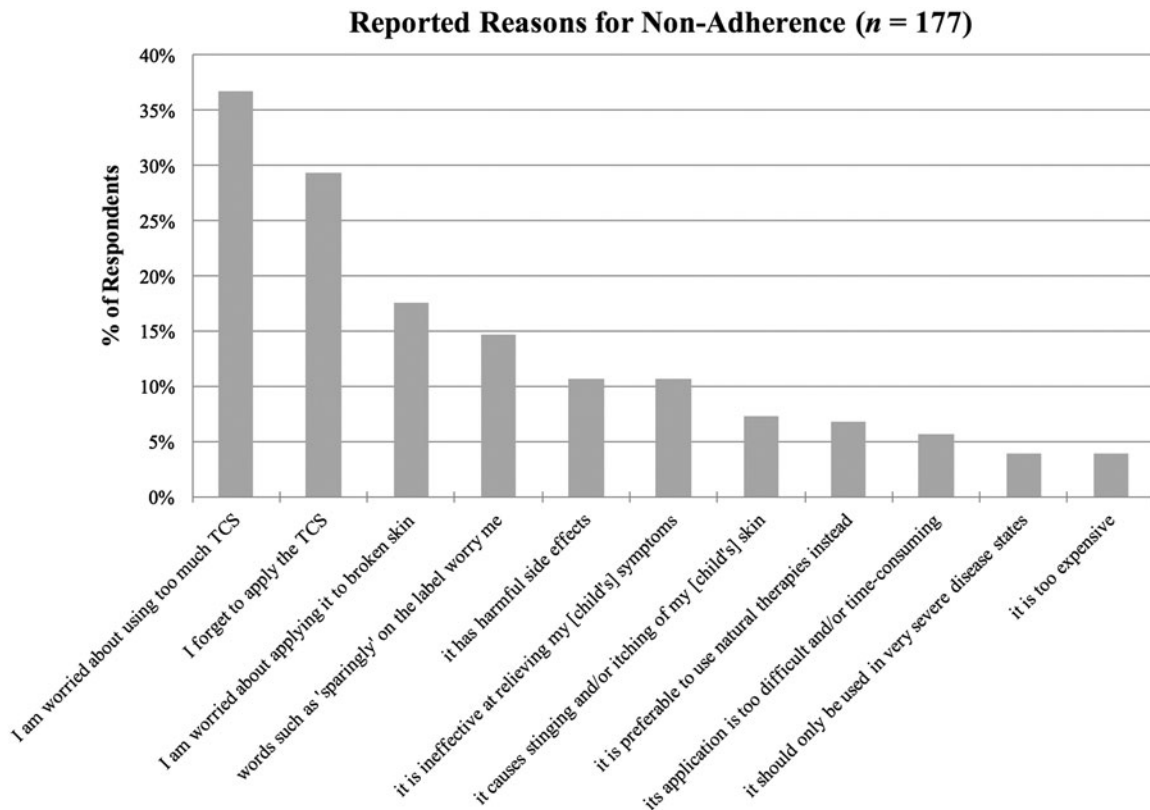
Survey type		
Adult patients	61.2%	$n = 123$
Pediatric patients	38.8%	$n = 78$
Mean age		
Respondents	47.9 years (range 20–82 years)	$n = 200$
Adult patients	53.1 years (range 20–82 years)	$n = 123$
Pediatric patients	7.5 years (range 5 months–17 years)	$n = 78$
Gender		
Respondents	21.1% male, 78.9% female	$n = 199$
Adult patients	26.2% male, 73.8% female	$n = 122$
Pediatric patients	38.7% male, 61.3% female	$n = 75$
Highest level of education attained		$n = 197$
Some High school	11.2%	$n = 22$
Completed Year 12	8.6%	$n = 17$
Diploma/Certificate	25.9%	$n = 51$
Bachelor degree	35.5%	$n = 70$
Master’s degree or Doctorate	18.8%	$n = 37$
Median duration of TCS use	2.0 years (IQR 0.5–7.0 years)	$n = 201$
TCS prescriber(s) ^a		$n = 201$
Dermatologist	70.1%	$n = 141$
GP	59.2%	$n = 119$
Other	23.4%	$n = 47$

^aPatients may have been prescribed TCS by more than one type of healthcare provider.

Table 2. Five-item medication adherence report scale (MARS) responses.

Question stem: "Many people find a way of using their medicines that suits them. This may differ from the instructions on the label or from what their doctor had said. For each statement please tick one circle that best applies to you [and your child]."

Statement	"Never" or "Rarely", <i>n</i> (%)	"Sometimes", <i>n</i> (%)	"Often" or "Always", <i>n</i> (%)	Missing, <i>n</i>
"I alter the amount of TCS that I use [on my child]."	90 (45.9%)	65 (33.2%)	41 (20.9%)	5
"I forget to use the TCS [on my child]."	124 (65.6%)	54 (28.6%)	11 (5.8%)	12
"I stop using the TCS [on my child] for a while."	84 (43.8%)	66 (34.4%)	42 (21.9%)	9
"I use less of the TCS [on my child] than instructed."	130 (69.1%)	46 (24.5%)	12 (6.4%)	13
"I decide to skip an application of the TCS [on my child]."	121 (63.4%)	57 (29.8%)	13 (6.8%)	10

**Figure 1.** Reported reasons for non-adherence to TCS therapy. Respondents could choose multiple responses.

behaviors "Sometimes", "Often", or "Always", ranged from 30.9 to 56.3%. These high rates of non-adherence are consistent with previous studies (5,6,8–10).

Respondents who reported imperfect adherence (i.e. did not answer "Never" to all five MARS items, *n* = 177) indicated their reasons for non-adherence by selecting any/all applicable reasons, as summarized in Figure 1.

Beliefs

Respondents' reported beliefs are summarized in Table 3. Overall, respondents described high rates of self-efficacy, and a majority of respondents acknowledged the necessity for TCS therapy. Rates of reported concern about TCS varied, depending on the specific concern. The concern statement with the highest "Agree"/"Strongly Agree" rate was "I worry about the long-term effects of TCS [on my child]" (58.1%, *n* = 115). Only 27.8% of respondents "Disagree" or "Strongly Disagree" with the statement "I worry that TCS thin my [child's] skin" (*n* = 55).

Only 44.8% of respondents "Agree" or "Strongly Agree" that "Pharmacists instruct me to apply the TCS exactly as directed by my doctor" (*n* = 87).

Messages

The reported frequencies of message receipt regarding TCS benefits and "risks" from GPs and pharmacists are presented in Table 4, along with the results of the Wilcoxon signed-rank tests comparing paired reported rates for GPs vs. pharmacists. The paired nature of the analyses required valid responses from both the GP and pharmacist subparts of a question. This resulted in relatively lower analyzable populations (*n* = 139–160).

Respondents reported receiving all four messages about the benefits of TCS significantly more often from GPs than from pharmacists (*p* < 0.001). They also reported being encouraged to "try natural or complementary and alternative therapies before resorting to the use of TCS" significantly more often by pharmacists than by GPs (*p* = 0.039).

The other five messages about the "risks" of TCS were not reported as being received significantly more often from either GPs or pharmacists. Overall, 76.6% of 192 respondents received at least one of the six messages about TCS "risk" from a GP and/or pharmacist "Often" or "Always".

Friedman tests (and post-hoc pairwise comparisons) between the reported frequencies of message receipt from GPs,

Table 3. Patient beliefs.

Question stem: "For each of the following statements, please place a tick in the circle under the level of agreement that best reflects your current opinion of using TCS [on your child]."

Category (not indicated on survey)	Statement	"Strongly Disagree" or "Disagree", n (%)	"Neutral", n (%)	"Agree" or "Strongly Agree", n (%)	Missing, n
Necessity	"My life would be more difficult without topical corticosteroids for my [child's] skin condition"	20 (10.3%)	39 (20.1%)	135 (69.6%)	7
	"The health of my [child's] inflamed skin, at present, depends on using TCS"	30 (15.2%)	24 (12.2%)	143 (72.6%)	4
	"In the future, the health of my [child's] inflamed skin will depend on using TCS"	30 (15.4%)	50 (25.6%)	115 (59.0%)	6
	"Without TCS, my [child's] inflamed skin would be worse"	15 (7.7%)	19 (9.7%)	161 (82.6%)	6
Concern	"TCS keep my [child's] inflamed skin condition under control"	15 (7.6%)	32 (16.2%)	150 (76.1%)	4
	"I worry that TCS cause changes in my [child's] skin color"	97 (49.5%)	60 (30.6%)	39 (19.9%)	5
	"I worry that TCS make my [child's] immune system less effective"	78 (40.2%)	76 (39.2%)	40 (20.6%)	7
	"I worry that TCS cause unwanted hair growth [on my child]"	123 (63.4%)	51 (26.3%)	20 (10.3%)	7
	"I worry about [my child] becoming too dependent on TCS"	72 (36.7%)	53 (27.0%)	71 (36.2%)	5
	"I worry that TCS thin my [child's] skin"	55 (27.8%)	56 (28.3%)	87 (43.9%)	3
	"I worry about the immediate effects of TCS [on my child]"	77 (39.3%)	60 (30.6%)	59 (30.1%)	5
	"I worry about the long-term effects of TCS [on my child]"	48 (24.2%)	35 (17.7%)	115 (58.1%)	3
	"Using TCS [on my child] is disruptive to my life"	127 (65.1%)	36 (18.5%)	32 (16.4%)	6
	"I worry that TCS may reduce my child's growth" (Pediatric question only)	38 (51.4%)	24 (32.4%)	12 (16.2%)	4
Self-efficacy	"I am capable of following the doctor's instructions to apply TCS"	6 (3.0%)	15 (7.6%)	176 (89.3%)	4
	"I am confident that I can follow the directions of the doctor in using TCS"	4 (2.0%)	14 (7.1%)	179 (90.9%)	4
	"Following the doctor's instructions to use TCS is easy"	10 (5.1%)	18 (9.1%)	170 (85.9%)	3
Information sources	"Pharmacists instruct me to apply the TCS exactly as directed by my doctor"	48 (24.7%)	59 (30.4%)	87 (44.8%)	7
	"I feel more confident following the advice of a pharmacist than a GP"	126 (64.3%)	53 (27.0%)	17 (8.7%)	5
	"I feel more confident following the advice of a pharmacist than a dermatologist"	162 (82.7%)	28 (14.3%)	6 (3.1%)	5
	"If a pharmacist gave me different advice to a doctor, I would follow the pharmacist's advice in preference to the doctor"	159 (81.1%)	27 (13.8%)	10 (5.1%)	5

pharmacists, family/friends and the Internet showed the following: family/friends and the Internet reportedly provided some of the messages about TCS benefits significantly less often than GPs and pharmacists, yet they provided some of the messages about TCS "risk" significantly more often. The exception to this was the "risk" message "Apply topical corticosteroids 'sparingly' or 'thinly'", which was reported as being received more often from GPs and pharmacists than from family/friends and the Internet ($n = 133$, $p < 0.001$).

Experiences

The reported experiences of respondents with GPs and pharmacists in relation to TCS use are detailed in Table 5. As with the message analyses, the paired nature of the Wilcoxon signed-rank tests required valid responses from both the GP and pharmacist subparts of a question. This resulted in relatively lower analyzable populations ($n = 124$ – 152). For all eight experiences examined, GPs were reported to perform incorrect behaviors significantly less often than pharmacists.

Discussion

Our study confirms the high rates of non-adherence with topical corticosteroid therapy reported by others (Table 2) (5,6,8–10). It also substantiates the high rates of concern about TCS use amongst patients and parents in the community (3,9–14), with a majority of respondents reporting that they worry about the long-term effects of TCS (Table 3). The high rates of risk-related messages received from pharmacists and GPs provide additional

evidence that these healthcare team members are inaccurately warning patients against purported "risks" of long-term TCS use (4,8,9,12).

Our study is unique in that it quantifies the frequency of patient-reported receipt of six of these risk-related messages (Table 4). These rates were very high with 29.9 and 35.3% of respondents reported "Often" or "Always" being told by their GPs and pharmacists, respectively, that TCS cannot be used long-term. Despite increased levels of education in and experience with inflammatory skin conditions, GPs performed similarly to pharmacists with regard to their frequency of TCS "warnings" (with the exception of encouraging "natural" and "complementary and alternative therapies" over TCS use, which is more commonly attributed to pharmacists). Adding to the concern, a majority of patients did not agree that pharmacist instructions on TCS application are exactly the same as instructions from their doctor.

Respondents reported that GPs delivered messages about the benefits of TCS use more frequently than pharmacists. While this is a positive indicator for how GPs support their patients with chronic inflammatory skin conditions when compared to pharmacists, there is still scope for improvement. Also, GPs are delivering messages about the benefits of TCS more often than pharmacists, most probably due to the different, more personal nature of their interactions with the patient. While community pharmacists and GPs are both constrained by limitations on time, pharmacists are also constrained by the lack of private consultation areas and a lack of access to the patient's clinical history (17,21).

Patient and parent experiences were reported as being more positive with GPs than with pharmacists (Table 5). Again, this could be explained by the comparatively thorough nature of GPs'

Table 4. Messages received from GPs and pharmacists, with Wilcoxon signed-rank test results.

Question stem: "The following are some messages that people receive about using TCS for their [child's] inflamed skin. Please indicate *how often* these messages have been received by you from each of the sources below. Please tick one circle for each statement from each source."

Category (not indicated on survey)	Statement	GPs				Pharmacists				Respondents for both questions, p values
		"Never" or "Rarely", n (%)	"Sometimes", n (%)	"Often" or "Always", n (%)	Missing, n	"Never" or "Rarely", n (%)	"Sometimes", n (%)	"Often" or "Always", n (%)	Missing, n	
Benefits	"[Having] my [child's] skin condition means that I [he/she] will need to use TCS"	25 (13.8%)	44 (24.3%)	112 (61.9%)	20	72 (50.7%)	28 (19.7%)	42 (29.6%)	59	n = 139 p < 0.001*
	"Inflamed skin conditions will improve with TCS"	18 (9.8%)	32 (17.5%)	133 (72.7%)	18	51 (35.7%)	19 (13.3%)	73 (51.0%)	58	n = 140 p < 0.001*
	"Using TCS is good for inflamed skin"	24 (13.6%)	48 (27.1%)	105 (59.3%)	24	53 (35.8%)	30 (20.3%)	65 (43.9%)	53	n = 144 p < 0.001*
	"TCS will control my [child's] symptoms, but they will not provide a permanent cure. Because of this, I [my child] need[s] to continue using TCS whenever necessary."	34 (19.1%)	35 (19.7%)	109 (61.2%)	23	69 (47.6%)	20 (13.8%)	56 (38.6%)	56	n = 140 p < 0.001*
Harms	"TCS may cause skin thinning"	107 (60.5%)	37 (20.9%)	33 (18.6%)	24	100 (60.6%)	25 (15.2%)	40 (24.2%)	36	n = 160 p = 0.087
	"Try non-prescription creams/ointments before resorting to the use of prescription TCS"	112 (64.7%)	35 (20.2%)	26 (15.0%)	28	99 (65.1%)	31 (20.4%)	22 (14.5%)	49	n = 145 p = 0.433
	"Try natural or complementary and alternative therapies before resorting to the use of TCS"	134 (80.2%)	21 (12.6%)	12 (7.2%)	34	114 (76.5%)	19 (12.8%)	16 (10.7%)	52	n = 141 p = 0.039*
	"Apply TCS 'sparingly', or 'thinly'"	38 (21.2%)	42 (23.5%)	99 (55.3%)	22	48 (30.0%)	18 (11.3%)	94 (58.8%)	41	n = 153 p = 0.185
	"TCS cannot be used long-term"	86 (49.4%)	36 (20.7%)	52 (29.9%)	27	73 (46.8%)	28 (17.9%)	55 (35.3%)	45	n = 150 p = 0.072
	"TCS may make my [child's] immune system less effective"	147 (83.1%)	22 (12.4%)	8 (4.5%)	24	132 (86.8%)	13 (8.6%)	7 (4.6%)	49	n = 148 p = 0.234

*Statistical significance.

Table 5. Experiences with GPs and pharmacists, with Wilcoxon's signed-rank test results.

Question stem: "For each of the following statements, please place a tick in the circle under the level of agreement that best reflects *your experiences with TCS* with both GPs and Pharmacists:"

Statement	GPs					Pharmacists					Respondents for both questions, <i>p</i> values
	"Strongly Disagree" or "Disagree", <i>n</i> (%)	"Neutral", <i>n</i> (%)	"Agree" or "Strongly Agree", <i>n</i> (%)	Missing, <i>n</i>	"Strongly Disagree" or "Disagree", <i>n</i> (%)	"Neutral", <i>n</i> (%)	"Agree" or "Strongly Agree", <i>n</i> (%)	Missing, <i>n</i>			
"Provide useful advice on how to deal with the practical difficulties of regularly applying TCS"	26 (14.4%)	44 (24.3%)	111 (61.3%)	20	43 (27.7%)	46 (29.7%)	66 (42.6%)	46	<i>n</i> = 152 <i>p</i> < 0.001*		
	30 (16.3%)	38 (20.7%)	116 (63.0%)	17	40 (25.0%)	42 (26.3%)	78 (48.8%)	41	<i>n</i> = 152 <i>p</i> = 0.010*		
"Provide me with a sufficient amount of information about using TCS"	93 (62.0%)	29 (19.3%)	28 (18.7%)	51	101 (73.2%)	29 (21.0%)	8 (5.8%)	63	<i>n</i> = 131 <i>p</i> = 0.001*		
"Notice when I have not requested/refilled TCS prescriptions in a long time, and ask why this is the case"	22 (12.4%)	53 (29.8%)	103 (57.9%)	23	52 (34.9%)	60 (40.3%)	37 (24.8%)	52	<i>n</i> = 145 <i>p</i> < 0.001*		
"Make me feel reassured about using TCS"	17 (10.4%)	51 (31.3%)	95 (58.3%)	38	23 (17.7%)	64 (49.2%)	43 (33.1%)	71	<i>n</i> = 127 <i>p</i> < 0.001*		
"Listen to my concerns about using TCS"	7 (3.9%)	35 (19.6%)	137 (76.5%)	22	15 (10.2%)	44 (29.9%)	88 (59.9%)	54	<i>n</i> = 142 <i>p</i> = 0.002*		
"Treat me [and my child] with respect when speaking about TCS"	151 (87.3%)	18 (10.4%)	4 (2.3%)	28	115 (77.2%)	20 (13.4%)	14 (9.4%)	52	<i>n</i> = 144 <i>p</i> < 0.001*		
"Make me [and/or my child] feel embarrassed about using TCS"	16 (9.5%)	36 (21.4%)	116 (69.0%)	33	20 (15.5%)	37 (28.7%)	72 (55.8%)	72	<i>n</i> = 124 <i>p</i> = 0.006*		
"Demonstrate sensitivity towards the physical appearance of my [child's] skin"											

*Statistical significance.

patient-provider relationships. However, both GPs and pharmacists need to improve their practices around TCS counseling since patients reported negative experiences with both groups. For example, only 24.8% of patients/parents “Agree” or “Strongly Agree” that pharmacists make them feel reassured about TCS, with the proportion increasing to only 57.9% for GPs.

Pharmacists may be unaware of their impact on patients using long-term TCS. In this study, only 64.3% of respondents said that they “Disagree” or “Strongly Disagree” with the statement “I feel more confident following the advice of a pharmacist than a GP”, while 27.0% were “Neutral”, and 8.7% said they “Agree” or “Strongly Agree” (i.e. they may preferentially follow the pharmacist's advice, with 5.1% agreeing that they would follow pharmacist advice in the event of a conflict with the doctor's advice). This suggests that pharmacist advice about TCS use is highly influential. In an unpublished pilot focus group study with seven community pharmacists by our research group (25), pharmacists did not recognize their role in the management of chronic inflammatory skin conditions, and explained that their influence primarily lies in the management of acute conditions with Schedule 3 (behind the counter) TCS. In addition, they did not perceive any patient concerns about TCS use, except in parents of pediatric patients. A lack of awareness of the extent of patient TCS phobia coupled with an under-appreciation of pharmacists' influence as trusted experts in chronic disease management constitutes a troubling combination. It is unlikely that community pharmacists are aware of the impact of their brief counseling or the impact of “throwaway” statements about TCS on patients.

Future research should include further exploration of community pharmacist and GP views on their TCS-related practices, and on their educational sources. To this aim, our research group will be holding focus groups with community pharmacists, based on the methodology already piloted (25). The focus group results will subsequently inform the development of a widely distributed survey of community pharmacists on their TCS beliefs and counseling practices with the ultimate aim being to change pharmacist behavior with respect to advice on using TCS.

This study is unable to place the respondents' answers within the context of their relationships with GPs and pharmacists. For example, a patient who does not have a regular GP may be counseled differently to a patient who has had a long-term relationship with a trusted GP. Similarly, a patient who has had their inflammatory skin condition managed exclusively by a GP may receive more extensive counseling on TCS use than a patient who only sees their GP for dermatologist referrals or TCS repeat prescriptions.

Another limitation of this study is its inability to consider personality and other personal factors, which may contribute to patient and parent behaviors and attitudes (26). While it was beyond the scope of this study, this is an important consideration for future exploration. There may be specific personality traits that are both readily identifiable and have a meaningful impact on TCS adherence and attitudes, thus warranting clinical intervention.

In interpreting the results of this study, it is important to recognize the possibility that a “negativity bias” (negative messages and experiences are more emotive and therefore more memorable than neutral or positive ones) has influenced respondents' recollection of messaging and experiences. This reinforces the importance of positive messaging when advising patients on the use of TCS.

Our study is statistically underpowered to draw conclusions about how adherence and beliefs are influenced by messages from and experiences with providers. Our research group is considering the feasibility of additional recruitment for this purpose.

As current practices and educational sources are better understood, we are becoming better-equipped as a dermatological community to target interventions toward problem areas (e.g. through continuing professional education, educational campaigns and modification of teachings at the university level). A collaborative approach to reeducation, involving dermatologists, community pharmacists, GPs, university educators, pharmaceutical companies and patients/parents, will ultimately yield the most robust results in combating topical corticosteroid phobia and improving treatment adherence. Dermatologists play a key role in efforts to reeducate other members of their healthcare team and in continuing to counsel patients about the conflicting and erroneous messages they may receive about TCS use until that reeducation is complete.

Conclusions

Adherence to long-term TCS therapy is poor, while patient and parent beliefs about the “risks” of TCS are common. Incorrect messages about the “dangers” of long-term TCS use are being received by a majority of patients and parents on a consistent basis from trusted health professionals such as pharmacists and GPs. Friends, family and the Internet also propagate these inaccuracies. Patients and parents report having negative TCS-related counseling experiences with both pharmacists and GPs, but these negative experiences occur more frequently with pharmacists. These findings indicate a need for reeducation of both pharmacists and GPs on the safety of TCS use and the potential impact of their counseling on treatment adherence.

Disclosure statement

The authors report no conflicts of interest.

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CHAPTER 8

Evaluation of the influence of family and friends, and the Internet on patient perceptions of long-term topical corticosteroid use.

This chapter contains the original research manuscript, “Evaluation of the influence of family and friends, and the Internet on patient perceptions of long-term topical corticosteroid use”, accepted for publication in Journal of Dermatological Treatment April **2017**

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Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

As co-author(s) of the paper:

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We confirm that Saxon D Smith has made a major contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
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ORIGINAL ARTICLE



Evaluation of the influence of family and friends, and the Internet on patient perceptions of long-term topical corticosteroid use

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ABSTRACT

Background: Topical corticosteroids (TCS) are key to managing chronic inflammatory dermatoses (CID). Parents/patients cite TCS phobia as an impediment to treatment adherence. Family/friends and the Internet are a source of misinformation on TCS which can negatively impact perceptions of TCS safety.

Purpose: To assess information from family/friends and the Internet, as related to and reported by patients/parents using long-term TCS.

Methods: A multicenter cross-sectional survey of patients (aged >18 years) and parents of patients (aged <18 years) with a history of CID requiring long-term (≥ 1 month) TCS use assessing messages about TCS received from family/friends and the Internet.

Results: A total of 123 patients and 78 parents completed the survey ($n = 201$). Parents/patients were more likely to be informed by the Internet "[having] my [child's] skin condition means that [I/he/she] will need to use topical corticosteroids" ($p < .001$) and that "inflamed skin conditions will improve with the topical corticosteroids" ($p = .007$). Family/friends were more likely to recommend parents/patients "try non-prescription creams/ointments before resorting to the use of prescription topical corticosteroids" ($p = .014$).

Conclusions: High rates of messages about TCS "risk" from family/friends and the Internet may affect patient/parent understanding about TCS safety. This may contribute to treatment non-adherence.

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Introduction

Chronic inflammatory dermatoses (CID) are commonplace dermatological conditions, with atopic dermatitis (AD) alone affecting more than 20% of children (1) and ~7% of adults (2). Topical corticosteroids (TCS) are a key to managing cutaneous inflammation with the safety and efficacy of TCS well-supported. In particular, dermatologists generally agree that with appropriate use, the benefits of TCS therapy continue to outweigh the low incidence of any putative risks and side effects (3–6). However, unsatisfactory treatment outcomes and inadequate disease control can result from poor compliance with medical therapy (7–11). There are several factors that can independently or collectively contribute to poor compliance (12). "Corticosteroid phobia" is anxiety regarding the use of TCS due to patient or parent concerns about their safety and efficacy despite the potential for AD and other CID to be disabling and disruptive for patients and their families (7,10,11,13,14). This can lead to poor adherence to topical treatment regimens and subsequent poor responses to treatment.

"Corticosteroid phobia" has been identified as a major cause of noncompliance and treatment failure in CID (15–18). However, this phenomenon is also seen by pediatricians and respiratory physicians attempting to manage asthma with inhaled corticosteroids (14–17). The amount of misinformation currently available about TCS means that this concern is widespread. This misinformation can range from a common belief among parents that medical treatment for AD with TCS is dangerous through to a preference for complementary and alternative medicine (CAM),

or that "natural" therapy is safe and therefore preferable (14). The most common belief that parents offer regarding perceived risk associated with the use of TCS is that it will thin the skin irreversibly. However, especially in the pediatric population, many parents also voice concerns about immune suppression and growth failure (14). Patients and parents cite a range of sources for their information on the safety and efficacy of TCS in AD (14). In particular, they clearly identify there is a significant role of family/friends and the Internet as an information resource. However, the information provided can detrimentally impact a patient's or parent's understanding of the safety and efficacy of TCS to manage their (or their child's) AD. This can lead to abandonment of evidence-based medical therapy with potentially serious detrimental outcomes, especially in children (19).

Objectives

To assess advice and information from family/friends and the Internet, as related to and reported by patients and parents of patients using TCS on a long-term basis.

Materials and methods

Materials and methods

Survey development

A cross-sectional survey was designed to assess the information and advice received from family/friends and the Internet in

relation to and as reported by patients and parents of patients using TCS on a long-term basis.

The following information was collected:

- Demographics
- Rates of TCS treatment adherence
- Reasons for non-adherence
- Beliefs regarding TCS concerns, necessity, and self-efficacy
- Beliefs regarding consistency and reliability of information sources
- Frequency of messages received from community pharmacists, general practitioners (GPs), family/friends, and the Internet regarding TCS-related risks and benefits

The survey was piloted with patients and parents prior to the commencement of data collection. The respondents' pilot survey responses and verbal feedback were utilized to optimize survey design. Piloting and feedback incorporation were iterated until no further changes were required.

Within questions, statements were ordered randomly so that related statements were not clustered together and positive and negative statements were interspersed. Questions were without jargon or abbreviations. Adult and pediatric versions of the survey differed in phrasing but not in content, except for one question pertaining only to the pediatric population ("I worry that TCS may reduce my child's growth").

A psychologist (A.B.) was involved with survey development.

The study protocol was approved by the Human Research Ethics Committee of the Northern Sydney Local Health District at Royal North Shore Hospital, and by the North Shore Private Hospital Ethics Committee.

Study participants and administration

The study participants included dermatological patients (aged >18 years) and parents of pediatric dermatological patients (patients aged <18 years) with a history of long-term (≥ 1 month) TCS use for CID. Participants were recruited in the waiting rooms of three dermatology outpatient clinical sites within Greater Sydney: public clinics at Royal North Shore Hospital, private pediatric and vulvovaginal clinics at North Shore Private Hospital, and a private clinic in Gosford. Both adult patients and parents of pediatric patients were recruited at each site. All qualifying participants with English language literacy were invited to participate in the study.

All study participants were informed about the objectives of the study prior to enrollment, and given an information sheet about the safety of TCS upon completion of the survey. Survey responses were anonymous, and participant consent was granted implicitly. Respondents were allowed to skip questions or mark them as "not applicable" if the topic was not relevant to their personal experiences to date. The participants did not receive compensation for their time.

Statistical analysis

Survey responses were analyzed using descriptive statistics. Wilcoxon signed-rank tests were used for paired comparisons between family/friends and the Internet. All statistical analyses were performed with SPSS version 23.0 (SPSS Inc., Chicago, IL). Note: results of the messaging received from GPs and pharmacists and the impact of these messages has previously been published (20) and are not included in the results herewith.

Two surveys were excluded from the final results due to incompleteness.

Results

A total of 201 completed surveys were collected between January 2015 and February 2016, with 61.2% from adult patients ($n = 123$) and 38.8% from parents of pediatric patients ($n = 78$). Each study site contributed surveys to this total, with 40.8% ($n = 82$) from North Shore Private Hospital, 39.3% ($n = 79$) from Royal North Shore Hospital, and 19.9% ($n = 40$) surveys from the private clinic in Gosford.

Respondent and patient information (Table 1) has previously been published in Journal of Dermatological Treatment (2016) (20).

Risk/benefit messages

Respondents reported that they received all four benefit messages from family/friends and the Internet (Table 2). Of respondents, 26.8% reported that the Internet often/always had informed them that "[having] my [child's] skin condition means that [I/he/she] will need to use topical corticosteroids" compared with only 15.3% from family/friends with Wilcoxon signed-rank test demonstrating

Table 1. Respondent and patient characteristics.

Survey type		
Adult patients	61.2%	$n = 123$
Pediatric patients	38.8%	$n = 78$
Mean age		
Respondents	47.9 years (range 20–82 years)	$n = 200$
Adult patients	53.1 years (range 20–82 years)	$n = 123$
Pediatric patients	7.5 years (range 5 months–17 years)	$n = 78$
Gender		
Respondents	21.1% male, 78.9% female	$n = 199$
Adult patients	26.2% male, 73.8% female	$n = 122$
Pediatric patients	38.7% male, 61.3% female	$n = 75$
Highest level of education attained		$n = 197$
Some high school	11.2%	$n = 22$
Completed Year 12	8.6%	$n = 17$
Diploma/certificate	25.9%	$n = 51$
Bachelor degree	35.5%	$n = 70$
Master's degree or doctorate	18.8%	$n = 37$
Median duration of TCS use	2.0 years (IQR = 0.5–7.0 years)	$n = 201$
TCS prescriber(s) ^a		$n = 201$
Dermatologist	70.1%	$n = 141$
GP	59.2%	$n = 119$
Other	23.4%	$n = 47$

^aPatients may have been prescribed TCS by more than one type of healthcare provider. IQR: interquartile range.

Table 2. Benefit messages received from friends/family and the Internet, with Wilcoxon signed-rank test results. Question stem: "The following are some messages that people receive about using TCS for their [child's] inflamed skin. Please indicate how often these messages have been received by you from each of the sources below. Please tick one circle for each statement from each source."

Statement	Friends/family					Internet			Respondents for both questions, <i>n</i>	<i>p</i> value
	"Never" or "Rarely", <i>n</i> (%)	"Sometimes", <i>n</i> (%)	"Often" or "Always", <i>n</i> (%)	Missing, <i>n</i>	"Never" or "Rarely", <i>n</i> (%)	"Sometimes", <i>n</i> (%)	"Often" or "Always", <i>n</i> (%)	Missing, <i>n</i>		
"[Having] my [child's] skin condition means that I [he/she] will need to use TCS"	90 (65.7)	26 (19.0)	21 (15.3)	64	68 (50.7)	30 (22.4)	36 (26.8)	67	<i>n</i> = 129	
"Inflamed skin conditions will improve with TCS"	68 (50.0)	31 (22.8)	37 (27.2)	65	54 (40.9)	30 (22.7)	48 (36.4)	69	<i>p</i> < .001 <i>n</i> = 128	
"Using TCS is good for inflamed skin"	77 (55.8)	29 (21.0)	32 (23.2)	63	72 (55.4)	31 (23.8)	27 (20.8)	71	<i>p</i> = .007 <i>n</i> = 130	
"TCS will control my [child's] symptoms, but they will not provide a permanent cure. Because of this, I [my child] need[s] to continue using TCS whenever necessary"	86 (62.4)	21 (15.2)	31 (22.5)	63	83 (61.5)	20 (14.8)	32 (23.7)	66	<i>p</i> = .966 <i>n</i> = 132	<i>p</i> = .629

a significant difference in the mean/distribution of the responses ($p < .001$). Furthermore, 36.4% reported that the Internet often/always informed them that "inflamed skin conditions will improve with the topical corticosteroids" as compared to 27.2% with Wilcoxon signed-rank test demonstrating a significant difference in mean/distribution of the responses ($p = .007$). For the other two benefit messages, there was no statistical significant variation on Wilcoxon signed-rank testing between the frequency of messaging between family/friends and the Internet: "Using TCS is good for inflamed skin" (23.2 versus 20.8%); "Topical corticosteroids will control my [child's] symptoms, but they will not provide a permanent cure. Because of this, [I/my child] need[s] to continue using topical corticosteroids whenever necessary." (22.5 versus 23.7%). Benefit messages, overall, were received by approximately a third of patients from both sources.

Furthermore, respondents reported that they received the six messages about the risks of TCS from both family/friends and the Internet (Table 3). In particular, parents/patients stated that they often/always received the message "Try non-prescription creams/ointments before resorting to the use of prescription topical corticosteroids" more frequently from family/friends than from the Internet (26.3 versus 19.2%, $p = .014$) with Wilcoxon signed-rank test demonstrating a significant difference in the mean/distribution of responses ($p = .014$). For the remaining five risk messages, there was not a statistically significant difference on Wilcoxon signed-rank testing between family/friends when compared with the Internet. However, it does indicate that parent/patients can consistently (often/always) receive these risk messages from both of these sources: "Topical corticosteroids may thin the skin" (28.2 versus 27.1%); "Try natural or CAM before resorting to the use of TCS" (29.0 versus 20.9%); "Apply TCS sparingly or thinly" (24.8 versus 32.8%); "TCS cannot be used long-term" (31.8 versus 30.1%, $p = .708$); "TCS may make my [child's] immune system less effective" (10.4 versus 10.3%). Overall, approximately one third of patients received multiple formative risk messages from both sources.

Discussion

Poor compliance with treatment is common in CID such as AD and can lead to treatment failure. Treatment failure has significant impacts on the patient, family and society (9)]. A previous study has shown that patients commenced on topical therapies for dermatological conditions frequently failed to comply with treatment instructions (21). One of the significant contributing factors affecting treatment adherence in AD and chronic skin conditions requiring long-term treatment is corticosteroid phobia. In fact, corticosteroid phobia is expressed by between 40 and 73% of dermatology patients and parents (15,22–24).

Parents often cite that they have been warned of the dangers of TCS not only by friends, relatives and the media but also by traditionally trusted sources including their GP and pharmacist (14). This helps to create a negative cultural environment for parents of children with AD and for adults with chronic dermatoses which they contend with whilst also managing the treatment demands of their own or their child's illness.

A recent Australian focus-group study showed that parents commonly believe that medical treatment for AD with TCS is dangerous and prefer "natural" therapy that they believe is safer (14). Charman et al. (15) found that 72.5% of people worried about using TCS on their own or their child's skin. Although skin thinning remains the most prevalent fear (34.5%), 9.5% of patients were concerned about systemic absorption resulting in retardation of growth and development. Hydrocortisone 1% was the most

Table 3. Risk messages received from friends/family and the Internet, with Wilcoxon signed-rank test results. Question stem: "The following are some messages that people receive about using TCS for their [child's] inflamed skin. Please indicate *how often* these messages have been received by you from each of the sources below. Please tick one circle for each statement from each source."

Statement	Friends/family				Internet				Respondents for both questions, <i>n</i>	<i>p</i> value
	"Never" or "Rarely", <i>n</i> (%)	"Sometimes", <i>n</i> (%)	"Often" or "Always", <i>n</i> (%)	Missing, <i>n</i>	"Never" or "Rarely", <i>n</i> (%)	"Sometimes", <i>n</i> (%)	"Often" or "Always", <i>n</i> (%)	Missing, <i>n</i>		
"TCS may cause skin thinning"	87 (53.4)	30 (18.4)	46 (28.2)	38	78 (51.6)	32 (21.2)	41 (27.1)	50	<i>n</i> = 147	
"Try non-prescription creams/ointments before resorting to the use of prescription TCS"	73 (46.8)	42 (26.9)	41 (26.3)	45	85 (60.3)	29 (20.6)	27 (19.2)	60	<i>p</i> = .370 <i>n</i> = 140	
"Try natural or complementary and alternative therapies before resorting to the use of TCS"	78 (51.3)	30 (14.9)	44 (29.0)	49	79 (56.8)	31 (22.3)	29 (20.9)	62	<i>p</i> = .014 <i>n</i> = 136	
"Apply TCS 'sparingly' or 'thinly' "	70 (48.7)	24 (16.7)	50 (34.8)	57	71 (51.8)	21 (15.3)	45 (32.8)	64	<i>p</i> = .137 <i>n</i> = 134	
"TCS cannot be used long-term"	73 (49.4)	28 (18.9)	47 (31.8)	53	68 (50.0)	27 (19.9)	41 (30.1)	65	<i>p</i> = .555 <i>n</i> = 134	
"TCS may make my [child's] immune system less effective"	111 (76.5)	19 (13.1)	15 (10.4)	56	107 (53.3)	15 (11.0)	14 (10.3)	65	<i>p</i> = .708 <i>n</i> = 135	<i>p</i> = .808

commonly used TCS and one-third of the patients using this classified it as being either strong, very strong, or unsure of its potency. This highlights the need for evidence-based health literacy education to improve patient education regarding the safety, potency, and appropriate use of TCS (15). It is important that the education provided to parents of children suffering pediatric AD acknowledges the impact of the pediatric AD and pays particular attention to addressing carers' treatment beliefs (25).

Previous research from our group has demonstrated a high level of consistent positive messaging from dermatologists (26). In contrast, there is a significant degree of variability in the knowledge of GPs (27) and pharmacists (28). Furthermore, it has been shown that misinformation offered by pharmacists and GPs in Australia has a major impact on perceptions of parents/patients TCS safety and efficacy in CID (20). This risk messaging from health professionals can exacerbate risk messages received from family/friends and Internet sources. This study clearly shows that of parents/patients who report receiving TCS messaging from friends/family and the Internet, only about a third receive benefit messages from these sources. Concurrently, a third of these parents/patients are also receiving misinformation in the form of exaggerated risk messages from the same sources. However, parents/patients are more likely to receive a benefit message about the role of TCS in AD from the Internet than from family/friends. On the other hand, they are more likely to receive a risk message from family/friends than the Internet. Our study did not evaluate which source has more influence but it is known that risk messages are more powerful than benefit messages.

Poor compliance with TCS treatment is costly to the community and to patients, disruptive to the family unit, frustrating to treating doctors and not based on evidence. Generation of more evidence of their safety should be a priority for researchers and every attempt should be made to disseminate this information to the community including through the Internet about the safety and efficacy of TCS in AD. The changing of public attitudes does take time but in the meantime it is important that all members of the multidisciplinary treatment team (Dermatologists, GPs and Pharmacists) provide consistent, evidence-based benefit messaging on safety and efficacy. This in turn helps to arm the parent/patient to combat the risk messaging from family/friends and potentially from the Internet.

Conclusion

It is evident that only a minority of patients and parents of children with chronic inflammatory skin diseases consistently receive benefit messaging from family/friends and the Internet whilst concurrently receiving misinformative risk messages from these influential sources. The varied and mixed nature of this messaging can help contribute to confusion and poor understanding about the safety and efficacy of TCS in CID. This in turn can lead to treatment non-concordance and poorer treatment outcomes.

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CHAPTER 9

A comparison between parental perception of disease severity and clinician assessed disease severity in childhood atopic dermatitis: perception of disease severity as a contributor to treatment adherence.

This chapter contains the original research manuscript which compares parent's perceived disease severity with clinician assessed disease severity in dermatology paediatric patients suffering atopic dermatitis.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

As co-author(s) of the paper:

Stone J, Harris V, Lee A, Dixit S, Blaszczyński A, Fischer G and **Smith SD**. Comparison between parent versus clinician assessment of disease severity in childhood atopic dermatitis.

We confirm that Saxon D Smith has made a major contribution to:

- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

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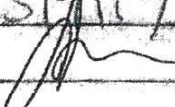
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Abstract

COMPARISON BETWEEN PARENT VERSUS CLINICIAN ASSESSMENT OF DISEASE SEVERITY IN CHILDHOOD ATOPIC DERMATITIS: A POTENTIAL INFLUENCER OF TREATMENT ADHERENCE

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Background

Atopic dermatitis (AD) is the most common paediatric dermatological condition [1] with 90% of cases presenting before five years of age [2]. Children with atopic dermatitis can live relatively symptom-free with adequate management. However, despite highly effective treatment regimens with minimal side-effect profiles [3] patients can suffer from poorly controlled disease due to poor treatment adherence [4]. Possible reasons for this include non-compliance with treatment due to topical corticosteroid (TCS) phobia. Treatment adherence is related to risk perception and perceptions of low disease severity may therefore result in compliance that is not optimal. This study examines parents' perception of disease severity in relation to the assessment of the clinician.

Objectives

To determine if there is a difference between clinician and caregiver perception of severity of childhood AD atopic dermatitis and the impact of any such difference on adherence to treatment. Secondary outcomes included the impact on quality of life of patients with undertreated AD.

Methods

Consecutive children aged <18 years and their parents, attending a paediatric dermatology outpatient clinic with a clinical diagnosis of AD were invited to participate in a prospective cohort study. At the first clinic visit patients and parents who participated in the study were informed regarding the nature of the study and were counselled on the nature of AD and its management including regular and liberal use of emollients, avoidance of potential irritants and were prescribed appropriate topical corticosteroids. Patients with severe atopic dermatitis or infected AD were followed up within two weeks, whereas those suffering mild to moderate AD were followed up within three months.

Fifty paediatric patients and their caregivers were recruited. Two independent clinicians completed the ratings tool Eczema Area and Severity Index (EASI) and caregivers completed the ratings tools Self-Administered EASI and Children's Dermatology Quality of Life Index (CDLQI). Data were analysed using a paired T-test in statistical analysis software SPSS.

Results

Of the 50 children affected with AD, 44% were reported by their parents to have moderate to severe impact on their quality of life as a result of their disease.

There was significant difference between clinician assessed EASI score ($M = 8.87$, $SD = 11.99$) and caregiver assessment of the severity of children's eczema ($M = 6.78$, $SD = 9.86$), $p < 0.001$. Parents underestimated the severity of their children's skin disease compared to validated clinician assessment.

On CDLQI testing AD impacted nearly all children with 44% reporting a moderate to very large effect.

Conclusion

This study shows that the majority of children and their families are negatively impacted by their AD and that their caregivers are significantly underestimating their disease severity. Improvement in patient education on the impact of AD and on the safety, efficacy and importance of disease control may improve patient outcomes. Ways this may be done include visual aids, illustrated treatment ladder information and nurse-led clinics for caregivers of children with AD to supplement the patient-doctor encounter.

Introduction

Atopic dermatitis (AD) is a common inflammatory skin condition that results from a dysfunctional epithelial barrier, sometimes due to mutations in the gene encoding filaggrin, and Type 2 immune responses [3]. AD can be inherited, as established in familial studies [5,6,7] and has associations with allergen sensitisation [8]. TCS play a central role in the management of AD [4]. Appropriate use of emollients, wet wraps and appropriate regimens to reduce the chance of infection, are recommended for children with atopic dermatitis [9,10]. Despite severity and symptomatic disease, paediatric patients are frequently undertreated. There are numerous factors contributing to poor treatment adherence including forgetfulness, inconvenience and fear of side effects of medications [11,12]. Parental factors are a significant aspect in adherence with treatment [11,13]. TCS phobia is prevalent among parents, and previous research has established the contribution of doctors, pharmacists and other sources, such as internet sites, contribute to the fear and stigma developing around their use [12]. Charman et al established that 24% of parents surveyed in regards to use of TCS treatment, admitted to having been non-adherent [14]. It has been previously reported that measures such as more frequent follow up, clear instructions and disease education are effective in improving treatment adherence and thus help to establish disease control [15].

Differences in perception of disease severity between caregiver and clinician of severity of disease have been studied in other areas of medicine, such as psychiatry [16] and oncology [17]. These studies outlined the impact of such discrepancies on treatment outcomes, patient attitude towards disease, assessment of effectiveness of treatment, patient's expectations of treatment effectiveness, underreporting side effects and quality of life impacts not directly attributable to disease or treatment side effects [16,17]. Studies of treatment adherence have shown that severity perception is directly related to compliance in atopic dermatitis [11] and other diseases [18].

The key component of management of AD is compliance with regular preventative treatment. However, there is a gap in the literature addressing a discrepancy between parent or caregiver and clinician perception of disease severity which may impact on treatment adherence and ultimately treatment outcomes. An understanding of the differences between parent and clinician assessment of disease may improve patient outcomes through improved communication and understanding of AD.

Methods

A prospective study comparing parents' perception of disease severity with clinician assessed disease severity was performed in public outpatient dermatology paediatric clinic within a tertiary hospital located in on the North Shore in Sydney, Australia. A total of 50 patients and their caregivers were recruited from the paediatric dermatology outpatient department clinic. Recruitment for the study commenced January 2015 and ceased when 50 consecutive subjects were recruited to the study. Ethics approval for the study was given by Northern Sydney Local Health District, Sydney, Australia (HREC: LNR/13/HAWKE/75)

All patients were seen by a dermatologist and appropriate treatment was suggested based on the severity of their disease. All parents/patients were counselled on preventative measures such as regular use of emollients, avoidance of irritants and use of bleach baths where appropriate. Parent/patients were given TCS of a potency to match the severity and anatomical distribution of their disease such as betamethasone dipropionate 0.05% (a potent TCS) to body and methylprednisolone acetate 0.1% (a moderate TCS) to the face for moderate to severe flares, or betamethasone valerate 0.2% (a moderate TCS) to the body and hydrocortisone 1% (a mild TCS) to the body for mild flares.

At the first visit the caregivers were asked to complete ratings on a Self-Administered Eczema Area and Severity Index (SA- EASI) tool, Children's Dermatology Life Quality Index (DLQI) tool, and a demographics questionnaire. In addition, two independent clinicians completed ratings on a separate Eczema Area and Severity Index (EASI) tool to assess the severity of the patient's AD.

Eczema Area and Severity Index

EASI is a statistically validated assessment tool for assessing severity of AD. It was developed to provide a reliable tool to easily assess the severity of AD across a wide range of patients (19). Each body area is assessed for percentage of area affected and the severity of disease present (20).

Self-Administered Eczema Area and Severity Index

The SA-EASI score allows caregivers to make an assessment of their child's atopic dermatitis. Calculation of the final score varies with patient age and chronicity of the disease (21). The SA-EASI score has been shown in this study to have a high correlation with the EASI score, and therefore enables statistical analysis to be undertaken between scores (21).

Children's Dermatology Life Quality Index (CDLQI)

The CDLQI is a quality of life index tool that can be completed by children, with assistance from caregiver if necessary (22,23). Scores range from 0 to 30 with higher scores correlating to greater impact on quality of life. The CDLQI can be analysed based on symptoms and feelings, and impact on leisure activities, school or holidays, personal relationships, sleep and treatment (22).

To evaluate reliability and consistency of the score between clinicians, the scores were compared for significance. A paired sample t-test was used to evaluate significant difference between clinician assessment for a given patient. If no significant difference between clinicians is established, an average of the EASI scores for each patient was taken in able to be utilised when comparisons with the SA-EASI were made.

EASI vs SA-EASI

A Spearman's rank-order correlation was performed to determine the relationship between EASI score and SA-EASI score. In order to be analysed for significance, correlation between these variables is required to be ascertained. A paired samples t-test was performed to test the hypothesis that the EASI and SA-EASI score means were equal.

Statistical analysis was undertaken by utilising SPSS statistical software.

Results

The median age of the patients was 5.08 years (range 3 months to 15 years). The median age band of parents was 30-39 years old. Nearly all (92%) of the parents had a bachelor degree or above higher education qualifications. Of the cohort, 14 had previously seen a dermatologist before attending the clinic.

Comparison of Inter-Clinician Assessment of EASI Score

A paired sample t-test was used to evaluate if there was any significant difference between clinicians for a given patient. There was no significant difference between clinician 1 ($M = 8.79$, $SD = 11.96$) and clinician 2 ($M = 8.95$, $SD = 12.04$), indicating strong inter-rater reliability.

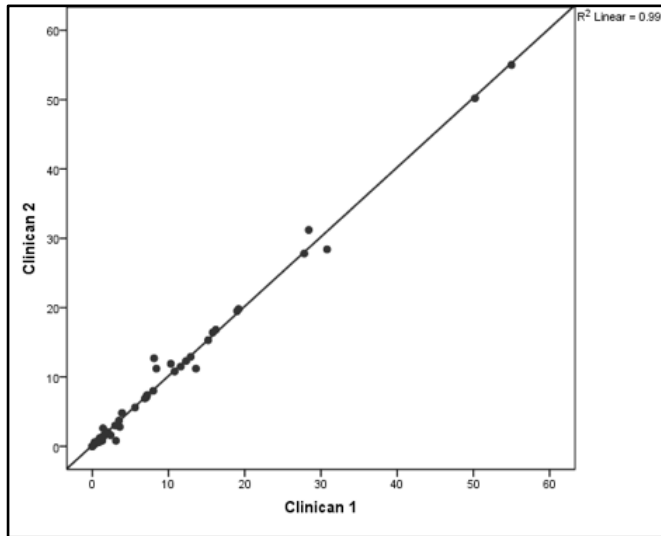


Figure 1: Analysis of Inter-Clinician Assessment of EASI score

Averages of the scores from the two clinicians were taken for statistical analysis of the SA-EASI.

EASI vs SA-EASI

Assessment of correlation between clinician EASI score and caregiver SA-EASI score performed using Spearman's rank-order (Table 1). There was a strong positive correlation between EASI score and SA-EASI score, ($r = 0.865$, $p = <0.01$). As there is statistically significant correlation between variables, a paired t-test were applied.

The mean EASI ($M = 8.87$, $SD = 11.98$) and the mean SA-EASI ($M = 6.780$, $SD = 9.86$) score means were equal, a paired samples t-test was performed.

The mean EASI score was significantly higher than the SA-EASI mean.

The degree of difference in mean EASI score and mean SA-EASI score is plotted below. This shows the overall patients assessed there was discrepancy between EASI and SA-EASI.

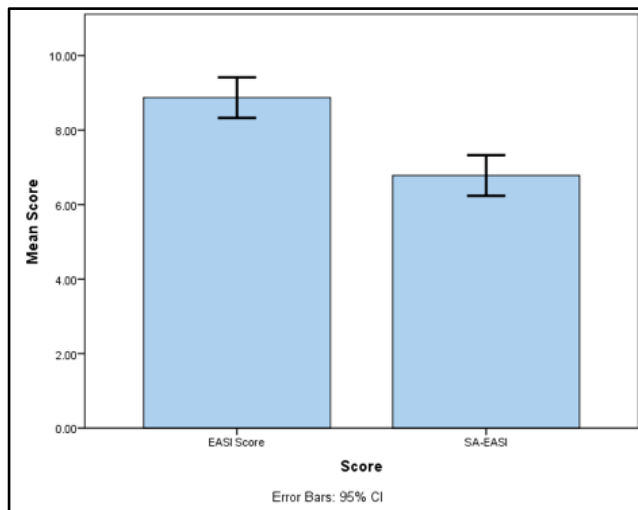


Figure 2: Mean difference between EASI score and SA-EASI score

CDLQI

The overall result of the CDLQI in the study participants is summarised in Figure 3. Nearly all children reported their disease impacted their quality of life (QoL) $n = 48/50$ (96%). Of the cohort surveyed 44% ($n = 22/50$) reported a moderate to extremely large impact on QoL. Only 4% ($n=50$) of the cohort reported no impact on QoL from AD.

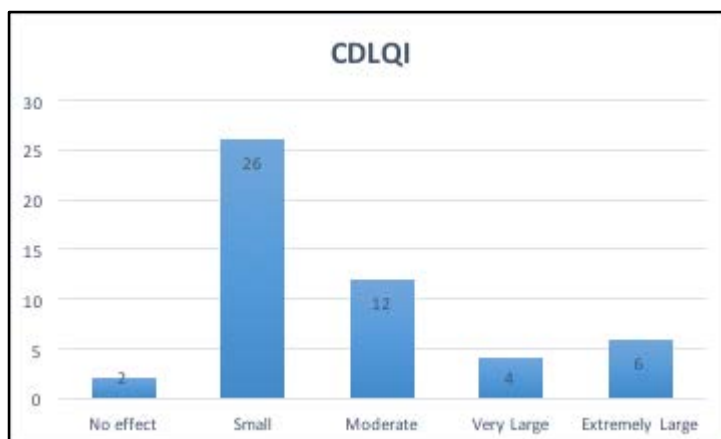


Figure 3: Children's Dermatology Life Quality Index (CDLQI): Overall effect on quality of life

QoL measures were categorised to determine what aspects of life were affected by the disease. These included symptoms, personal relationships, leisure activities, school or holiday activities and sleep. The relative contribution of disease on aspects of quality of life is summarised in Figure 4, with symptoms of disease having greatest impact, and leisure activities most affected (Table 2).

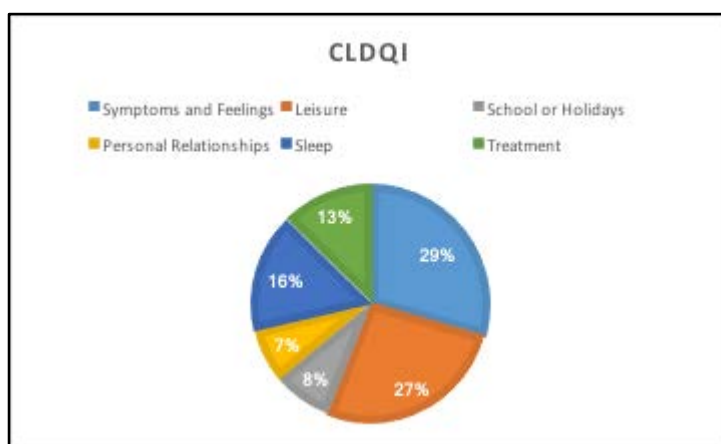


Figure 4: Quality of life areas affected by atopic dermatitis

Discussion

The primary aim of this study was to compare parental perception of disease severity with clinician assessed disease severity in childhood AD. The secondary aim was to estimate quality of life impact in the families studied. Statistical analysis of EASI scores of clinicians showed consistency. Therefore, this analysis supports clinician assessment as a reliable assessment of disease severity and provides the baseline from which caregiver assessment can be compared.

Comparison of EASI score to SA-EASI score showed that EASI and SA-EASI scores were highly correlated for a given patient. However statistical analysis showed a significant

difference between caregiver and clinician assessment of disease severity. Scores given by caregivers were consistently lower than those given by clinicians. This cohort of well educated parent caregivers significantly underestimated disease severity of their children's AD. This has the potential to result in undertreatment. A common statement heard in the clinic is "I only use the TCS when things are really bad."

Quality of life data was examined and showed that impact is variable. These findings are consistent with a meta-analysis conducted by Olsen et al 2016 which showed that most children will experience a small impact, but a significant proportion will experience a very large impact on quality of life [23]. Furthermore, Holm et al have shown that AD has a negative impact on quality of life which is proportional to the severity of the disease [25].

Understanding of the parental tendency to underestimate the severity of AD provides clinicians with a greater insight into poor treatment adherence commonly observed in clinical practice. It highlights a need to provide parents with a greater understanding of their child's disease. Aspects of treatment adherence such as steroid phobia [12] and influence from other health care professionals such as general practitioners and pharmacists [26] have previously been examined. It is clear that inadequate treatment of the disease impacts quality of life of patients and families [27-30]. Understanding this aspect of the problem informs clinicians that this is a target for intervention.

There is a tendency for skin conditions to be trivialised because of the perception that they do not pose a significant risk to life however the impact of severe eczema has been shown to be similar to other severe debilitating diseases [31]. The relationship between risk perception and adherence to treatment is well recognised. If parents are in touch with the risk to their child's quality of and the impact on the family of AD, and if they are given a realistic benchmark of severity it may assist them in achieving better treatment outcomes.

The limitations of this study include: demographic data showed variation in all aspects of areas examined, including caregiver age, education level and household income; however, there were inadequate numbers to draw conclusions. The population studied were mainly middle class, well educated individuals and the results may not be generalizable to the whole population.

This survey does however, provide useful information regarding trends in patient attendance to the clinic and areas in which cultural and socioeconomic identifiers may help assist in disease severity and treatment explanation, and possible educational tools that may be necessary in the future. Further study in relation to demographic influence on treatment adherence is required in this population.

CONCLUSION

The management of AD in children often requires parents to adjust the potency and frequency of topical therapies. However, this study demonstrates that there is a significant gap in parent's perception of disease severity relative to severity assessed by a clinician.

When parents under-appreciate the severity of their child's disease this may lead to decreased treatment adherence and poorer treatment outcomes. Therefore, it is important for clinicians to help parents understand the impact of AD on their child and where they are located in terms of absolute clinical severity. This may help to educate parents how to assess flare severity and guide management.

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Table 1: Comparison of clinician EASI score and caregiver SA-EASI score

Patient	Average Clinician Score	SAEASI
1	7.3	4
2	16.5	12.6
3	0	0.8
4	2	1.2
5	4.35	1
6	29.8	29.2
7	29.6	20
8	1.95	1.1
9	8	4
10	11.1	3.2
11	0.6	0.5
12	12.3	13.3
13	0.2	0.6
14	0.75	0
15	10.8	7
16	9.8	5.4
17	19.5	21
18	10.4	6.3
19	0.8	0.8
20	19.25	11.2
21	1.1	0.4
22	0.45	1.2
23	11.55	5.4
24	15.25	8
25	3.6	2.4
26	0	1.2
27	0.9	0.6
28	3	1.6
29	0.9	3.3
30	2	2.1
31	16.1	10.5
32	50.2	37.74
33	1.2	1.8
34	27.8	15.2
35	1.1	0.4
36	1.5	6.4
37	0.4	1.4
38	3.2	1.6
39	12.4	9.8
40	1.8	2
41	1.05	2

42	12.9	3.9
43	55	50.4
44	2	6.5
45	1.4	0.28
46	1.2	1.8
47	5.6	5.1
48	1	0.8
49	6.9	6
50	7.1	6

Table 2: Specific *Children's Dermatology Life Quality Index (CDLQI)*Impacts

Grading = 0-1: No effect; 2-6: Small effect; 7-12: Moderate effect; 13-18: Very large effect; 19-30: Extremely large effect.

Patient	Symptoms and Feelings (/6)	Leisure (/9)	School or Holidays (/3)	Personal Relationships (/6)	Sleep (/3)	Treatment (/3)	Severity Banding
1	3	1	0	0	2	0	Small
2	3	0	0	0	2	2	Moderate
3	0	0	0	0	1	0	No effect
4	0	0	0	0	0	0	No effect
5	2	2	0	0	1	0	Small
6	2	2	0	0	2	3	Moderate
7	2	2	0	0	2	2	Moderate
8	1	4	0	2	2	2	Moderate
9	3	0	1	0	1	0	Small
10	5	6	3	0	3	2	Extremely large
11	1	1	1	0	0	1	Small
12	3	4	0	0	2	1	Moderate
13	3	0	0	1	0	1	Small
14	3	4	0	0	0	0	Moderate
15	2	1	0	0	0	1	Small
16	4	5	2	0	2	1	Very large
17	6	0	0	0	3	0	Moderate
18	2	1	0	0	1	1	Small
19	2	4	0	0	0	0	Small

20	3	2	1	0	1	1	Moderate
21	3	0	1	0	2	0	Small
22	0	0	0	0	1	2	Small
23	3	5	2	4	2	1	Very large
24	6	9	3	6	3	3	Extremely large
25	6	1	3	0	3	3	Very large
26	1	2	0	0	0	1	Small
27	6	6	3	5	2	2	Extremely large
28	2	0	0	0	1	1	Small
29	2	1	0	0	1	2	Small
30	1	0	0	0	0	1	Small
31	1	2	1	1	1	0	Small
32	5	9	0	0	3	2	Extremely large
33	6	6	3	0	3	2	Extremely large
34	3	7	3	0	1	1	Very large
35	1	1	0	0	1	1	Small
36	2	2	0	0	0	1	Small
37	1	1	0	5	1	1	Moderate
38	1	0	0	0	1	1	Small
39	3	0	0	0	3	0	Small
40	1	0	0	0	1	1	Small
41	1	1	0	0	1	0	Small
42	4	2	1	1	2	1	Moderate
43	5	6	3	4	3	2	Extremely large
44	1	3	0	0	1	1	Small
45	1	1	0	0	2	1	Small
46	2	0	0	0	1	0	Small
47	1	1	0	0	2	1	Small
48	1	1	1	0	1	2	Small
49	2	4	1	0	0	0	Moderate
50	3	3	1	2	1	1	Moderate

CHAPTER 10

Discussion Part 1:

Impact of healthcare professionals on fears about the safety and efficacy of TCS and treatment adherence

This chapter contains the original systematic review article, “Childhood atopic dermatitis: exploring the safety, efficacy and potential misinformation around topical corticosteroids,” published in Australian Journal of Pharmacy 2016;October:83-88.

Publication Statement

Statement from co-authors confirming the authorship contribution of the PhD Candidate Clinical Associate Professor Saxon D Smith

As co-author of the paper:

Smith SD and Fischer G. Childhood atopic dermatitis: exploring the safety, efficacy and potential misinformation around topical corticosteroids. *Australian Journal of Pharmacy* October:83-88, **2016**.

I confirm that Saxon D Smith has made a major contribution to:

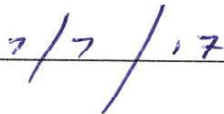
- Conception and design of the research
- Data collection
- Analysis and interpretation of the findings
- Writing the manuscript, critical appraisal of the content and response to reviewers

Signed: _____



Name: _____ Associate Professor Gayle Fischer _____

Date: _____





Childhood atopic dermatitis: exploring the safety, efficacy and potential misinformation around topical corticosteroids

▲ *Clinical Associate Professor Saxon D Smith and Associate Professor Gayle Fischer, Department of Dermatology, Royal North Shore Hospital, St Leonards; Northern Clinical School, Sydney Medical School, University of Sydney.*

Corticosteroid phobia' has been identified as a major cause of non-compliance and treatment failure in atopic dermatitis.

Atopic dermatitis (AD) is the most common chronic inflammatory skin condition affecting more than 20% of children¹ and around 7% of adults.² However, it can be a condition that is not well managed. Topical corticosteroids (TCS) play a central role in the management of the cutaneous inflammation in AD. The safety and efficacy of TCS are well-supported with dermatologists generally agreeing that with appropriate use, the benefits outweigh the very low incidence of any possible risks and side effects.^{3,6}

On the other hand, poor compliance with medical therapy is common and often related to an exaggerated fear of possible side effects. This can lead to poor compliance to topical treatment regimens and subsequent poor responses to treatment.⁷⁻¹¹ There are various factors that contribute, directly or collectively, to poor compliance with "corticosteroid phobia" identified as a key contributor.¹² 'Corticosteroid phobia' is a misnomer as it is not a true phobia. It is the term given to parent and patient anxiety regarding the use of TCS due to concerns regarding safety and efficacy in AD despite AD being disabling and disruptive for patients and their families.^{7,10,11,13,14}

'Corticosteroid phobia' has been identified as a major cause of non-compliance and treatment failure in

AD.¹⁵⁻¹⁸ It is not unique to dermatology and is also seen by paediatricians and respiratory physicians in the management of asthma with inhaled corticosteroids.¹⁴⁻¹⁷

Currently, there appears to be a large amount of misinformation about the safety and efficacy of TCS in AD which means that this concern is widespread. It has previously been identified that this misinformation can range from a common belief among parents that medical treatment for AD with TCS is dangerous through to a preference for complementary and alternative medicine (CAM), or that 'natural' therapy is safe and therefore preferable.¹⁴

However, by far the most common belief that parents identify as a perceived risk associated with the use of TCS is irreversible skin thinning. Many parents also voice concerns about immune suppression and growth failure.¹⁴ Parents cite that there are a wide range of sources of information and misinformation on the safety and efficacy of TCS in AD including family/friends, the Internet, pharmacists and general practitioners (GPs).¹⁴ However, this sea of information and sometimes misinformation can detrimentally impact a patient's or parent's understanding of the safety and efficacy of TCS to manage their (or their child's) AD. Unfortunately, this can lead to abandonment of evidence-based medical therapy with potentially serious detrimental outcomes, especially in children.¹⁹

AFTER COMPLETING THIS ACTIVITY PHARMACISTS SHOULD BE ABLE TO:

- discuss the contributors to poor adherence to topical corticosteroid therapy for childhood atopic dermatitis;
- counsel patients and carers about the appropriate use of topical corticosteroids for childhood atopic dermatitis.

The 2010 Competency Standards addressed by this activity include (but may not be limited to): 4.2, 4.3, 6.3, 7.2



apc | ACCREDITED
CPD

Accreditation Number: A1610AJP2

This activity has been accredited for 1.0 hour of Group 1 CPD (or 1.0 CPD credits) suitable for inclusion in an individual pharmacist's CPD plan which can be converted to 1.0 hour of Group 2 CPD (or 2.0 CPD credits) upon successful completion of relevant assessment activities.
Expiry date: 01/10/2018.

Safety and efficacy

What is the evidence of safety and efficacy and where does the concept of "thin skin" originate?

Research into the safety of topical corticosteroids dates back to the 1960s. Epstein *et al* published an article in 1963²⁰ which was the first to suggest a 'skin thinning' role for TCS. However, this was a small case series of five male adult patients who were using potent TCS unsupervised in an 'overuse' fashion.

Later on in 1981, Frosch *et al*²¹ explored corticosteroid atrophy using Durhing chambers (occlusive chambers) using normal skin in 20 adult volunteers.

However, the confidence intervals of the telangiectasia (dilated capillaries or tiny blood vessels visible in the skin) assessed by dermatoscope and atrophy assessed by histology for each strength of TCS used all crossed 1.0 and had cross over with the comparison vehicles.

This makes it difficult to accept their conclusions that TCS may induce atrophy. Despite slim evidence, the concept of thin skin as a side effect has received widespread notoriety.

Unfortunately, anecdotal reports have appeared in the literature of side effects of TCS including Cushingoid features. The fact that these publications appear as single case reports in itself indicates the rarity of such events and when the evidence is critiqued it invariably

sites by dermoscopy. For each of the 70 TCS-exposed children examined, three difference sites and a control site were assessed and no significant atrophy was found. Mild grade 1 telangiectasia of the cubital fossa (elbow pit) was observed in 3.3% of the test group and a similar amount (3.1%) was seen of the control group of 22 TCS naive children.

The authors concluded “that routine, appropriate, long-term use of TCS in children with dermatitis does not cause skin atrophy”.

Most recently an evidence-based consensus statement published from paediatric dermatologists from Australia and New Zealand explored the broader literature on all of the potential side effects from the use of TCS in the setting

group stated that “when they are used to treat active eczema and stopped once the active inflammation has resolved, adverse effects are minimal”.

On the balance of the available evidence, parents, pharmacists, and health practitioners should be confident about the safety of using this treatment.

Negotiating the sea of misinformation

There is a wide range of sources of information and misinformation on the safety and efficacy of TCS in AD. An Australian focus group study¹⁴ found that all participating parents reported they had been told by other people that topical corticosteroids were dangerous. Friends were the most common group of people who had given parents this information (88%). They had also been advised that topical corticosteroids were dangerous by family (50%), pharmacists (44%) and general practitioners (25%).

There is a wide range of sources of information and misinformation on the safety and efficacy of TCS in AD. An Australian focus group study found that all participating parents reported they had been told by other people that topical corticosteroids were dangerous.

What pharmacists say to patients²⁵

In 2014 a cross sectional survey of 292 Australian pharmacists attending a continuing professional development conference demonstrated that they have significant knowledge gaps about the use and safety of TCS in childhood AD. It was concluded that their advice to patients might, therefore, potentially contribute to poor treatment compliance.

Application advice

A large portion (67%) of pharmacists surveyed advised that the maximum duration TCS could be used was two weeks or less. When instructing parents of the amount of TCS to be applied, 54% reported informing the patient that TCS should be used sparingly, while 41% reported advising patients to use TCS either generously or based on fingertip unit guidelines.

Further analysis of the results demonstrated that pharmacists younger than 40 years of age and those that had been practising less than 10 years were more likely to recommend TCS use for a short duration. Furthermore, only 14 out of 95 that had been practising for less than 10 years (15%) recommended that TCS be used until the eczema was clear.

Knowledge

Nearly half (46%) of pharmacists surveyed believed that skin atrophy (skin thinning) was the most common side effect of

describes inappropriate use.^{22,23,24} The most recent attack on TCS is the concept of “steroid addiction”.

This is simply the flip side of corticosteroid phobia but again if the literature is carefully analysed these cases are invariably due to inappropriate use.

With no studies in the paediatric setting and only decades old adult literature, in 2011 Hong *et al* specifically sought to explore whether cutaneous atrophy is seen in children using TCS appropriately under medical supervision for treatment of atopic dermatitis.⁶ A cross-sectional observational study was undertaken to assess the potential of TCS to cause cutaneous atrophy in children with dermatitis requiring long-term TCS suppression. All children who were able to achieve good disease control, as determined by a maximum Eczema Area and Severity Index score of 1.0, who were using TCS were examined for adverse effects. Cutaneous atrophy was assessed by examining sites exposed to TCS compared with non-exposed

of childhood AD.⁵ They contended that the treatment of atopic dermatitis is complex and multifaceted but a core component of therapy is to manage the inflammation with TCS.

However, it was noted that parents often underutilise TCS due fears about their potential adverse effects which can lead to extended and unnecessary exacerbations of eczema for children. Critically the consensus group concluded that based on both clinical and research evidence that “contrary to popular perceptions, (TCS) use in paediatric eczema does not cause atrophy, hypopigmentation, hypertrichosis (abnormal body hair growth), osteoporosis, purpura (purple bruise-like spots caused by small bleeding vessels near the skin surface) or telangiectasia when used appropriately as per guidelines”.

However, they also conceded that “in rare cases, prolonged and excessive use of potent TCS has contributed to striae (stretch marks), short-term hypothalamic-pituitary-adrenal axis alteration and ophthalmological disease”. The consensus

TCS. Again, pharmacists who had been practising for less than 10 years were more likely to incorrectly understand this side effect of TCS than those who had been practising more than 10 years.

Of those surveyed, 64% believed that poor TCS compliance was a major reason why patients with atopic dermatitis fail to get better. The survey did not explore the source of this information and it was therefore not clear if this was because of patients not following pharmacist advice or medical advice however it was clear that the majority are aware of this problem.

What GPs say to patients²⁶

In 2015 a cross sectional study of 258 Australian GPs was performed with a surveyed through three separate continuing professional development (CPD) interactions: a web-based education module and two face-to-face CPD lectures on management of atopic eczema.

It demonstrated significant differences across GPs on their knowledge of the safety and efficacy of TCS in childhood atopic dermatitis. Furthermore, it was concluded that their advice to patients may potentially contribute to poor treatment compliance.

Application advice

While 47% of GPs instruct patients to use TCS until eczema is clear, 41% instruct use for a maximum of two weeks or less. Nearly half (49%) recommend to use TCS sparingly or the smallest amount possible and only 39% recommend finger-tip unit measurements.

Knowledge of safety

Just under a third (30%) believe cutaneous atrophy is the most common side effect seen in this patient population using TCS and reassuringly 58% indicated there are no side effects when used appropriately.

Most (66%) strongly agree/agree that lack of treatment compliance is a major reason for treatment failure but most (64%) strongly disagreed/disagreed that this is impossible to prevent.

What dermatologists say to patients²⁷

A cross-sectional survey of 455 dermatologists working in Australia in 2014 was completed assessing their attitudes to safety and efficacy of TCS in

childhood AD. There were 198 (43.5%) completed surveys from the population of dermatologists. Unlike GPs and pharmacists, there is consensus in the knowledge of safety and efficacy of TCS amongst Australian dermatologists.

It was concluded that this likely arises from the specific training but also the general experience of TCS use among dermatologists.

Application advice

Only a minority of dermatologists (20.9%) indicated that they instructed patients to use TCS sparingly. This was increasingly likely as the number of years practiced increased ($p<0.001$).

While most dermatologists (61%) answered that they will give patients a time limit guidance on how long TCS can be used they will temper this by further also advising parents to use their treatment until their skin had normalised regardless of how long it took.

Safety and efficacy of TCS

The majority (69.2%) reported that the most common side effect encountered from TCS use was not skin thinning but peri-orificial dermatitis (red rash with red small lumps around the mouth, nose and/or eyelids) with 15.9% reporting bruising. Only a small minority (5.6%) reported that the most common side effect seen was cutaneous atrophy.

Importantly the vast majority of dermatologists (92.5%) either agreed (16.7%) or strongly agreed (75.8%) that TCS if used as directed at an appropriate dose and duration in accordance with disease severity is unlikely to cause cutaneous atrophy.

Labelling of TCS

Furthermore, most dermatologists (77.3%) either agreed (26.8%) or strongly agreed (50.5%) that the term "sparingly" should not be written on the label of prescribed tubes of topical corticosteroid. Only a minority (11.6%) were ambivalent (11.6%) or disagreed (11.2%) with this statement.

It is evident from these studies that there is potential for parents and patients to receive differing advice from their dermatologists, GP and pharmacist. This can lead to confusion or misinformation that in turn can affect compliance to prescribed therapy.

What is the impact of the advice that pharmacists and GPs give patients?²⁸

A multicentre cross-sectional survey of patients (aged >18) and parents of paediatric patients (aged <18) with a history of long-term (≥ 1 month) TCS use explored the impact and influence of the benefit and risk messages on parents and patients.

A total of 201 surveys were completed consisting of 123 adult patients and 78 parents. Most respondents (76.6%) reported that they consistently ('Often' or 'Always') received one or more message(s) regarding TCS 'risk' from a GP and/or pharmacist.

Application advice received

Just over half (52.8%) of patients were aware of the 'fingertip unit' as a measure of the amount of TCS to apply.

Of those that were aware, they reported various sources of information on the concept, noting that respondents could select multiple sources if applicable: Dermatologist (54.8%, $n=57$), GP (25.0%, $n=26$), Pharmacist (16.3%, $n=17$), Other (e.g. another type of specialist, the Internet, or written materials) (30.8%, $n=32$).

Knowledge of safety and efficacy

In general, the majority acknowledged the necessity for TCS therapy to manage their condition. However, the rates concerned about the safety of TCS varied, depending on the specific concern.

The concern statement with the highest 'Agree'/'Strongly Agree' rate was 'I worry about the long-term effects of TCS [on my child]' (58.1%, $n=115$).

Only 27.8% of respondents 'Disagree' or 'Strongly Disagree' with the statement 'I worry that TCS thin my [child's] skin' ($n=55$).

Interestingly, less than half (44.8%) of respondents 'Agree' or 'Strongly Agree' that 'Pharmacists instruct me to apply the TCS exactly as directed by my doctor'.

Messages of risk/benefit patients and parents report receiving

Survey respondents reported that they had received messages about the benefits of TCS significantly more often from GPs than from pharmacists ($p<0.001$). On the other hand, they also reported they were encouraged to 'try natural or complementary and alternative therapies

before resorting to the use of TCS' significantly more often by pharmacists than by GPs ($p=0.039$).

Messages about the 'risks' of TCS were equally reported to have been received from both GPs or pharmacists without a statistical significance between them.

Furthermore, most respondents (76.6%) of 192 respondents received at least one of the six messages about TCS 'risk' from a GP and/or pharmacist 'Often' or 'Always'.

The variation in the risk/benefit messaging received from GPs and pharmacists may contribute to poor treatment compliance and ultimately may lead to poorer treatment outcomes.

Other factors contributing to poor treatment outcomes

The misinformation and subsequent fears about the safety and efficacy of TCS in atopic dermatitis are not the only contributing factor affecting treatment adherence and treatment outcomes. It is important for us all, as part of the multidiscipline treatment team, to recognise when one of these other factors may be contributing to issues with treatment adherence.

Complexity of treatment regimens

The nature of skin-based treatment regimens often are perceived to be complex and particularly burdensome due to the multiple prescription medications used, the frequent dosing schedules and the challenge of applying the topical preparations.²⁹ This is especially the case when long-term treatment is required. Evidence shows that even with a twice-daily application of topical therapy compliance drops by 60% after a few days from the commencement of treatment.³⁰ In order to simplify treatment regimens and make them fit their activities of daily living, parents and caregivers admit taking shortcuts, such as the reduced frequency of topical therapy application.²⁹

Lack of knowledge

There is commonly a lack of understanding of the disease pathogenesis and benefits of prescribed treatments in AD.^{10,31} In fact, when questioned, nearly half the parents and caregivers cannot correctly identify the potency of commonly prescribed TCS or the nature of the antimicrobial components correctly.³¹

This lack of knowledge may result

in the incorrect application of topical therapy and confusion about the escalation of treatment, leading to poor treatment compliance and outcomes.

Impaired quality of life

As AD is a chronic waxing and waning condition it requires ongoing commitment and resolve from patients and parents to be successful. This can be a thankless and exhausting task.

Even when there is no active disease, emollients are applied which means patients and parents are given little respite from their treatment duties. It is not surprising that health-related quality of life (HRQoL) is significantly impaired in children with AD and their caregivers, which has direct negative implications for treatment compliance.^{32,33}

Patient dissatisfaction

Treatment compliance is significantly affected by patient satisfaction.^{34,35} For example, a Japanese cross-sectional survey reported that a satisfactory patient/caregiver–clinician relationship was the most important factor driving treatment compliance in their population.³⁶

On the other hand, a survey of the UK National Eczema Society showed that only 19% of initial consultations with a dermatologist met patients' expectations and only 40% of patients were satisfied with the treatment given.³⁷

There are strategies to improve this dissatisfaction with the patient/parent–clinician relationship. It is important to acknowledge the patient/parent's preferences when recommending topical therapies.

This could include taking into consideration patient/caregiver vehicle preference,³⁸ the type of preparation³⁹ and the frequency of application.²⁹ Treatment plans designed without the patient/caregiver preferences in mind are more likely to lead to treatment failure.¹⁰

Frequency of follow up

The frequency of follow-up appointments does increase compliance to topical therapy in AD as it increases significantly around the time of follow-up appointments.³⁰ This is called 'white coat compliance',⁴⁰ and has also been reported in other skin conditions such as psoriasis⁴¹ and hand dermatitis.⁴² The timing of follow-up appointments also seems to be

important, with earlier follow up resulting in higher rates of treatment compliance.⁴³

Use of complementary and alternative medicine

CAMs continue to be a popular adjunct to treatment despite the lack of evidence for their role in the management of AD.⁴⁴

Common CAM strategies that patient/parents seek include homeopathy, the use of botanical extracts and Chinese herbal medicine.⁴⁴ In fact, more than half of AD patients may include a form of CAM in their management.⁴⁵

Patients with a long duration of disease or if orthodox treatment has failed are more likely to CAM, usually upon recommendation by friends or family.⁴⁵

However, side-effects, medication interactions and even the worsening of AD symptoms have been reported with the use of some CAM,^{19,46–48} and these confound treatment outcomes.⁴⁹ Furthermore, the inappropriate sole use of CAM to manage AD can have catastrophic consequences.¹⁹

What is the risk of non-adherence?

The case of Gloria Sam highlights the extreme and catastrophic.

This tragic case, which occurred in Sydney, came before the courts in 2009⁵⁰ and 2011.⁵¹

A child, presented with her parents to GPs for medical treatment on several instances over an extended period with AD, but her parents did not follow through with recommended medical advice or with referrals to dermatologists. The child's father, a CAM practitioner, administered homeopathic remedies.⁵²

The child finally presented to hospital and died as a result of overwhelming sepsis from secondarily infected atopic dermatitis.

This case was judged to constitute a case of child abuse. The father's homeopathic treatment of his daughter was also assessed and he was found culpable under the "reasonable parent" test and the "reasonable homeopath" test, on the basis that a "reasonable homeopath" would have referred non-improving patients to conventional medical assessment for treatment.⁵⁰

This tragic case represents an extreme end of the spectrum of neglect due to alternative health belief however lesser cases are seen constantly in dermatology

practice. Although children who are being inadequately treated are not at risk of serious harm, they and their parents can suffer from disruptive exhaustion and sleep deprivation as a result of their child being constantly itchy.

The biopsychosocial impacts

Typically, childhood AD can be managed and remits with age. However, it still places a significant burden on patients and their whole family.

It has been repeatedly shown that a child with AD has a significantly higher biopsychosocial impact on the family unit than a child with diabetes, due to problems such as itching, sleep loss, problems at school and mood and behavioural changes.^{8,9,11,53}

A 1997 Australian study calculated conservative estimates of the annual personal cost of managing childhood AD with mild disease costing \$1100 and rising to around \$6000 for severe disease.⁵³

The cost estimates included doctor visits, hospitalisations, medicines, over-the-counter therapeutic preparations, time off work and transport.

In fact, this study concluded that the personal financial cost of managing AD was greater than that for asthma.

Furthermore, there are other practical difficulties that need to be considered when caring for a child with AD including skin care, feeding, shopping, washing and cleaning, psychological pressure, physical exhaustion and restriction of the family's lifestyle.⁵⁴

Recent changes in Australia

There has been recognition of a need to change our approach to the use of TCS in Australia. The Pharmaceutical Benefits Scheme has recently introduced a group of streamline authority numbers to allow doctors to prescribe increased quantities (to a maximum of 10 tubes and 5 repeats) of TCS for steroid responsive dermatoses. This will enable GPs to move past their reluctance to call the Medicare Authority Prescription telephone line to obtain increased quantities for patients requiring them.

Furthermore, some of the pharmacy prescription programs have taken the step of removing the automatic generation of the term 'sparingly' on all TCS prescriptions. Parents and patients are unable to articulate what 'sparingly'

means practically,¹⁴ so the removal of this confusing term on prescriptions may help to improve treatment compliance.

Conclusion

TCS have been successfully used to treat AD for more than 50 years. There is no convincing evidence that they pose a risk if used correctly, that is not in overdose, and overwhelming evidence that they are effective.

The current backlash against them lacks logic, is driven by incorrect information and is at worst dangerous and at least disruptive. The exaggerated risk messages and advice that limits ongoing use in the chronic conditions for which they are indicated adversely

same as taking a pill with a pre-determined amount of medication. It can be varied enormously by the patient and will be minimised unless they have confidence. Furthermore, most skin conditions are chronic and require ongoing treatment.

Advice that puts a short time limit on treatment is likely to result in treatment failure and indirectly delivers a message about putative risk from the use of TCS.

It is important for all members of a patient's multidisciplinary treatment team to take time to support and educate parents whose children have atopic dermatitis because it helps to deconstruct this complex issue.

This in turn can dramatically increase treatment compliance. This

Topical corticosteroids have been successfully used to treat AD for more than 50 years. There is no convincing evidence that they pose a risk if used correctly... and overwhelming evidence that they are effective.

impacts treatment outcomes.

It is costly to the community, with patients who could be successfully treated in general practice requiring referrals to dermatologists simply so that they can be reassured that the correct treatment is in fact safe.

Corticosteroid phobia is widespread among Australian patients and significantly reduces compliance to appropriate treatment of AD. This belies the fact that these products, when used properly and under medical supervision are very safe. The reasons for corticosteroid phobia are many but recent Australian research into the benefit and risk messages sent to patients by GPs and pharmacists has told us that risk messages are outweighing benefit messages from both groups.

With so much misinformation circulating in social media it is essential that health professionals provide a balanced argument and are not seen to be complicit in incorrect messaging.

It is time for all primary care providers to upskill on the evidence base about TCS and deliver messages that are reassuring to patients. It is important to also recognise that applying topical therapy is not the

'health educator' role is critical for all clinicians to, but they themselves must have confidence in the safety and appropriateness of TCS before they can recommend these medications to patients. Up to date information on the safety aspects of TCS and on appropriate use is essential for health professionals.

Pharmacists, GPs and dermatologists must all be on the same page and it is essential that the medical advice provided supports patients/parents as they manage their chronic skin condition which often already affects the rest of their life so much. ●

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2

CPD CREDITS
GROUP TWO

PRACTICE UPDATE

Childhood atopic dermatitis: exploring the safety, efficacy and potential misinformation around topical corticosteroids

This unit attracts up to 2 Group Two CPD credits. Accreditation number: A1610AJP2

Expiry date: 01/10/2018. Each question has only one CORRECT answer.

1. Which of the following best describes the advice that should be given on the duration of use of TCS in active childhood atopic dermatitis?

- A Maximum of three consecutive days
- B 5 days of active treatment and 5 days off
- C Two weeks
- D One month
- E Until that area of atopic dermatitis has resolved

2. Which of the following best describes the advice that should be given on the amount of TCS to use in active childhood atopic dermatitis?

- A Smallest amount possible
- B Sparingly
- C As much as the parent feels necessary
- D Based on Finger-Tip-Unit
- E Generously

3. Which of the following is NOT a contributor to poor treatment compliance?

- A Complicated combinations of topical therapies
- B Concern about the safety of topical therapies
- C Inability to open container/tube of TCS

- D Patient dissatisfaction with therapeutic relationship
- E Infrequent follow up with multi-disciplinary team

4. Which of the following is the most common potential side effect from the use of TCS in children?

- A Cutaneous atrophy
- B Hypertrichosis
- C Easy bruising
- D Peri-orificial dermatitis
- E Hypothalamus-pituitary-adrenal (HPA) axis depression

5. Which of the following are recognised potential sources of 'corticosteroid phobia'?

- A Family
- B Friends
- C Internet
- D Pharmacists
- E General practitioners
- F All of the above

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CHAPTER 11

Discussion Part 2:

Impact of Non-healthcare professional on fears about the safety and efficacy of TCS and treatment adherence

This chapter is presented as an unpublished manuscript.

Introduction

Treatment adherence, also known as treatment compliance or treatment concordance, is an essential component to successful disease management. Treatment non-adherence may arise from intentional conscious decision making by the patient or by unintentional effects.

Intentional non-adherence to their treatment may arise for a variety of reasons such as health beliefs [1, 2] and a desire to pursue complementary and alternative medicine therapies [3]. Importantly, intentional non-adherence may occur when patients are afraid of the treatment due to a perceived risk of treatment adverse effects which may lead patients to make changes to their own treatment plan and adherence to treatment independently of the doctor's original guidance [4]. Furthermore, the visual nature of dermatology conditions may contribute to a negative effect on adherence because the perceived severity of their condition can be 'assessed' by the patient on a day to day basis [4]. This may lead patients to alter their dosage, increase or decrease, or even stop therapy completely without the direct involvement of their treating physician. Furthermore, the complex nature of treatment regimens for skin conditions leads patients and parents/caregivers to take shortcuts to simplify their treatment, such as the reduced frequency of topical therapy application [5].

On the other hand, patients may also become unintentionally non-adherent to treatment with the most common reasons being forgetfulness or lack of knowledge about the disease and its treatments [4]. This has been reported in dermatology where there is a level of inconvenience at having to apply material to their skin, with forgetfulness being the most common reason for non-application of sunscreen [6] and skin conditions [4]. This can be further compounded by poor knowledge about the amount and frequency of application, whether by poor instructions or conflicting information from members of the healthcare professional team [7].

Regardless of whether non-adherence to treatment is intentional or unintentional, divergence from physician directed management plans can lead to poorer treatment outcomes with the consequences ranging from periodic or complete loss of efficacy through to increased risks of adverse events and toxicity [4]. Close to a quarter of patients consistently fail to follow their treating doctor's recommended treatment plan across various medical conditions such as asthma [8] and HIV [9]. Adherence rates can vary considerably across disease conditions [1] and treatment regimens, and can be quite low, even for treatments that are highly effective such as seen in paediatric AD [10]. In fact, in paediatric AD where the patient relies on a parent to assist with implementation of treatment, non-adherence occurs in 24% of cases [10]. Treatment adherence relies on multiple factors which researchers explore to improve adherence. The factors that predict adherence, including the cognitive, psychological, social, environmental, contextual, and therapeutic elements of the experience of living with illness [1].

Paediatric Atopic Dermatitis

In the setting of paediatric AD intentional and unintentional adherence factors impact on treatment adherence. Whilst the available treatments for AD are effective [11,12], the treatment regimens are often complex, consisting of regular application of emollients and long-term TCS or the use of calcineurin inhibitors as well as adjuvant strategies include environmental modification, avoidance of triggers, phototherapy and the management of complications such as secondary infections. In severe cases, oral anti-inflammatory medications and immunomodulators may be required. However, poor treatment adherence is common, and only 32% of patients have been found to be adherent to topical therapy in AD

when measured with electronic monitoring [13], leading to poor treatment outcomes.

Therefore, non-adherence to treatment is an important cause of treatment failure [14].

Treatment adherence is even more complex in the paediatric AD because the patient is reliant on their parent or caregiver to help or administer in entirety the treatments. This means parents and caregivers are a critical factor in treatment outcomes. However, they are influenced by their personal health belief biases, information on disease pathophysiology, and the safety and efficacy of treatment from external non-healthcare professionals such as family, friends and the Internet.

There are significant implications that arise from poor treatment adherence in AD for patients and their families [14]. With respect to the patient, children with AD suffer from sleep disturbance, are more irritable, require greater attention [15–17] and are at increased risk of mental health problems by the age of ten [18]. This in turn has substantial flow on effects with psychosocial implications for their caregivers and families [19]. The ability of parents to work, complete household duties and engage in social activities is impaired [14, 20–22] and parents also experience significant psychological strain from self-blame, guilt and sadness [15]. There can also be significant economic burden to the parents/family [22] as well as to society more broadly with significant costs resulting from primary care and emergency department presentations, hospital.

Parental Beliefs

There seems to be a commonly held belief in parents in Australia [3] and internationally [23, 24] that treatment of paediatric AD with TCS carries a risk to their child and that ‘natural’

therapy is safe and therefore preferable. The commonest belief is that use of topical corticosteroids will thin the skin irreversibly. However, concerns about immune suppression and growth failure are also expressed by many parents [3, 23]. This ‘corticosteroid phobia’ has been previously documented as a major cause of non-adherence and treatment failure in AD [10, 25-27]. The safety and efficacy of TCS in paediatric AD have been affirmed [28]. However, parents have many reasons to be rationally frightened of topical corticosteroids because of warnings not only from friends, relatives and the Internet [29], but also from traditionally trusted sources including their general practitioner and pharmacist [30].

Perception of disease severity

The existence of differences in perception of disease severity between parent/caregiver and clinician impacts on treatment outcomes, patient attitude towards disease, assessment of effectiveness of treatment, patient’s expectations of treatment effectiveness, underreporting side effects and quality of life impacts not directly attributable to disease or treatment side effects [31,32]. Furthermore, severity perception is directly related to treatment adherence in atopic dermatitis [24] and other disease settings [1].

Our recent Australian study [33] of the 50 parents of children affected with AD found that 44% of children were reported by their parents to have moderate to severe impact on their quality of life as a result of their disease. However, Parents underestimated the severity of their children’s skin disease compared to validated clinician assessment with a significant difference between clinician assessed EASI score ($M= 8.87$, $SD = 11.99$) and caregiver assessment of the severity of children’s eczema ($M= 6.78$, $SD = 9.86$), $p < 0.001$.

The tendency of parents/caregivers to underestimate the severity of AD in their children is commonly seen in clinical practice. This provides an insight into understanding a further source of poor treatment adherence because the parent/caregiver perceives the AD to not as

severe and therefore undertreat. This highlights a need for clinicians act as health educators to provide parents/caregivers with a greater understanding of their child's disease. It is important to provide education into expectations surrounding treatment, explore potential factors leading to non-adherence, and facilitates an approach to the fears and misconceptions that caregivers may have.

Family and Friends

Patients and parents clearly identify there is a significant role of family/friends as an information resource about the safety and efficacy of TCS [3]. The information provided can detrimentally impact a patient's or parent's understanding of the safety and efficacy of TCS to manage their (or their child's) AD, which can lead to poor treatment adherence to evidence-based medical therapy [3].

Our published cross-sectional survey [29] explored that type and frequency of positive and negative messaging that dermatological patients (aged 18+) and parents of pediatric dermatological patients (patients aged <18) with a history of long-term (≥ 1 month) TCS use for chronic inflammatory dermatoses receive from family and friends. Of the 201 participants 61% were adult patients (n=123) and 39% were parents of pediatric patients (n=78).

The study we performed demonstrated that of parents/patients who report receiving TCS messaging from friends/family, only about a third receive benefit messages from these sources. Concurrently, a third of these parents/patients are also receiving misinformation in the form of exaggerated risk messages from the same source. However, parents/patients are more likely to receive a risk message than a benefit message about the role of TCS in atopic dermatitis from the family/friends. The study did not evaluate which source has more

influence but it is known that risk messages are more powerful than benefit messages.

Furthermore, often the messaging received from family and friends is unbidden by the patient/parent [3]. This may in turn increase the anxiety of the messaging received.

Charman et al [10] have also reported the high frequency of family and friends as a source of information about safety and efficacy of TCS in 26% (14.5% family and 11.5% friends) of their study cohort. This study was performed in 2000 and with the explosion of the advent of social media as a source of communication as a way by which to communicate with family and friends, it is possible that this percentage would be much higher now. In fact, in 2006, Hon et al [34] indicated that 57% of their research cohort indicated that they receive information about safety and efficacy of TCS from family and friends.

It is clear that family and friends are a frequency source of information about the safety and efficacy of TCS for patients and parents. Furthermore, it has been demonstrated that the messaging received is potentially a mixture of benefit messages and risk messages. The mixture of these messages can contribute to confusion about the evidence-based safety and efficacy of TCS which in turn can impact upon treatment adherence.

The Internet

Patients and parents also clearly identify there is a significant role of the Internet as an information resource about the safety and efficacy of TCS [3]. Patients and parents have suggested that the information provided can detrimentally impact their understanding of the safety and efficacy of TCS to manage their (or their child's) AD, which can contribute to poor treatment adherence to evidence-based medical therapy [3].

The same published cross-sectional survey [29], referred to above, explored that type and frequency of positive and negative messaging that dermatological patients (aged 18+) and parents of pediatric dermatological patients (patients aged <18) with a history of long-term (\geq 1 month) TCS use for chronic inflammatory dermatoses receive from the Internet. Of the 201 participants 61% were adult patients (n=123) and 39% were parents of pediatric patients (n=78).

The study performed also demonstrated that of parents/patients who report receiving TCS messaging from the Internet, only about a third receive benefit messages from this source. Furthermore, a third of these parents/patients are also receiving misinformation in the form of exaggerated risk messages from the same source. However, parents/patients report that they are more likely to receive a benefit message than a risk message about the role of TCS in atopic dermatitis from the Internet.

In 2006, Hon et al [34] reported that 17% of their patients use the Internet as a source of information about TCS. By 2015, Lee et al [35] reported that the Internet was the most common source of information about TCS as reported by 49% of their study cohort. This growth in numbers may reflect the advent of ‘Dr Google’ and the tendency of many patients and parents to increasingly rely on the Internet for medical information.

The Lee et al [35] and Hon et al [34] studies also highlighted other media streams as a source of information on TCS such as television/broadcast media (Lee et al 45% and Hon et al 52% of their cohorts), and newspapers/magazines (Lee et al 34% and Hon et al 62% of their cohorts).

The Internet is a frequent source of information about the safety and efficacy of TCS for patients and parents. Furthermore, it has been demonstrated that the messaging received can contain benefit and risk information. The mixture of these messages can contribute to confusion about the evidence-based safety and efficacy of TCS which in turn can impact upon treatment adherence.

Conclusion

There are several non-healthcare professional influences which can contribute to poorer treatment adherence with topical corticosteroids in AD. These factors can compound the potential mixed risk and benefit messaging about the safety and efficacy of topical corticosteroids that parents and patients may receive from their healthcare professional. It is important to identify these potential treatment adherence factors in order to address them through evidence based disease and treatment education. This will provide patients and parents with the tools to negotiate this sea of conflicting information and achieve the best control of their AD.

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CHAPTER 12

Conclusions, clinical implications, limitations and future directions

Concluding remarks

AD is a readily treatable common dermatological condition. Poor treatment outcomes are often a result of non-adherence with treatment. The fear surrounding the use of corticosteroids has been proposed as a cause for failure of compliance [1,2]. “Skin thinning” and systemic effects are among the fears expressed by parents, despite evidence that side effects are minimal if used appropriately [1]. This is a situation which is seen not only in Australia, but also cross-cultural phenomenon seen in many countries around the world [3]. This highlights an information gap which can lead to a possible disconnect between patient, parent and clinician in treatment and safety. There is a need for better education of caregivers. Studies have demonstrated that parental training, multidisciplinary support, specialist training nursing support and empowering parents with appropriate education improves treatment adherence [4,5,6].

Identifying factors which contribute to treatment non-adherence in AD

The systematic review in Chapter 2 helps to identifying the major factors that lead to poor treatment adherence of importance in childhood AD. A common cause of treatment failure in AD is poor adherence rather than disease severity or the ineffectiveness of treatment. The review indicates that poor adherence is very prevalent for a variety of reasons. A fear about side effects arising from the use of TCS, also known as TCS phobia, was a key factor identified as contributing to poor treatment adherence. This is driven by a poor understanding of disease pathophysiology. Building a strong patient/caregiver–clinician relationship, simplifying treatment regimens, implementing comprehensive education sessions and increasing the frequency of follow up are important mitigating strategies against poor treatment adherence in childhood AD. It was determined that future research was

required to define the actual risk from side effects from TCS use as well as identifying the sources of misconception about the safety and efficacy of TCS.

Identifying the likelihood of side effects from TCS use in paediatric AD

TCS remain the mainstay of the management of active atopic eczema in combination with the regular use of emollients, the management of triggers and the treatment of concurrent infection. An Australasian consensus statement, outlined in Chapter 3, has been developed to explore the actual reported frequency and severity of side effects from TCS in the setting of paediatric AD. The safety profile of TCS remains robust when it is used appropriately. Appropriate use is defined as 1–2 generous applications per day to all the inflamed skin until the active eczema is controlled as per guidelines. It was found that the advice given by dermatologists to parents of children with eczema regarding the use of TCS is unfortunately frequently undermined by other health professionals. Therefore, it was important to explore the knowledge and attitudes of members of the multidisciplinary healthcare team.

Dermatologist as member of the multidisciplinary healthcare team

Dermatologists in Australia are the experts in the management of paediatric AD and commonly utilise potent or super-potent TCS for its treatment. Research was carried out to explore the knowledge and attitudes of Australian dermatologists to the safety and efficacy of TCS in this setting. Chapter 4 outlines this research which demonstrated that most dermatologists report skin atrophy to be rare and that in general side-effects are uncommon when TCS are used appropriately. Dermatologists believe that the effective management of pAD is affected by TCS phobia, for which pharmacists are cited as the main contributor. Most dermatologists support removing the phrase ‘use sparingly’ from TCS labelling. However, despite the known facts on the safety of TCS a substantial number of

dermatologists still advise their patients that cutaneous atrophy is a risk of this treatment. This may unwittingly contribute to TCS phobia if negative messages about the safety and efficacy of TCS are received from other members of the multidisciplinary team.

Pharmacists as a member of the multidisciplinary healthcare team

Pharmacists are a key member of the multidisciplinary healthcare professional treatment team and are typically the last interaction with a healthcare professional when they attend to fill the prescription from their doctor. Therefore, research, which was reported in Chapter 5, was performed to explore the knowledge and attitudes of Australian pharmacists about the safety and efficacy of TCS in paediatric AD. This research demonstrated evidence that there are wide education gaps in Australian pharmacists' knowledge of the use and safety of TCS in pAD. This ultimately can contribute to the misinformation parents and patients receive about the use and safety of TCS. This, in turn, can directly affect the adherence to evidence based treatments used to manage their AD. Targeted education, especially in pharmacy journals and at undergraduate level, preferably delivered by a dermatologist, is needed to Pharmacist knowledge of topical steroids to improve pharmacist's knowledge and eliminate misconceptions. Our data indicate that their attitudes may be modified by evidence-based, clinically centred re-education.

General practitioners are a member of the multidisciplinary healthcare team.

General Practitioners are the other key member of the multidisciplinary healthcare professional treatment team. They are the gate keepers to referrals to specialists in Australia and often have long established therapeutic relationships developed over years with their patients and their families. Therefore, research, which was reported in Chapter 6, was

performed to explore the knowledge and attitudes of Australian general practitioners about the safety and efficacy of TCS in paediatric AD. The research highlighted that there may be education gaps in Australian GPs' knowledge of the use and safety profile of topical corticosteroids in pAD. This may contribute to exaggerated risk messaging that reinforces misinformation parents/patients currently receive about use and safety of topical corticosteroids from other members of the multidisciplinary healthcare professional treatment team. Furthermore, this can directly impact upon treatment adherence because patients/parents are more likely to avoid/minimise the use of a medication if they do not understand it or are fearful of perceived side effects.

Impact of advice from pharmacist and general practitioners

As the research documented in Chapters 4, 5 and 6 clearly demonstrated the risk of mixed benefit and risk messaging from a patient/parent's multidisciplinary healthcare professional treatment team, it was important to try and assess the impact of the messaging received. Chapter 7 reported the outcomes of research into the patient/parent reported impact of treatment advice around the safety and efficacy of TCS in paediatric AD, as well as exploring the actual adherence to treatment by patient/parents. The results confirmed that in patients with chronic inflammatory dermatoses such as AD, adherence to long-term TCS therapy is poor. Furthermore, patient and parent beliefs about the "risks" of TCS are common. The negative risk messages about the "dangers" of long-term TCS use are being received by a majority of patients and parents on a consistent basis from members of their multidisciplinary healthcare professional treatment team, especially pharmacists and GPs. Patients and parents report having negative TCS-related counselling experiences with both pharmacists and GPs, but these negative experiences occur more frequently with pharmacists. These findings

indicate a need for re-education of both pharmacists and GPs on the safety of TCS use and the potential impact of their counselling on treatment adherence. Analysis of the data also suggested that friends, family and the Internet also propagate the inaccurate messages about the safety and efficacy of TCS.

Chapters 4, 5, 6 and 7 documented the potential for members of a patients multidisciplinary multidisciplinary healthcare professional treatment team to provide differing advice on the safety and efficacy of TCS in paediatric AD. This is likely to be a significant contributor to the reported high level of poor treatment adherence with TCS in this and other chronic inflammatory dermatoses. However, this research also helped to highlight the possible role of family, friends and the Internet as a non-healthcare professional source of misinformation on TCS safety and efficacy in paediatric AD.

Impact of information about TCS from family, friends and the Internet

Family, friends and the Internet have previously been indicated as a source of information about the safety of TCS [7-10]. However, the type of advice and the influence of this advice on patient/parent perception of the safety of TCS has not previously been assessed. Chapter 8 reported the results of research seeking to explore these gaps in the literature. This research demonstrated that only a minority of patients and parents of children with chronic inflammatory skin diseases consistently receive benefit messaging from family/friends and the Internet. On the other hand, family/friends and the Internet are a frequent source of misinformative risk messages about TCS. The varied and mixed nature of this messaging can help contribute to confusion and poor understanding about the safety and efficacy of TCS in CID. This in turn can lead to treatment non-adherence and poorer treatment outcomes.

Parents perception of disease severity

Atopic dermatitis is a condition characterised by flares and remissions. Therefore, a key factor in the management of paediatric AD is that parents have to often commence and adjust the potency and frequency of topical therapies depending on the severity of the active AD. It was documented in the Chapters 3, 4, 5, 6, 7, and 8 of this thesis that negative messaging about the safety and efficacy of TCS from a range of sources in paediatric AD contributed poor treatment adherence. However, it was important to explore whether parents accurately assessed the active disease severity in their child in order to be adherent to the treatment advice of their treating clinician. Chapter 9 reported a study assessing whether was a difference in parent perception of disease severity when compared to clinician assessed disease severity. This study demonstrates a significant gap in parent's perception of disease severity relative to severity assessed by a clinician. When parents under-appreciate the severity of their child's disease this may lead to decreased treatment adherence and poorer treatment outcomes. Therefore, it is important for clinicians to help parents understand the impact of AD on their child and where they are located in terms of absolute clinical severity. This may help to educate parents how to assess flare severity and guide management.

Conclusion

The treatment of paediatric AD is impacted up on by mixed benefit and risk messaging about the safety and efficacy of TCS. There are multiple healthcare professional and non-healthcare professional source for information on TCS. This means there are multiple opportunities for both negative and positive influencers on the perceptions around the long

term use of TCS. This can create a sea of misinformation which is difficult for parents to negotiate and in turn contributes to treatment non-adherence and poorer disease outcomes.

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Clinical and Social Implications

This thesis helps to define the frequency of treatment non-adherence in paediatric AD and how fears about the safety and efficacy of treatment mainstay TCS plays a key role. This means that whether at the onset of a new patient-doctor relationship or during well established patient-doctor relationship there is potential for targeted education and support as an intervention by the members of the multidisciplinary healthcare professional treating team to increase treatment adherence with focused counselling. Therefore, it is important for the members of the healthcare team to act as both clinician and health educator for their patients and in the wider lay and medical communities. Institutions, particularly the Australasian College of Dermatologists, have a role to play in defending and promoting the safety of TCS in the treatment of pAD. This thesis has identified the problem. The solutions lie in better education for all groups involved.

Limitations

A key limitation to the research performed is the difficulty in obtaining research funding to perform larger cohort studies. Dermatology research, outside of melanoma, tends to benefit little from classic research funding models. Instead it relies on the willingness of the researcher and the research team to carry out largely unfunded research.

The studies performed in this thesis necessarily focused on the Australian environment. This means that potentially the results are not generalisable to other cultures or countries. However, many publications document the existence of the problem in other western countries and a recent international meta-analysis highlighted the cross-cultural commonality of fears towards the use of TCS in paediatric AD [1].

A key limitation to the studies presented in this thesis is that the patient populations sampled were collected from those attending dermatology clinics. This is a self-selected group due to either having difficulty to control disease or more severe disease. Therefore, it may not represent the broader Australian community.

A key limitation to the studies presented in this thesis is that the general practitioner and pharmacist populations sampled were voluntarily attending continuing professional development education sessions. It is possible that they choose to attend these specific sessions because they felt they were not up to date with the latest evidence-based information on the safety and efficacy of TCS in paediatric AD. This might bias the results to indicate a larger issue than may actually exist. On the other hand, as we were unable to sample non-

attendees to continuing professional development education sessions, it is possible that our results under report the extent of the knowledge gap about the safety and efficacy of TCS.

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Future directions and research

Research to explore the information content of the Internet

The Internet is a key source of health information. It is common place for patients to supplement the information provided to them by the members of their multidisciplinary healthcare professional treating team, with information gathered from the Internet.

Therefore, a future research opportunity would be to explore the content of the Internet to assess the level and type of information that patients and parents will obtain from this source.

Research into the knowledge of family and friends about the safety and efficacy of TCS in paediatric atopic dermatitis.

This thesis has clearly defined that patients/parents receive mixed benefit and risk messages from family and friends. Therefore, a future research project could be to explore the knowledge of the general population towards TCS.

Developed educational materials to target the sources of TCS phobia.

General practitioners and pharmacists could be better equipped with contemporaneous evidence-based continuing professional education sessions and revised guidelines focused on the safety and efficacy of TCS in the treatment of paediatric AD. These will be best delivered to the target audience through the education sessions being provide in their conference and continuing professional development events, as well as publishing in their specific professional peer-reviewed journals.

There is also an opportunity to develop novel medical education programs such as smartphone applications. This would deliver the target education directly to the hand of the healthcare professional holding their electronic device as well as providing flexibility with the way in which they interact with the evidence-based educational materials.

The Australasian College of Dermatologists has recently developed an evidence-based statement on the safety and efficacy of TCS in paediatric AD. This will help to counter-balance other sources of misinformation and hopefully increase awareness of evidence-based sources of medical information.

Evaluation of the Atrophogenic Potential of Topical Corticosteroids in Pediatric Dermatology Patients

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Abstract: We conducted a cross-sectional observational study to determine the atrophogenic potential of TCS in children with dermatitis requiring long-term TCS suppression. Children who were able to achieve good disease control, with a maximum Eczema Area and Severity Index score of 1.0, using TCS were examined for adverse effects of treatment. Cutaneous atrophy was assessed using a validated dermoscopic technique. Cutaneous sites exposed to TCS were compared with nonexposed sites in all patients. There was no significant atrophy in 70 TCS-exposed and 22 TCS-naïve children. Mild grade 1 telangiectasia of the cubital fossa was observed in 3.3% of the test group and 3.1% of the control group ($p > 0.99$). We conclude that routine, appropriate, long-term use of TCS in children with dermatitis does not cause skin atrophy. These data do not support the widely held belief that routine use of TCS will “thin the skin.” Parents, pharmacists, and health practitioners should be confident about the safety of using this treatment.

Topical corticosteroids (TCS) are the mainstay of treatment for many inflammatory skin conditions and the criterion standard for treating atopic dermatitis (AD) (1). Children with corticosteroid-responsive dermatoses are often undertreated because of parental corticosteroid phobia (2–5). Parents most often cite “skin thinning” as the side effect they most fear (6). This fear is entrenched not only in Australian parents, but also worldwide (7–9). Although cutaneous atrophy is a well-documented side

effect of TCS, particularly when potent products are used under occlusion, the fear of atrophy in the lay and medical community has become so exaggerated that many parents cannot bring themselves to treat their children appropriately (3,4). TCS phobia is a problem that is not confined to parents, but also influences many nondermatologist health care practitioners. As a result, children suffer with uncontrolled AD, and many hours of consulting time is wasted convincing parents that the information on which they base their fears is without evidence.

We conducted a cross-sectional observational study to determine the atrophogenic potential of TCS in pediatric dermatology patients requiring long-term TCS maintenance treatment.

Our primary aim was to detect and quantify TCS-related cutaneous atrophy in these children using

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a previously validated dermoscopic methodology (10–12).

Our secondary aim was to demonstrate that routine use of TCS in sufficient quantities and potency to produce excellent control of inflammatory dermatoses in children does not result in cutaneous atrophy. We hope thereby to increase the confidence of parents and health practitioners in the safe, appropriate use of this essential medication for children with chronic skin disease.

MATERIALS AND METHODS

The Northern Sydney Central Coast Area Health Service Human Research Ethics committee approved the study.

Participants were invited to take part in the study if they were younger than 18, had atopic dermatitis (defined by Hanifin and Rajka) (13) or eczema–psoriasis overlap (atopic dermatitis with associated features of psoriasis, a diagnosis we use in our clinic previously defined in another study) (14), had used TCS regularly for at least 3 months, and were assessed as being under excellent control, with a maximum Eczema Area and Severity Index (EASI) score of 1.0. Those who had not been adherent to treatment when assessed on interview during clinic consultation were excluded until it was deemed that adequate adherence had been met. Non-adherence was invariably associated with fear of use of TCS and evidenced by poor control and underuse of prescribed medication. Children in our clinic who are not able to be controlled with TCS despite good adherence are offered systemic therapy. These children are not the norm and were excluded from the study.

Parents were given a range of TCS to control their children's dermatitis, including strong, medium, and weak preparations. None of our patients were using calcineurin inhibitors other than on the eyelids. Parents were instructed to use potent TCS preparations two to three times a day while skin was flared and then, once cleared, to reduce treatment to a moderate-strength TCS twice a day for a further 3 days. Emollients and moisturizers were also provided to all patients for application with TCS and alone as part of routine skin care between flares. Parents were taught how and when to apply their medication, including flare management, with the aid of explanation in the clinic, video demonstration, written information, and in some cases hospitalization. Parents were instructed to use enough TCS to create a thin film over areas of active eczema. The amount of TCS used was assessed according to self-reporting by parents and the number of prescriptions supplied. Wet dressing technique was taught, but none were instructed to use plastic wrap occlusion. Appropriate environmental modification was recommended, and fears of TCS were

addressed using information developed during a previous study by our group (6).

Evidence of atrophy was assessed using a validated 5-point dermoscopic scale previously demonstrated to show good correlation with histologic measurement (10). Histologic investigation was not considered desirable or feasible in pediatric patients.

The following data were recorded:

- Demographic (age, gender)
- Diagnosis (skin condition requiring use of TCS)
- Distribution of skin signs or rash
- Type of TCS used
- Areas of body on which TCS was used
- Amount, frequency, and duration of treatment with TCS (ascertained by directed questioning during clinical consultation and self-reporting by parents and number of prescriptions provided)
- Dermoscopy: two independent observers graded for skin atrophy and telangiectasia using a 5-point scale (Table 1)

Measurements were recorded from three TCS-treated sites and one untreated self-control site in each patient. Two observers each scored the four sites for atrophy and telangiectasia.

Seventy children with well-controlled AD and eczema–psoriasis overlap were assessed (dermatitis group). The total number of observations for both observers was 560 (8×70), of which 140 (25%) were control sites. The total number of sites in the dermatitis group was 280 (70×4). The same assessment was performed in a control group of 22 age-matched children who had never used TCS and presented to the same

TABLE 1. *Dermal Atrophy and Telangiectasia (Five-Point Scale Used By Frosch et al (10))*

Atrophy	
0	No change
1	Slight increase in transparency and dermoglyphic pattern irregularity
2	Moderate increase in transparency and flattening of furrows and ridges
3	Severe increase in transparency and dermoglyphic pattern effacement
4	Very severe thinning with complete loss of dermoglyphics ("glazed skin")
Telangiectasia	
0	Normal vascular pattern with fine capillary loops
1	Capillary hyperemia with slight elongation and dilatation of blood vessels
2	Moderate telangiectasia just visible to the naked eye
3	Severe telangiectasia with marked reduction of capillary loops
4	Very severe telangiectasia with large blunt vessels and absence of capillary loops

pediatric dermatology clinic with unrelated noninflammatory conditions.

Statistical Analysis

Inter-observer reliability (kappa coefficient) and statistical differences (p-values) were calculated using Graphpad Software 2010 (Graphpad Software Inc., La Jolla, CA). All other statistical analyses were performed using SPSS 17.0 (SPSS Inc., Chicago, IL).

RESULTS

Seventy children in the study group and 22 children in the control group were assessed. The study group (dermatitis group) consisted of 52 children with AD and 18 children with eczema-psoriasis overlap. There were no statistical differences in baseline characteristics between the groups; 46% of the study cohort and 41% of the control group were boys ($p = 0.81$), the mean age of the study group was 3.2 years, and the average duration of TCS use was 10.6 months.

The majority (93%) of patients in the study group were using a combination of potent (betamethasone dipropionate 0.05% ointment, methylprednisolone aceponate 0.1% ointment or mometasone furoate 0.01% ointment), moderate (betamethasone valerate 0.02% ointment), and weak (hydrocortisone acetate 1% ointment) TCS as appropriate to severity and site of application (Table 2).

All of the children included in the study were under excellent control, with a maximum EASI score of 1.0.

Neither investigator observed any degree of atrophy in any of 280 sites from the study group and 88 sites from the control group.

Only minimal telangiectasia (grade 1) was observed in our patients. All cases of telangiectasia were in cubital fossa sites. None of the patients showed evidence of striae, atrophic scars, or purpura.

There was no statistical difference between the dermatitis and control groups for rate of telangiectasia (study group 7/210 = 3.3%, control group 3/88 = 3.1%; $p > 0.99$).

There was 98% agreement between observers (disagreement in five of 280 sites rated), which corresponded to an interobserver reliability kappa coefficient of 0.887, which demonstrated very good strength of agreement (Graphpad Software).

DISCUSSION

“Corticosteroid phobia” is a term that describes an exaggerated and at times irrational fear of using topical corticosteroids and that presents a major problem for doctors using these medications in skin and respiratory disease (2–4).

Although atrophy is a well-documented side effect of TCS, previous reports detail inappropriate usage or safety evaluation usage tests under extreme conditions, for example the use of potent topical corticosteroid under plastic wrap occlusion (10,15). Although not documented in the medical literature, overuse of TCS by parents in an attempt to prevent flares is a potential cause of atrophy, although it was unusual in our cohort, who were almost universally corticosteroid phobic (6). These reports have a great effect on clinicians’ perceptions of safety but do not address the reality of routine clinical use. Our experience reflects that general practitioners and even nonpediatric dermatologists are fearful of the use of appropriate TCS to control AD (6).

Adherence is an important factor in treatment outcome in dermatitis (3). The widely held fear that TCS cause “skin thinning” causes many parents and doctors to hold back on appropriate treatment (3,4). Even with written action plans (which have been shown to be effective in increasing adherence) (16), barriers to successful treatment can exist if underlying fear of the treatment itself has not been sufficiently addressed.

The study was aimed specifically at adherent families from our dermatology outpatient clinic who had been persuaded to adhere to treatment with TCS and thereby achieve excellent long-term disease control. Patients who were not able to be adequately treated as outpatients were admitted to the hospital for treatment with TCS wet dressings. During hospital admission, parents received further education and support in how to manage their children’s skin. When these patients achieved adequate adherence, evidenced by an EASI score of 1.0 or less, they were included in the study. In all cases, we spent substantial time explaining the relative safety of TCS to parents, supplementing this with written information and following up closely. Additionally we ensured that environmental modification, such as use of emollients and soap substitutes was in place and that appropriate amounts and potency of TCS were used to produce a target outcome of normal skin. Mild to moderate TCS

TABLE 2. Strength and Amount of Topical Corticosteroid (TCS) Used in the Group with Atopic Dermatitis

TCS type	Number of patients regularly using, %	TCS used per month, g, mean (range)
Potent	93	79 (15–180)
Moderate	77	128 (50–150)
Weak	70	34 (15–50)



Figure 1. Grade 1 telangiectasia in topical corticosteroid-naïve cubital fossa. Dermoglyphic patterns are normal, and there is grade 0 atrophy.

was used for routine maintenance and potent TCS for flares. Calcineurin inhibitors were used only on the eyelids.

Gross, macroscopic signs of cutaneous atrophy such as striae and translucent skin were not seen in any patient. We used a simple noninvasive technique to evaluate microscopic dermal atrophy. This was also not encountered.

Minimal grade 1 telangiectasia (Fig. 1) was observed in some cases (seven cubital fossae sites out of 210 TCS-exposed sites [3.3%]). The same degree of telangiectasia was found in cubital fossa sites from TCS-naïve control patients (three out of 88 sites [3.1%]) ($p > 0.99$), suggesting that some telangiectasia in the cubital fossa may be a normal variation in the pediatric population.

Our data do not support the widely held fear that TCS treatment produces cutaneous atrophy even in a group using a substantial amount of medication and achieving excellent control of chronic dermatitis.

CONCLUSION

This study demonstrates that, in children with mild to moderately severe dermatitis, it is possible to obtain excellent control using TCS without also producing cutaneous atrophy. The ubiquitous fear that all forms of use of TCS will cause “thin skin” appears to be unfounded if TCS are used appropriately, even in substantial quantity and potency.

Patients should be strongly reassured that routine short- and long-term use of TCS is safe, and pharmacists

and health professionals who may propagate misinformation regarding their safety require re-education.

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ORIGINAL ARTICLE

Corticosteroid phobia and other confounders in the treatment of childhood atopic dermatitis explored using parent focus groups

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ABSTRACT

Background/Objectives: Anxieties associated with corticosteroid treatment and preference for ‘safer natural therapy’ are common in parents of children with atopic dermatitis. We used focus groups to explore the source of these attitudes.

Methods: The study involved 16 parents. Parents expressed difficulties with living with and treating atopic dermatitis which were categorized into themes using qualitative data analysis software.

Results: Themes identified include: emotional impact of atopic dermatitis; difficulty in accepting ‘control’ verses ‘cure’; topical corticosteroid negative perceptions; anxiety and confusion with treatment; preference for ‘natural’ therapy; and attitude-changing positive experiences.

Conclusions: Our findings illustrate the emotional impact of atopic dermatitis and the frustration with the lack of potential cure. ‘Corticosteroid phobia’ was universal among parents in our cohort and is a fear generated by doctors, pharmacists, close acquaintances and information from the internet. Participants expressed high levels of parental guilt linked to a desire for an eradicable ‘cause’ for atopic dermatitis, despite intellectually understanding this is a genetically determined condition. Parents were willing to change attitudes with accurate information from perceived reliable sources, positive hospitalization experiences and a relationship with a trusted dermatologist. Parents’ suggestions to improve confidence

included the provision of readily available information and better access to doctor- and nurse-led paediatric dermatology services.

Key words: atopic dermatitis, fear, focus group, management, paediatric, phobia, topical corticosteroid.

INTRODUCTION

One of the major reasons for an unsatisfactory treatment outcome in the treatment of childhood atopic dermatitis is inadequate compliance.^{1–5} Previous studies have highlighted the fact that even though severe atopic dermatitis is disabling and disruptive for the patients and their families, adherence to topical treatment is poor and anxiety regarding the use of treatment is high.^{1,4–6} A number of studies have evaluated educational interventions to improve compliance. These include written and video-aided information, written action plans, nurse-led clinics and educational group sessions with parents.^{5,7–9}

Topical corticosteroids remain the mainstay of atopic dermatitis treatment. A major cause of anxiety and barrier to effective compliance is what has been termed ‘corticosteroid phobia’, a phenomenon that causes problems not only for dermatologists attempting to treat atopic dermatitis with topical corticosteroids, but also for paediatricians managing asthma with inhaled corticosteroids.^{10–12} Fear of topical corticosteroids appears to be strongly linked to a preference for what parents of patients frequently term ‘natural therapy’. Alternative and complementary medicines are commonly used by parents of children with atopic dermatitis.^{13,14}

A focus group is a qualitative research tool in which a group of up to 12 people are interviewed by a facilitator. Focus groups allow interviewers to study people in an interactive setting. They have high validity and have been widely used in the social sciences to obtain data and insights, sometimes unexpected, on topics of interest. Focus group

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theory has been used previously to study the psychological, physical and social impact of atopic dermatitis.¹⁵

The aim of our study was to use focus group theory to explore parental attitudes to the use of corticosteroids and the associated desire for natural therapy. Our hypothesis was that in a group situation, the parents of children with atopic dermatitis would voice their attitudes to both issues, and that they would emerge as major barriers to compliance. Our primary aim was to explore these phenomena in order to generate further hypotheses regarding how to manage them. Our secondary aim was to derive suggestions from the parents themselves about how health professionals might help them to become more confident in the use of effective management strategies in atopic dermatitis which would ensure good long-term control of their children's disease.

MATERIALS AND METHODS

A qualitative approach using focus group discussion was adapted in this study to gain in-depth views of parents about the use of topical corticosteroids to manage their children's atopic dermatitis.

The study protocol was reviewed and approved by the Health Research Ethics Committee of the Northern Sydney Central Coast Area Health at Royal North Shore Hospital. All participants were informed about the objectives of the study and written consent was obtained. The participants did not receive compensation for their time.

Study participants

The participants were recruited from parents of children with atopic dermatitis who required the regular use of topical corticosteroids and who regularly attended the paediatric dermatology clinic at Royal North Shore Hospital. The hospital has a catchment area predominately from the North Shore of Sydney and the Central Coast of New South Wales. Individuals were considered for participation if they were parents of children aged 0–18 years old who suffered from atopic dermatitis, as confirmed by a paediatric dermatologist, and who required the regular use of topical corticosteroids to manage their atopic dermatitis. Recruitment was not based on the severity of skin disease.

A total of 16 parents agreed to participate in the study and consent was obtained before the focus session. Parents who were unable to speak and read English were excluded.

Focus groups

Focus groups were conducted at the Dermatology Department within Royal North Shore Hospital between August 2008 and February 2009. Group discussions were conducted in English. The participants in the focus group included the parents and two facilitators: a dermatologist and a clinical psychologist. There were two observers.

Data saturation was reached after the second focus group was conducted. An additional focus group discussion was

carried out to ensure that no new data were identified. Thus, the study comprises three focus group discussions.

Before each group discussion, a brief questionnaire was administered to the participants to gather information regarding their demographic background (age, sex, relationship to child). Before the first focus group, the questionnaire was pilot-tested to ensure the wording was understandable and that the questions elicited the information sought. After the pilot test, any wording issues and ambiguities that had been detected were addressed, minor amendments were made, and the final version was consistently used across all focus groups. The items included in the pre-focus group questionnaire were scored using a 5-point scale (where 1 = strongly disagree, 2 = agree, 3 = neither agree nor disagree, 4 = agree and 5 = strongly agree) and are listed in Table 1.

The group discussion began with an introductory welcome before the facilitator-prompted discussion began with an open-ended question. The facilitator did not participate in the discussion. The open-ended questions used to generate discussions are listed in Table 2.

Discussions were conducted for between 1.5 and 2 h. These discussions were audiotaped and transcribed in a Word document. Notes were taken by the facilitator and the

Table 1 Pre-focus group questionnaire items

1. I believe that my child is not cooperative with treatment
2. I believe that treatment with creams is too time-consuming
3. I believe that treatment with creams is expensive
4. The word 'sparingly' on the label of cortisone creams worries me
5. I believe that cortisone creams are dangerous
6. I believe that cortisone creams cause thinning of the skin
7. I believe that cortisone creams may reduce my child's growth
8. I believe that cortisone creams may affect my child's immune system
9. I believe that cortisone creams should be reserved for treating only very severe eczema
10. I believe that cortisone cream is a waste of time because the eczema just comes back when I stop it
11. I believe that my child's problem is due to allergy
12. I believe that many treatments cause stinging and itching
13. I think it should be possible to cure eczema
14. I believe that cortisone creams are too dangerous to use on my child
15. I feel I have been adequately informed by my doctor about how to manage my child's eczema
16. I would prefer to use natural therapy to treat my child's eczema rather than cortisone cream
17. Information on the internet caused me to be more concerned about cortisone creams
18. I would be interested to take part in an educational support group on eczema treatment
19. Information from my friends with children caused me to become concerned about cortisone creams
20. Written instructions would help me to know what to do to help my child
21. I would find a video with instructions on applying wet dressings helpful
22. I found an admission to the hospital a positive experience
23. I was more positive about cortisone creams after admission to hospital

Table 2 Open-ended questions

What is it like to have a child with atopic dermatitis?
How do you feel about control versus cure?
What is your view on allergy?
Tell us about cortisone treatment?
Where did you get your information about eczema?
What about natural therapy?
How do you conceptualise 'thin skin'?
What were some of the problems you have encountered with treatment?
What are your concerns about treatment?
How do you feel about petroleum products?
What is a 'natural product'?
What can we do to help you?
What would give you the most confidence?
Tell us about positive experiences
Tell us about negative experiences

research team. These notes were used to supplement the audiotapes of the discussions. Consistent with grounded theory methods, focus groups were continued until data saturation was reached or no new information was uncovered.

Statistical analysis

QRS NVivo qualitative software (QRS International Pty Ltd, Doncaster, Victoria, Australia) was used for the data analyses. The transcripts were analysed by two of the investigators using open-, axial- and selective-coding procedures. The process of analysis first involved open coding, whereby data of specific themes and categories were identified. When specific themes were identified, more specific axial coding was used to develop axial nodes from the core categories. Subsequently, selective coding was used to integrate the core categories with other categories. The coding was carried out by a single independent coder, and the consistency of coding assessed by an inter-observer. In the final coding stage, the study's researchers integrated the selective codings with the core categories.

Themes identified were used to form a list of suggested strategies for dermatologists that might enable them to increase patient confidence in treatment.

RESULTS

Participants

A total of 16 parents attended three focus groups. All were parents of children with a skin condition requiring the use of a topical corticosteroid. All but one of the participants were female and aged between 34 and 49 years. All parents were from the catchment area of Northern Sydney and Central Coast area health service, which is a middle to high socio-economic-strata area. All participated equally and enthusiastically to the discussion.

Pre-focus group questionnaire

The demographic data collected are presented in Table 3 and disease-specific questions (such as age of diagnosis, the

Table 3 Data from questionnaire (*n* = 16)

Age range of parents	34–49 years
Mean age	40.2 years
Sex of parent	15 female, 1 male
Mean age of child at eczema onset	8.5 months
Cost of treatment per month:	
Less than \$10	2/16
\$11–20	2/16
\$21–30	4/16
More than \$30	7/16
Unsure	1/16
Respondents were told by the following people that topical corticosteroids are dangerous (%):	
Friends	14/16 (88)
Family	8/16 (50)
Pharmacist	7/16 (44)
General practitioner	4/16 (25)
Dermatologist	0/16 (0)
Frequency of medical follow up desired by parents:	
Monthly	2/16
3-monthly	2/16
6-monthly	7/16
12-monthly	1/16
As needed	4/16

use of topical corticosteroids, the cost per month of managing their child's atopic dermatitis, and the impact of atopic dermatitis on their child and family unit) are presented in Figure 1.

All parents (100%) reported they had been told by other people that topical corticosteroids were dangerous. Friends were the most common group of people who had given parents this information (88%). They had also been advised that topical corticosteroids were dangerous by family (50%), pharmacists (44%) and general practitioners (25%).

Most parents believed that topical corticosteroids were dangerous or were unsure. Skin thinning was the most prevalent cause for parents' concern as a perceived risk of using topical corticosteroids. While most parents did not believe that topical corticosteroids would interfere with their child's growth, they were unsure about its effect on the immune system. Only one parent disagreed that allergy was the cause of atopic dermatitis. Given the choice, the majority of parents indicated they would prefer to use 'natural' therapies over topical corticosteroids.

Most parents did not believe that treatment was too time-consuming, which suggests a general acknowledgement of the amount of parental effort required to treat children with a chronic skin disease. However, over half of parents thought that the cost of treatment was expensive. Most parents indicated a desire for regular scheduled visits with their doctor for their child's skin condition.

All but one of the parents had children who were admitted to hospital for treatment of their skin condition, and the majority found this to be a positive experience that alleviated their fears about topical corticosteroids. Most parents agreed that information about the treatment of childhood atopic dermatitis in the form of written or audiovisual material would be useful.

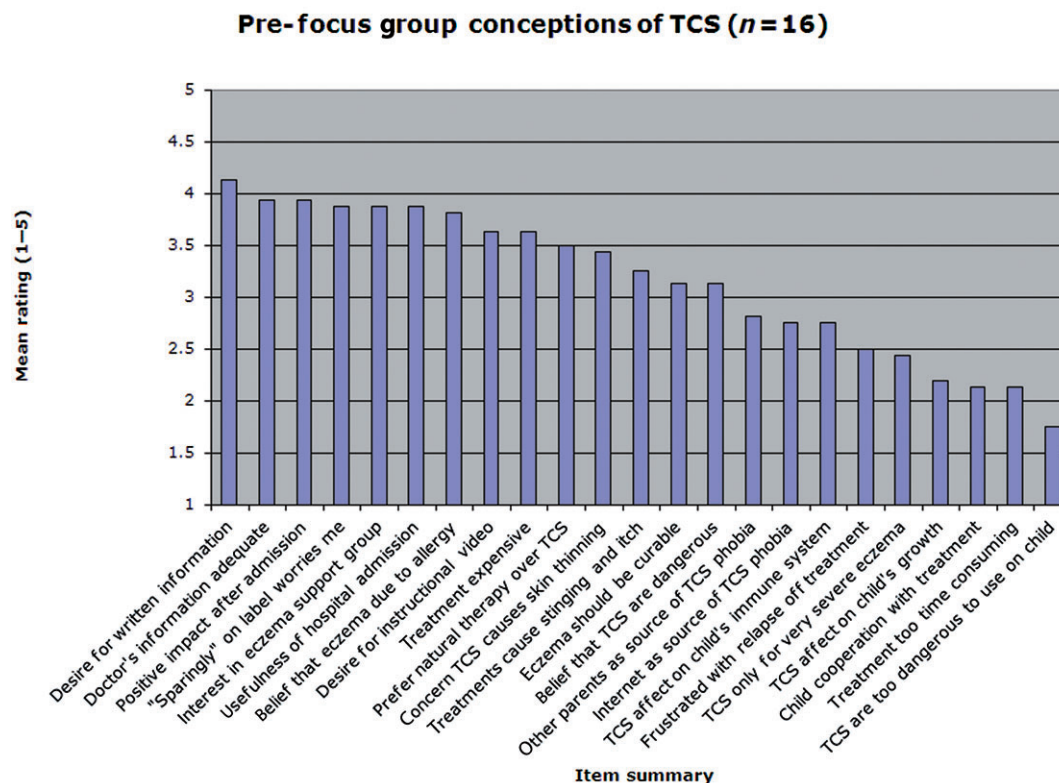


Figure 1 Mean rating of answers to disease specific questions in pre-focus group questionnaire. Items were scored on a visual analog scale where 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree.

Focus group discussion

All statements made by parents were able to be categorized into seven broad themes (emotional impact, negative perceptions towards corticosteroids, sources of anxiety and confusion with treatment, complementary and alternative medicine, problems with accepting control not cure, supportive or positive experiences that changed attitudes and key parent-suggested improvements), which were thus considered to be key issues in atopic dermatitis management. Table 4 outlines these themes and the corresponding subthemes relating to examples of the parents' enunciated experiences.

DISCUSSION

In September 2009, a couple whose daughter died in Sydney, Australia as a result of sepsis secondary to severe, medically untreated atopic dermatitis, was convicted of criminal negligence in the New South Wales Supreme court and sentenced to jail. The father, a homoeopath, had treated the child himself.¹⁶ This unusual case illustrates the extreme end of a phenomenon which is becoming increasingly common behaviour in parents of children with atopic dermatitis: rejection of treatment that is recognized by dermatologists to be safe and effective in favour of complementary medicine^{15,14} and restricted diets that are based on a belief in allergy as the cause of atopic dermatitis.¹⁷

Treatment of atopic dermatitis with topical corticosteroids is accepted as the gold standard, with very few side-effects

if correctly used. The belief that medical treatment for atopic dermatitis with topical corticosteroids is dangerous and that 'natural' therapy is safe and therefore preferable is common among Australian parents. The majority of parents of a child with atopic dermatitis seen in our paediatric dermatology clinic express a fear of the use of topical corticosteroids. The commonest belief is that use of topical corticosteroids will thin the skin irreversibly; however, concerns about immune suppression and growth failure are also expressed by many parents. Much valuable time is wasted arguing the case for topical corticosteroid treatment in an attempt to persuade doubting parents that it is the safest and most effective treatment for their child. Even when children are severely affected by atopic dermatitis, many parents resist advice that involves the use of topical corticosteroids. Fear of medical treatment includes fear of the use of ointment-based moisturizers now characterized by some patients as 'toxic petrochemicals'.

Previous reports document 'corticosteroid phobia' as a major cause of non-compliance and treatment failure in atopic dermatitis.^{10-12,18} In fact, this term may be a misnomer. A phobia is an irrational fear. Parents have many reasons to be rationally frightened of topical corticosteroids because of warnings not only from friends, relatives and the internet, but also from traditionally trusted sources including their general practitioner and pharmacist.

The aim of our study was to explore the complex aetiology of the fear of topical corticosteroid treatment for atopic dermatitis. Our primary aim was to confirm the importance

Table 4 Results of focus group discussion

Analysis of the qualitative data revealed seven key themes:

Theme 1. Emotional impact associated with having a child with significant atopic dermatitis

Parents reported guilt and emotional distress associated with five sub-themes:

1. *Physical appearance*: a sense of discomfort/distress in response to intrusive comments or reactions by strangers to the physical appearance of the child.
2. *Stresses*: dealing with interruption to the child and parents' routine and daily obligations, their child's distress, and the effects of lack of sleep and exhaustion from attending to their child's needs at night.
3. *Strain on parent-child relationship*: interpersonal strain and frustrations associated with conflicts over the need to coerce their child to comply with treatment that causes pain/discomfort.
4. *Parental guilt and sense of helplessness*: feelings of inadequacy and failure in their inability to prevent the eczema, envy of other parents with perceived normal children, feeling judged by others as inadequate parents, and feeling a failure as a parent. One participant remarked that she felt shame in response to her belief that others viewed her child as a victim of child abuse.
5. *Anxiety related to future prospects*: fears and concerns for the child's future due to their condition, particularly social interactions with peers, self esteem and dealing with relationships.

Theme 2. Perception of cortisones: negative

A consistent theme of strong negative perceptions, anxiety and lack of clear information over the potential harmful effects and proper application/use of cortisones emerged:

1. *Concern over long-term negative effects*: parents expressed the belief that repeated cortisone use would result in skin atrophy ('Won't it thin their skin?'), and possible long-term harm from treatment, for example, leading to suppression of the immune system.
2. *Anxiety regarding appropriate use of steroids*: concerns that were generated by warning labels that cautioned users to 'Use sparingly'. This created the impression that cortisone should only be used when eczema is severe and contributed to the under-utilization of the cream.
3. *Belief that cortisone masks but does not treat the underlying cause of the condition*: failure to see the point of using a treatment considered simply a 'band-aid solution'. This belief is reinforced by cautionary comments offered from general practitioner that 'you should only use this strong cortisone for 3 days', pharmacist's cautioning parents to 'Be careful' and 'Do you realize this is cortisone?', and non-health professional third parties suggesting that 'everyone has a friend or relative that had terrible side effects from cortisone'. The implicit message is that cortisone does not cure and has side effects, and therefore parents should limit or avoid prolonged use.

Theme 3. Sources of anxiety and confusion in atopic dermatitis treatment

Qualitative data revealed that parents often had difficulty locating relevant and accurate information about the management of ectopic dermatitis and cortisone use.

1. *Access to accurate information*: participants consistently reported a lack of information from expected sources, particularly their general practitioner. As a consequence, parents felt the need to seek information for themselves from varying unreliable sources such as the Internet, or media discussing allergies and natural products. Participants indicated that they were not able to evaluate the accuracy of information obtained from these sources.
2. *Negative experiences with general practitioner/pharmacist*: participants indicated that they obtained insufficient information from general practitioners, received conflicting opinions from different sources causing confusion, had problems obtaining specialist referrals, and general practitioners tended to trivialize eczema and were unwilling to refer parents to specialists.
3. *Information gleaned from non-medical others*: strongly opinionated statements from teachers, family and friends insinuating that medical treatment is dangerous and unnecessary, and recommending alternative therapies.

Theme 4. Complementary and alternative medicine

Participants expressed several views regarding alternative therapies:

1. *Treatment sequence*: that medication is scientifically tested is not appreciated by participants is indicated by preferences to begin with 'natural' approaches before trying medication. Preferences for 'natural products' appear to be related to their beliefs in lower side effects and better safety profiles, and that moisturizers are 'toxic petrochemicals', a view perpetuated by the media. The promotion of natural therapy in the media and pressure from families and friends effectively influenced most participants to consult naturopaths in pursuit of natural remedies. Participants' apparent lack of knowledge as to what constitutes a 'natural therapy', combined with naturopathic claims of a cure, and the promotion of an allergy as the underlying cause are reinforcing factors. Cost and the realization that complementary 'natural' medicines do not work become deterrent factors in their continued use.

Theme 5. Problems accepting concept of control rather than cure

Participants reported experiencing difficulties accepting the notion that management is based on the concept of controlling the severity of the eczema rather than intervening to cure the condition:

1. *Control versus cure*: even when participants acknowledged that they understood the genetic basis of the condition, they reported that they found it difficult to let go of the notion that they may be able to find a 'cause' that can be eliminated: 'I will never stop searching'. As a consequence, recognizing the need for long-term management was described as a major factor wearing down participants. Participants indicated that there was a need to fully understand the rationale for cortisone before they considered they could accept this as standard treatment

Theme 6. Supportive or positive experiences that produced attitude change

Participants reported a number of significant positive factors that reduced their uncertainties and anxieties, and led to greater understanding and acceptance of cortisone treatment. These included:

1. *Positive experience and outcomes of hospital treatment*:
 - a. Evidence of rapid improvement in their child's condition.
 - b. Demonstration of the liberal application of cortisone and emollient by nurses.
 - c. Demonstration of the use of wet dressings.
 - d. Supportive experience with nursing staff.

These observations and experiences resulted in participants reporting that they benefitted from gaining insights and guidelines into the appropriate use of cortisone, resulting in an increased sense of control. Applying their newly learnt techniques and knowledge resulted in positive results and improved their confidence in using cortisone and their quality of life through improved sleep, concentration, and self-esteem, and the child's improved performance at school.

In addition, participants reported that the involvement of other specialists such as immunologists was seen as a positive step, with trust in their dermatologist a key factor improving compliance.

Theme 7. Key parent-suggested improvements

Participants were asked to express their views on possible changes to current practices and sources of information that they considered would enhance their knowledge and reduce anxieties related to their child's atopic dermatitis and use of cortisone. Emerging themes suggested improvements in doctor-patient communication, sources of information, and importantly, observation of nursing staff applying wet dressings:

1. *Doctor-patient communication*: participants suggested that doctors should be more cognizant of the challenges confronting anxious parents absorbing information during a consultation and stresses linked to:
 - a. Consultation time limits.
 - b. Children's attention spans.
2. *Information source*: participants indicated greater confidence in the quality information from perceived reliable source, such as a university or hospital department, presented through various forms of media: websites, information sheets and information/demonstration DVD.
3. *Access to services*: participants reported that improved and earlier access to paediatric dermatology services would increase their knowledge and reduce their anxieties. In particular, observing a dermatology nurse apply regular wet dressings in clinics was identified as a significant factor alleviating anxieties and improving the management of their child's atopic eczema.

of fear of topical corticosteroids in treatment failure, with the corollary of this being that the only viable alternative left to parents was 'complementary medicine and/or allergen avoidance', the latter often being advocated by natural therapists. We expected that if parents were allowed to discuss their experiences in a group session, this would emerge as a major concern. We also expected that group discussion would generate possible solutions for the problem.

The emotional impact of atopic dermatitis is well reported to be substantial.^{2,5,6,15,19} In addition to this, parents of children with atopic dermatitis do not have access to the level of support and public understanding experienced by parents of children with other chronic conditions such as diabetes.¹⁹ This theme emerged strongly, relating to the appearance of the child, sleep deprivation, social isolation and the stress of administering treatment, as well as conflict between parent and child over treatment. Our results are similar to those documented in a previous focus group study.¹⁵

There is a high degree of guilt experienced by parents, who voiced feelings of failure, inadequacy and sense that they could have somehow prevented the disease. We hypothesize that this is linked to the desire to find an external cause for their child's condition, resulting in a focus on allergy by many parents. It may also explain how relentless some parents can be in the search for such a cause, despite an intellectual appreciation that the disease is genetically determined.

Fear of topical corticosteroids did emerge as a major deterrent to effective treatment. All parents expressed an initial fear of topical corticosteroids before seeking treatment. Concern that topical corticosteroids use would 'thin the skin' was the major concrete fear; however, a vaguer concern about unknown long-term effects was also voiced. The term 'use sparingly' on labels dispensed by pharmacists emerged as a major deterrent to correct use. This has previously been documented in a UK study.²⁰

Sources of fear of topical corticosteroids included not only the Internet and similarly worried friends and relatives, but also general practitioners and pharmacists.

With regard to complementary therapy, parents related that the media and the Internet placed a great emphasis on natural products and focussed on allergy as having a central role in the aetiology of atopic dermatitis. Their preference in treatment order was to commence therapy with something 'natural' and move on to topical corticosteroids only when the atopic dermatitis was 'very severe'. Parents also felt under pressure from family, friends and even school teachers to avoid 'dangerous and unnecessary' medical treatment.

When prompted to discuss their understanding of what a 'natural product' was, parents were unable to give a clear answer. However, their belief was that it was safer and would have fewer side-effects than topical corticosteroids. Parents did not have an understanding of regulatory testing, including safety testing. Thus, despite the excellent therapeutic results available using conventional medicine, parents still sought unproven complementary treatments. The simplistic theories on which these preferences are based are easily understood by lay people, but have been noted in the past to result in the withholding of effective treatment.²¹

Despite the well-documented impact on quality of life, an unexpected finding was that parents related how difficult it had been to convince their general practitioner to refer them to a dermatologist for what was allegedly seen by the general practitioner as a trivial condition, and one for which the dermatologist would offer nothing over and above the general practitioner. This was a great source of frustration.

A theme that emerged which was relevant to beliefs about medical treatment was the parents' inability to accept the concept of 'Control rather than cure' that is central to effective atopic dermatitis management. Recurrence of disease during treatment or when treatment was suspended was a source of disappointment and discouragement relating to a poor acceptance of the need to control a chronic condition. This underpinned rejection of topical corticosteroids, which parents saw as simply masking the underlying condition. Their hope was not for treatment but for cure and this was another reason for the search for an allergen that, if avoided, would resolve the atopic dermatitis. This also explained the preference for naturopathy, which itself focuses on allergy and promises cure.

All of the parents in the group had initially been scared of topical corticosteroids but had been persuaded to use them effectively to control their children's disease. They related that the influences that changed their attitude were the rapid improvement witnessed during inpatient treatment, interaction with nursing staff who confidently showed use of topical corticosteroids, improved quality of life of the child and family once the atopic dermatitis was under control, and gaining an understanding of safety issues from a trusted source. Parents voiced the view that 'knowledge is power' but that knowledge must be from what is perceived to be a reliable source. When asked for examples, they nominated an Australian university or teaching hospital as being most reliable.

An interesting point that emerged was how important it was to the parents to have a trusting relationship with a dermatologist and how early referral to a dermatologist would have saved them a great deal of uncertainty and suffering. This has been reported previously.²²

Parents also saw the involvement of other specialists, particularly allergists, as positive, even when the outcome of investigation was to rule out allergy in their children. This is not surprising when one understands the significance that parents place on allergy and suggests that dermatologists will validate their patients' concerns and thus improve compliance by carrying out allergen testing, even if they expect the outcome to have minimal impact on management.

The key suggestions for dermatologists which emerged from the study are shown in Tables 5 and 6. Dermatologists should understand the sources of parental concern and realize that corticosteroid 'phobia' is in fact a rational fear generated by misinformation, which can be modified by correct information. They should not underestimate the power of the trust that a patient will place in them if they provide adequate support, which involves alleviating guilt, providing facts and encouraging an understanding of the chronic nature of atopic dermatitis. Despite the fact that

Table 5 Suggestions for dermatologists

- Understand, respect and validate parental concerns
- Do not dismiss the desire to investigate allergy
- Alleviate guilt
- Emphasize the positives: outcome, safety, prognosis
- Encourage acceptance of 'no cure'
- Use your hospital
- Re-educate pharmacists
- Realize parental trust in you is a major factor
- Empower parents to withstand negative forces
- Provide written and videotaped information that addresses parents fears
- Encourage general practitioners to refer children with atopic dermatitis

Table 6 Suggested information to increase parental confidence

- Safety data on topical corticosteroids
- Safety data on moisturizers
- Information on relative potencies of prescribed topical corticosteroids
- Demonstration of use of topical corticosteroids
- Understanding of the concept of scientific testing
- True role of allergy in atopic dermatitis
- Explanation of how topical corticosteroids work in atopic dermatitis
- Possible outcomes of failure to treat
- Importance of improving the child's quality of life

allergy is of limited importance in many patients, a willingness to validate parental hopes by investigating is seen as part of this support.

Parents require empowerment to withstand the many negative influences they encounter on a day-to-day basis. When providing facts, ensuring that parents see them as coming from a reliable source and including information on the parent's areas of concern is important. The use of video recordings was also seen as very helpful. Utilization of a hospital stay emerged as a powerful tool and one which dermatologists should not hesitate to use.

Finally, re-education of other healthcare providers, particularly pharmacists and general practitioners, emerged as a potential solution which could help to improve confidence in medical treatment.

CONCLUSIONS

Atopic dermatitis has a substantial effect on the quality of life of the subject child and the entire family. Children and parents suffer needlessly because of inadequate disease control as a result of poor compliance. Fear of treatment, particularly with topical corticosteroids, is a realistic reaction to misinformation, much of which comes from sources which patients trust: their general practitioners and pharmacists. An understanding of parents' difficulties and fears provides a framework from which dermatologists can develop strategies to increase confidence in treatment and improve quality of life.

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Assessing Dermatologist Attitude to and Use of Topical Corticosteroids

I have been a consultant dermatologist for:

- a. 0-5 years
- b. 6-10 years
- c. 11-15 years
- d. 16-20 years
- e. >20 years

1. On an average day in my rooms I write scripts for topical corticosteroids

- a. 1-5 times
- b. 6-10 times
- c. 11-15 times
- d. 15-20 times
- e. >20 times

2. The strongest topical corticosteroid I prescribe is

- a. Weak
- b. Moderate
- c. Potent
- d. Superpotent
- e. I avoid topical corticosteroids in preference for other topical medications

3. The commonest side effect I see from topical steroid use is

- a. Cutaneous atrophy
- b. Striae
- c. Telangiectasia
- d. Bruising
- e. Peri-orificial dermatitis

4. Patients are often concerned about topical corticosteroid use. What do you think is the most common source of this fear?

- a. Pharmacist warnings
- b. GP warnings
- c. Naturopaths or other complementary and alternative medicine provider
- d. The internet
- e. Influence from friends and family

5. When prescribing topical corticosteroids I do the following

Warn that the medication may thin their skin

Yes ☐ No ☐

Instruct them to use the medication sparingly

Yes ☐ No ☐

Give patients a time limit on how long they can use their treatment

Yes ☐ No ☐

Tell patients to use their treatment until their skin has normalised regardless of how long this takes

Yes ☐ No ☐

6. On a scale of 1 (strongly disagree) to 5 (Strongly agree) indicate to what extent you agree with the following statement

If used as directed at an appropriate dose and time for skin site and severity of disease, topical corticosteroids are very unlikely to cause cutaneous atrophy

1	2	3	4	5
Strongly disagree				Strongly agree

7. On a scale of 1 (strongly disagree) to 5 (strongly agree) indicate to what extent you agree with the following statement

The term sparingly should NOT be written on the label of prescribed tubes of topical corticosteroid

1	2	3	4	5
Strongly disagree				Strongly agree

Pharmacists Responder Session Questions

Age:

- A. <30
- B. 30-40
- C. 40-50
- D. 50-60
- E. >60

Years of practice after graduating:

- A. <5
- B. 5-9
- C. 10-14
- D. 15-19
- E. >20

On an average day, how many patients do you dispense topical corticosteroids (prescribed or OTC) to your practice:

- A. <1
- B. 1-5
- C. 6-10
- D. 11-15
- E. >15

My primary source of information about the prescription of topical corticosteroids is:

- A. Pharmacy journals
- B. Clinical dermatology journals
- C. Internet-based sources
- D. Pharmaceutical representatives
- E. Pharmacy meetings

In my undergraduate/postgraduate pharmacy degree I received information on corticosteroids from

- A. A lecturer who was a pharmacist
- B. A lecturer who was a dermatologist
- C. A lecturer who was a non-dermatologist medical practitioner
- D. A pharmacologist
- E. Other source

When I dispense topical corticosteroids I spend time informing the patient/parent about using them:

- A. Rarely
- B. Only when purchased over the counter
- C. Even when prescribed by a General Practitioner
- D. Even when prescribed by a non-dermatologist Specialist (e.g., Paediatrician, Immunologist, etc.)
- E. Even when prescribed by a Dermatologist

When I dispense topical corticosteroids I recommend that it should be applied frequently:

- A. Once a day regardless of formulation
- B. Twice a day regardless of formulation
- C. Once/twice a day depending on formulation
- D. Only as indicated on the prescription supplied

E. I suggest alternative frequency of application

When I dispense topical corticosteroids I recommend that they be used for (Duration)

- A. Maximum of 3 days
- B. Maximum of 1 week
- C. Maximum of 2 weeks
- D. Maximum of 1 month
- E. Until the eczema is clear

When I dispense topical corticosteroids I instruct the patient/parent to apply:

- A. Only the smallest amount possible
- B. Sparingly
- C. As the patient/parent feels appropriate
- D. Generously
- E. Based on fingertip unit guidelines

The most common side effect from the regular use of topical corticosteroids is:

- A. Stinging/itching
- B. Hypo- or hyperpigmentation of the skin (discolour the skin)
- C. Thinning of the skin (Skin atrophy)
- D. Growth retardation
- E. None of the above when used appropriately

Compliance/adherence with the use of topical corticosteroids in the treatment of skin conditions

- A. An insignificant problem as patients with eczema use their medication
- B. Impossible to prevent
- C. A major reason patients with eczema fail to get better
- D. A more significant problem with oral agents
- E. A poor excuse for ineffective drug treatment

When I counsel patients about using topical corticosteroids:

- A. Take them to a separate room
- B. Take them aside so that other patients are out of earshot
- C. Talk to them in front of other patients
- D. Ask them why they are using their treatment
- E. Ask them where they will be applying their treatment

After presentation

In the future, when I dispense topical corticosteroids I will recommend that it is applied frequently:

- A. Once a day regardless of formulation
- B. Twice a day regardless of formulation
- C. Once/twice a day depending on formulation
- D. Only as indicated on the prescription supplied
- E. I suggest alternative frequency of application

In the future, when I dispense topical corticosteroids I will recommend that it is used for (Duration)

- A. Maximum of 3 days
- B. Maximum of 1 week
- C. Maximum of 2 weeks
- D. Maximum of 1 month

E. Until the eczema is clear

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- C. As the patient/parent feels appropriate
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- D. Ask them why they are using their treatment
- E. Ask them where they will be applying their treatment



GP Responder Session Questions (Please circle the appropriate response for each item)

Age:

- A. <29
- B. 30-39
- C. 40-49
- D. 50-59
- E. >60

Years of practice after graduating undergraduate/postgraduate medical degree:

- A. <5
- B. 5-9
- C. 10-14
- D. 15-19
- E. >20

On an average day, to how many patients do you prescribe topical corticosteroids?:

- A. <1
- B. 1-5
- C. 6-10
- D. 11-15
- E. >15

My primary source of information about the prescription of topical corticosteroids is (please circle the main source **ONE ONLY**):

- A. General Practice journals
- B. Clinical dermatology journals
- C. Internet-based sources
- D. Pharmaceutical representatives
- E. Clinical meetings/conferences

In my undergraduate/postgraduate medical degree training I received most of my teaching on topical corticosteroids from (please circle the main **ONE ONLY**):

- A. A lecturer who was a pharmacist
- B. A lecturer who was a dermatologist
- C. A lecturer who was a non-dermatologist specialist medical practitioner
- D. A lecturer who was a general practitioner
- E. Other source

In my general practice training I received most of my primary teaching on topical corticosteroids from (please circle the main **ONE ONLY**):

- A. A lecturer who was a pharmacist
- B. A lecturer who was a dermatologist
- C. A lecturer who was a non-dermatologist specialist medical practitioner
- D. A lecturer who was a general practitioner
- E. Other source

PLEASE TURN OVER



When I prescribe topical corticosteroids the maximum strength I use is (**MAY ANSWER MORE THAN ONE**):

- A. I avoid prescribing topical corticosteroids in preference to other topical options
- B. Weak topical corticosteroid (1% Hydrocortisone or equivalent)
- C. Moderate topical steroid (Betamethasone Valerate 0.02% or equivalent)
- D. Potent topical corticosteroid (Betamethasone dipropionate 0.05% or equivalent)
- E. Based on severity of atopic dermatitis
- F. Based on site of atopic dermatitis

When I prescribe topical corticosteroids for atopic dermatitis I recommend that they be used for (Duration) (please circle the most typical **ONE ONLY**):

- A. Maximum of 3 days
- B. Maximum of 1 week
- C. Maximum of 2 weeks
- D. Maximum of 1 month
- E. Until the eczema is clear

When I prescribe topical corticosteroids I instruct the patient/parent to apply (please circle the most typical **ONE ONLY**):

- A. Only the smallest amount possible
- B. Sparingly
- C. As the patient/parent feels appropriate
- D. Generously
- E. Based on fingertip unit guidelines

The most common side effect from the regular use of topical corticosteroids is (please circle the most common **ONE ONLY**):

- A. Stinging/itching
- B. Hypo- or hyperpigmentation of the skin (discolour the skin)
- C. Thinning of the skin (Skin atrophy)
- D. Growth retardation
- E. None of the above when used appropriately

Non-Compliance/non-adherence with the use of topical corticosteroids in the treatment of atopic dermatitis is (Answer for each question from 1 = **STRONGLY DISAGREE** TO 5 = **STRONGLY AGREE**):

- A. An insignificant problem as patients with eczema use their medication

1 2 3 4 5

- B. Impossible to prevent

1 2 3 4 5

- C. A major reason patients with atopic dermatitis fail to get better

1 2 3 4 5

- D. A more significant problem with oral agents

1 2 3 4 5

- E. A poor excuse for ineffective drug treatment

1 2 3 4 5

Topical Corticosteroid Use and Pharmacy Experiences: Patient Survey

1. Your age: _____ years
2. Your gender (circle one): Male / Female
3. What is the highest level of education you have completed? (circle one):
 - a) Some High School
 - b) Completed Year 12
 - c) Diploma/Certificate via TAFE or other vocational course
 - d) Bachelor Degree (University)
 - e) Master's Degree or Doctorate
4. Approximately how long have you used prescribed topical corticosteroids?:
 _____ years, _____ months
5. Approximately how old were you when you first noticed symptoms of the condition being treated with prescribed topical corticosteroids?:
 _____ years
 - a) Have you had any other experiences with topical corticosteroid cream/ointment use

No ☐

Yes (please check all that apply):

☐ my partner also uses/used topical corticosteroid cream/ointment

☐ my child also uses/used topical corticosteroid cream/ointment

☐ other (please specify): _____
6. Which medical practitioners have prescribed topical corticosteroids to you? (check all that apply):

☐ a general practitioner (GP)

☐ a dermatologist

☐ another type of doctor (please specify): _____
7. Are you aware of the concept of 'fingertip unit' as a guide to the amount of topical corticosteroid cream/ointment to be applied?

Yes ☐

No ☐

➤ If "Yes", I learnt about the concept of 'fingertip unit' from:

☐ a pharmacist

☐ a general practitioner (GP)

☐ a dermatologist

☐ other (please specify): _____

8. Many people find a way of using their medicines that suits them. This may differ from the instructions on the label or from what their doctor had said.

For each statement please tick (✓) one circle that best applies to you.

	Never	Rarely	Some-times	Often	Always
I alter the amount of topical corticosteroids that I use.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I forget to use the topical corticosteroids.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I stop using the topical corticosteroids for a while.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I use less of the topical corticosteroids than instructed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I decide to skip an application of the topical corticosteroids.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[if you answered 'Never' to everything in question 8, you may skip question 9]:

Please turn to the next page

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Topical Corticosteroid Use and Pharmacy Experiences: Patient Survey

9. I use less topical corticosteroid than recommended by my doctor because (check any/all that apply):

- ☐ it is too expensive
- ☐ its application is too difficult and/or time-consuming
- ☐ it is ineffective at relieving my symptoms
- ☐ it is preferable to use natural therapies instead
- ☐ it has harmful side effects
- ☐ it causes stinging and/or itching of my skin
- ☐ it should only be used in very severe disease states
- ☐ words such as 'sparingly' on the label worry me
- ☐ I am worried about using too much topical corticosteroid
- ☐ I am worried about applying it to broken skin
- ☐ I forget to apply the topical corticosteroid
- ☐ other (please specify): _____

10. For each of the following statements, please place a tick (✓) in the circle under the level of agreement that best reflects your current opinion of using topical corticosteroids:

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a	The health of my inflamed skin, at present, depends on using topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b	In the future, the health of my inflamed skin will depend on using topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c	I worry about the immediate effects of topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d	I worry about the long-term effects of topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e	I am confident that I can follow the directions of the doctor in using topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f	Without topical corticosteroids, my inflamed skin would be worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g	Using topical corticosteroids is disruptive to my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h	I worry that topical corticosteroids thin my skin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i	Following the doctor's instructions to use topical corticosteroids is easy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j	Topical corticosteroids keep my inflamed skin condition under control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k	I worry that topical corticosteroids cause changes in my skin colour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l	I worry that topical corticosteroids make my immune system less effective	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m	My life would be more difficult without topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n	I worry that topical corticosteroids cause unwanted hair growth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o	I am capable of following the doctor's instructions to apply topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p	I worry about becoming too dependent on topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
q	Pharmacists instruct me to apply the topical corticosteroid exactly as directed by my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
r	I feel more confident following the advice of a pharmacist than a GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
s	I feel more confident following the advice of a pharmacist than a dermatologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
t	If a pharmacist gave me different advice to a doctor, I would follow the pharmacist's advice in preference to the doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Topical Corticosteroid Use and Pharmacy Experiences: Patient Survey

- 11. The following are some messages that people receive about using topical corticosteroids for inflamed skin.** Please indicate **how often** these messages have been received by you from each of the sources below. Please tick (✓) one circle for each statement from each source.

I have received the following messages		from:	Never	Rarely	Some-times	Often	Always
a	Topical corticosteroids may cause skin thinning	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b	Having my skin condition means that I will need to use topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c	Inflamed skin conditions will improve with the topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d	Try non-prescription creams/ointments before resorting to the use of prescription topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d	Try natural or complementary and alternative therapies before resorting to the use of topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e	Apply topical corticosteroids 'sparingly' or 'thinly'	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f	Topical corticosteroids cannot be used long-term	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g	Using topical corticosteroids is good for inflamed skin	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h	Topical corticosteroids may make my immune system less effective	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i	Topical corticosteroids will control my symptoms, but they will not provide a permanent cure. Because of this, I need to continue using topical corticosteroids whenever necessary.	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please turn to the next page

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12. For each of the following statements, please place a tick (✓) in the circle under the level of agreement that best reflects *your experiences with topical corticosteroids* with both GPs and Pharmacists:

			Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
a	Provide useful advice on how to deal with the practical difficulties of regularly applying topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b	Provide me with a sufficient amount of information about using topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c	Notice when I have not requested/refilled topical corticosteroid prescriptions in a long time, and ask why this is the case	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d	Make me feel reassured about using topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e	Listen to my concerns about using topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f	Treat me with respect when speaking about topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g	Make me feel embarrassed about using topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h	Demonstrate sensitivity towards the physical appearance of my skin	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. Is there anything else that your pharmacist already does to improve your experience and/or strengthen your knowledge of topical corticosteroid treatment?:

14. What could your pharmacist do differently to improve your experience and/or strengthen your knowledge of topical corticosteroid treatment?:

Thank you for participating in this survey!
Please turn this completed survey into reception, or give it to your dermatologist.
You will be provided with a post-survey information sheet.

Admin use only:

1. **Your age:** _____ years
2. **Age of your child:** _____ years, _____ months
3. **Your gender (circle one):** Male / Female
4. **Gender of your child (circle one):** Male / Female
5. **What is the highest level of education you have completed? (circle one):**
 - a) Some High School
 - b) Completed Year 12
 - c) Diploma/Certificate via TAFE or other vocational course
 - d) Bachelor Degree (University)
 - e) Master's Degree or Doctorate
6. **Approximately how long has your child used prescribed topical corticosteroids?:**
 _____ years, _____ months
7. **Approximately how old was your child when you first noticed symptoms of the condition being treated with prescribed topical corticosteroids?:**
 _____ years
- a) **Have you had any other experiences with topical corticosteroid cream/ointment use**
 No ☐
 Yes (please check all that apply):
☐ another child of mine uses/used topical corticosteroid cream/ointment
☐ my partner also uses/used topical corticosteroid cream/ointment
☐ I use/used topical corticosteroid cream/ointment
☐ other (please specify): _____
8. **Which medical practitioners have prescribed topical corticosteroids to your child? (check all that apply):**
☐ a general practitioner (GP)
☐ a dermatologist
☐ another type of doctor (please specify): _____
9. **Are you aware of the concept of 'fingertip unit' as a guide to the amount of topical corticosteroid cream/ointment to be applied?**
 Yes ☐
 No ☐
 ➤ **If "Yes", I learnt about the concept of 'fingertip unit' from:**
☐ a pharmacist
☐ a general practitioner (GP)
☐ a dermatologist
☐ other (please specify): _____
10. **Many people find a way of using their medicines that suits them. This may differ from the instructions on the label or from what their doctor had said.**
 For each statement please tick (✓) one circle that best applies to you and your child.

	Never	Rarely	Some-times	Often	Always
I alter the amount of topical corticosteroids that I use on my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I forget to use the topical corticosteroids on my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I stop using the topical corticosteroids on my child for a while.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I use less of the topical corticosteroids on my child than instructed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I decide to skip an application of the topical corticosteroids on my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[If you answered 'Never' to everything in question 10, you may skip question 11]:

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11. I use less topical corticosteroid than recommended by my child's doctor because (check any/all that apply):

- ☐ it is too expensive
- ☐ its application is too difficult and/or time-consuming
- ☐ it is ineffective at relieving my child's symptoms
- ☐ it is preferable to use natural therapies instead
- ☐ it has harmful side effects
- ☐ it causes stinging and/or itching of my child's skin
- ☐ it should only be used in very severe disease states
- ☐ words such as 'sparingly' on the label worry me
- ☐ I am worried about using too much topical corticosteroid
- ☐ I am worried about applying it to broken skin
- ☐ I forget to apply the topical corticosteroid
- ☐ other (please specify): _____

12. For each of the following statements, please place a tick (✓) in the circle under the level of agreement that best reflects *your current opinion of using topical corticosteroids on your child*:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a The health of my child's inflamed skin, at present, depends on using topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b In the future, the health of my child's inflamed skin will depend on using topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c I worry about the immediate effects of topical corticosteroids on my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d I worry about the long-term effects of topical corticosteroids on my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e I am confident that I can follow the directions of the doctor in using topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f Without topical corticosteroids, my child's inflamed skin would be worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g Using topical corticosteroids on my child is disruptive to my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h I worry that topical corticosteroids thin my child's skin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i Following the doctor's instructions to use topical corticosteroids is easy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j Topical corticosteroids keep my child's inflamed skin condition under control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k I worry that topical corticosteroids cause changes in my child's skin colour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l I worry that topical corticosteroids make my child's immune system less effective	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m My life would be more difficult without topical corticosteroids for my child's skin condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n I worry that topical corticosteroids cause unwanted hair growth on my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o I am capable of following the doctor's instructions to apply topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p I worry about my child becoming too dependent on topical corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
q I worry that topical corticosteroids may reduce my child's growth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
r Pharmacists instruct me to apply the topical corticosteroid exactly as directed by my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
s I feel more confident following the advice of a pharmacist than a GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
t I feel more confident following the advice of a pharmacist than a dermatologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
u If a pharmacist gave me different advice to a doctor, I would follow the pharmacist's advice in preference to the doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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13. The following are some messages that people receive about using topical corticosteroids for their child's inflamed skin. Please indicate **how often** these messages have been received by you from each of the sources below. Please tick (✓) one circle for each statement from each source.

	I have received the following messages	from:	Never	Rarely	Sometimes	Often	Always
a	Topical corticosteroids may cause skin thinning	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b	My child's skin condition means that he/she will need to use topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c	Inflamed skin conditions will improve with the topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d	Try non-prescription creams/ointments before resorting to the use of prescription topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d	Try natural or complementary and alternative therapies before resorting to the use of topical corticosteroids	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e	Apply topical corticosteroids 'sparingly' or 'thinly'	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f	Topical corticosteroids cannot be used long-term	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g	Using topical corticosteroids is good for inflamed skin	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h	Topical corticosteroids may make my child's immune system less effective	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i	Topical corticosteroids will control my child's symptoms, but they will not provide a permanent cure. Because of this, my child needs to continue using topical corticosteroids whenever necessary.	GPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Pharmacists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- 14. For each of the following statements, please place a tick (✓) in the circle under the level of agreement that best reflects *your experiences with topical corticosteroids* with both GPs and Pharmacists:**

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
a	Provide useful advice on how to deal with the practical difficulties of regularly applying topical corticosteroids	○	○	○	○	○	○
		○	○	○	○	○	○
b	Provide me with a sufficient amount of information about using topical corticosteroids	○	○	○	○	○	○
		○	○	○	○	○	○
c	Notice when I have not requested/refilled topical corticosteroid prescriptions in a long time, and ask why this is the case	○	○	○	○	○	○
		○	○	○	○	○	○
d	Make me feel reassured about using topical corticosteroids on my child	○	○	○	○	○	○
		○	○	○	○	○	○
e	Listen to my concerns about using topical corticosteroids on my child	○	○	○	○	○	○
		○	○	○	○	○	○
f	Treat me (and my child) with respect when speaking about topical corticosteroids	○	○	○	○	○	○
		○	○	○	○	○	○
g	Make me (and/or my child) feel embarrassed about using topical corticosteroids	○	○	○	○	○	○
		○	○	○	○	○	○
h	Demonstrate sensitivity towards the physical appearance of my child's skin	○	○	○	○	○	○
		○	○	○	○	○	○

- 15. Is there anything else that your pharmacist already does to improve your experience and/or strengthen your knowledge of topical corticosteroid treatment?:**

- 16. What could your pharmacist do differently to improve your experience and/or strengthen your knowledge of topical corticosteroid treatment?:**

Thank you for participating in this survey!

Please turn this completed survey into reception, or give it to your dermatologist.

You will be provided with a post-survey information sheet.

Admin use only:

Study: A comparison between parental perception of disease severity and clinician assessed disease severity in childhood atopic dermatitis

**Department of Dermatology
Royal North Shore Hospital**

Demographic QUESTIONNAIRE

Parent's initials: _____

Suburb/Town: _____ Postcode: _____

Your Age bracket (circle): 18-24 25-29 30-39 40-49 50-59 60+

Your child's initials: _____

Age of your child: _____

Number of other children in household: _____

Your household's ethnic/cultural heritage: _____

Occupation: _____

Your highest education level obtained: HSC
 Diploma
 Grad Dip
 Bachelor
 Masters/PhD
 Other: _____

Your approximate household income: \$0-50,000
 \$50,000-100,000
 \$100,000-150,000
 \$150,000+
 Decline to answer

Estimated cost for managing your child's eczema in last month: \$0-25
 \$25-50
 \$50-75
 \$75-100
 \$100+

With respect to your child's eczema, Prior to today's appointment:

- a) Number of different General Practitioners visited: 0
 1
 2
 3+

- b) Have you seen a dermatologist before: Yes/No
- c) Have you seen another specialist before: Yes/No
 - i) If yes which of the following: Paediatrician
Immunologist
- d) Have you seen a provider of alternative and complementary medicine:
 - i) If yes, which of the following: Herbalist/Chinese Medicine
Naturopath
Homeopathy
Iridologist
Chiropractor
- e) Do you see your child's atopic dermatitis as (circle one):
 - Mild
 - Moderate
 - Severe

Thank you for this preliminary information. If you have any questions or concerns please contact Dr Andrew Lee through the hospital switch board on (02) 9926 7111.