Title: Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate chronic condition self-management in children? A systematic review

(1) Authors:
Nicole Saxby¹,², Sean Beggs², Nadish Kariyawasam³, Malcolm Battersby¹, Sharon Lawn¹

(2) Address of the department or institution to which the work should be attributed
¹ College of Medicine and Public Health, Flinders University
Adelaide, South Australia
² Tasmanian Cystic Fibrosis Service, Tasmanian Health Service
Hobart, Tasmania
³ eHealth Services Research Group, University of Tasmania
Hobart, Tasmania

(3) Full postal address of each author

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(4) Name, telephone, email address and fax number of the author responsible for correspondence

Nicole Saxby
mica009@flinders.edu.au
Telephone: 0410341646
Fax: 08 7221 8200

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Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate chronic condition self-management in children? A systematic review

Abstract

Objectives
To determine whether evidence-based practice guidelines promote developmentally appropriate chronic condition self-management (CCSM) for children with asthma, type 1 diabetes mellitus (T1DM), and cystic fibrosis (CF).

Methods
Systematic review of clinical guidelines current as at 22nd September 2017, including assessment of quality of each guideline using the iCAHE ‘Guideline Quality Checklist’, and mapping of the supporting evidence.

Results
Fifteen guidelines were identified: asthma (n=6) and T1DM (n=8), CF (n=1). Guideline quality was variable, and eleven different grading systems were used. In total, there were 29 recommendations promoting age/developmental considerations. Recommendations focused on: collaboration (n=15), CCSM education (n= 17), clinicians’ skills (n= 4); personalized action plans (n=3), problem-solving (n=2); and the assessment of children’s CCSM needs (n=3). Developmental transitions are highlighted as important time points in some guidelines: preschool (n=2), and adolescence (n=2). All guidelines encouraged triadic partnerships between children, adult caregivers and clinicians. Evidence supporting the developmental aspects of the guidelines’ recommendations was poor; only 14 out of 57 journals listed as evidence were concordant.

Discussion
Current guidelines articulate that developmentally appropriate CCSM is important; however, more work needs to be done to translate the concept into practical clinical tools.
Introduction

More than one in 10 Australian children lives with a chronic medical condition. To maximise health and allow participation in ‘normal’ childhood activities, children with chronic conditions and their families need to complete daily treatments and monitoring activities, referred to as chronic condition self-management (CCSM). Unfortunately, many children (particularly adolescents) do not effectively engage in CCSM. Poor CCSM is linked to worse health outcomes, decreased quality of life, increased interactions with the acute health system and amplified financial burden.

As children grow, they become more confident and autonomous in managing their own affairs, relating to other people, and being involved in decisions impacting on them. For children with chronic conditions, this process also includes learning how to look after their own healthcare needs and the establishment of lifelong views towards healthcare. Children’s developmental stage will affect their capacity to understand, cope with and manage their chronic condition, and the type of health education strategies that are likely to be most effective. It is important to recognise that developmental stage is not necessarily defined by children’s age. Children with chronic conditions can, and do, develop self-management skills at varying rates and intervals.

Self-management support is what clinicians, families and health care systems do to assist children develop the skills, knowledge, and behaviours they need to manage their chronic conditions. Children with chronic conditions are likely to interact with clinicians regularly, learning the skills they need to manage their health over a long period. This frequent contact offers clinicians opportunities to provide CCSM support in a ways that help children to build the complexity of their skills on top of skills they have previously acquired. The term ‘clinician’ encompasses a variety of disciplines including medicine, nursing and allied health. In paediatric settings, clinicians work together as an interdisciplinary team towards common CCSM goals with children and their families.

Developmentally appropriate CCSM is a re-emerging concept. The term ‘self-management’ was originally proposed in the mid-1960s by Creer and his colleagues to describe children being active participants in their own asthma care. This early work by Creer’s team was based on the developmental theory of Bandura. Over time, however, CCSM research has shifted away from children and increasingly focused on adults. Thus, the majority of the literature in this area is adult-based.
In the first framework to support paediatric CCSM, Modi et al. (p.e474) concluded, “developmental transitions [....] are critical windows of opportunities to instigate family and health care system-based interventions to sustain adaptive self-management”. As described in this framework, childhood development has a dynamic, heterogeneous nature. It changes over time with age and is influenced by a child’s experiences. Young children cannot be expected to assume full responsibility for their conditions management. However, over time, they can be encouraged to become cooperative self-managers, together with their adult caregivers and clinicians. The manner in which clinicians are implementing CCSM in a developmentally appropriate way is currently unknown.

Three chronic conditions of childhood particularly relevant to Australian and international practice are asthma, type 1 diabetes mellitus (T1DM) and cystic fibrosis (CF). Asthma is the most common chronic condition affecting Australian children (affects one in 10 children), and is among the most frequent reasons for emergency department presentations. While the numbers of children with T1DM are smaller (affects one in 100 children), incidence is on the rise amongst Australian children. CF is the most common life-threatening recessive inherited condition that affects Caucasians. Asthma, T1DM and CF were selected due to their differing natures (i.e. etiologies, symptoms and prognosis) and differing complexities of treatment regimens. There are also similarities between these conditions, including the need for daily management and monitoring. Studying these conditions allows identification of commonalities, and differences, in guidelines recommending CCSM support for children.

Self-management support is an important guideline component in the care of chronic conditions. In Australia, the National Health and Medical Research Council (NHMRC) recommends the use of clinical practice guidelines to improve quality of care through the application of consistent evidence-based practice. The aim of this systematic review was to examine if evidenced-based guidelines promote developmentally appropriate self-management support for children diagnosed with asthma, T1DM and CF.
Methods

Data sources
A comprehensive literature search, supported by a medical librarian, was conducted. Seven international guideline databases were searched: National Guideline Clearinghouse (United States of America (USA)), Canadian Medical Association Infobase (Canada), National Health Service Evidence and The National Institute for Health and Care Excellence (NICE) (United Kingdom), Scottish intercollegiate Guidelines Network (SIGN) (Scotland), New Zealand Guidelines Group, and the NHMRC.

To ensure that no guidelines of international significance to CCSM were missed, 15 clinicians from across Australasia (n=6), Europe (n=3) and North America including Canada (n=6), each with more than five years’ experience in the care of children with asthma, T1DM and CF, were consulted. Furthermore, the websites of 32 professional asthma, T1DM and CF organisations were searched for current guidelines (e.g. American Academy of Allergy Asthma and Immunology, International Society for Pediatric and Adolescent Diabetes, Cystic Fibrosis Foundation, European Cystic Fibrosis Society).

Eligibility

Inclusion criteria
Guidelines were included if they were current as of the 22 September 2017 and if they were created by a professional organisation to assist a single discipline or an interdisciplinary team in managing asthma, T1DM, or CF. To meet inclusion criteria, guidelines also needed to have a section dedicated to CCSM and within that section contain the words “development*” or “age” or “age-appropriate” or “throughout life*”.

Exclusion criteria
Guidelines were excluded if they focused on other childhood chronic conditions or were hospital based guidelines.

Data extraction
A two-staged screening process was completed by the first author (NS) to confirm that guidelines met inclusion criteria – In stage 1 guidelines were screened for relevance through title and abstracts (i.e. they covered children and may include CCSM), and duplicates were removed. Stage 2 excluded guidelines that did not promote developmentally appropriate
CCSM and guidelines that were rescinded. Reasons that guidelines were excluded were recorded on an Excel database.

For guidelines meeting inclusion criteria, the following data was extracted by the first author (NS) and confirmed by a second person (NK): general guideline characteristics, methodological development process, clinicians/patient groups targeted, settings and circumstances in which to use developmental CCSM, and practice recommendations for age/developmental CCSM inclusive of evidence hierarchy ranking. Recommendations were then classified into six research defined groups reflecting the components of effective CCSM.

- Collaboration *(i.e. promotion of an active a health care triad i.e. children, families and clinicians working together)*;
- Education *(i.e. the provision of information, and the teaching of skills and techniques to children in a developmentally appropriate way to improve CCSM)*;
- Clinicians’ CCSM support skills *(i.e. clinicians who are adequately trained and who will support children’s ability to learn CCSM skills at differing ages and developmental stages)*;
- Personalised action plans *(i.e. the provision of a written instructions to help children and their adult caregivers manage the chronic condition and respond proactively to changes in signs and symptoms)*;
- Problem-solving and decision-making *(i.e. the developmentally appropriate teaching of strategies for problem resolution, and the ability to select an appropriate education strategy)*; and
- Assessment and monitoring of CCSM needs *(i.e. measuring the CCSM capacity of children over time)*

The above groupings were based broadly on CCSM components outlined in Model et al.³ It is worth noting that there may be some overlap between groupings (e.g. collaboration would be required for effective education and also for problem-solving and decision making).

**Data synthesis**

Descriptive analysis was undertaken by NS to present each guideline’s general characteristics, including the grading system used to assess evidence quality and strength of recommendations. Full-text journal articles listed as evidence for recommendations were then assessed for concordance with developmentally-based CCSM considerations.
Two independent assessors (NS and NK) appraised guideline quality using the International Centre for Allied Health (iCAHE) ‘Guideline Quality Checklist’, which measures quality across six domains: availability (i.e. available in full text, complete reference list, summary of recommendations provided); dates (i.e. date of completion and planned review stated); underlying evidence (i.e. strategy to assess evidence and quality stated); guideline developers (i.e. developers qualified to develop the guideline); guideline purpose and users (i.e. purpose and uses clearly articulated); and ease of use (i.e. readable and easy to navigate). This checklist is validated for construct validity, inter-tester reliability and clinical utility against the research-focused AGREE-II instrument. The research team chose to use the iCAHE Checklist because it is time-efficient to administer and Australian-based. Quality rankings were expressed as average % total iCAHE scores with standard deviations to represent agreement between the two appraisers (total agreement SD=0, moderate agreement SD<15, poor agreement SD>15).

This review was an analysis of published work. Thus, it did not require ethical approval.
Results

Seven guideline databases yielded 1636 results. Review of professional organizational websites identified 79 potential guidelines, and international clinicians an additional 13 guidelines. After removing duplicates and screening (stage 1), 46 guidelines met the inclusion criteria and full texts were obtained. Further screening (stage 2) resulted in the inclusion of 15 guidelines (see Figure 1).

General Guideline Characteristics

In relation to country of origin, guidelines originated from the USA (n=5), Canada (n=4), United Kingdom (n=3), Australia (n=2), and Belgium (n=1). They included guidelines for T1DM (n=8), asthma (n=6), and CF (n=1) (see Table 1 for summary characteristics of included guidelines).
PRISMA 2009 Flow Diagram

Identification

Records identified through database searching (n= 1636)

Additional records identified through websites of professional organisations (n=79) and clinicians (n=13)

Records after duplicates removed (n=1632)

Screening

Records screened (n=1632)

Records excluded (n=1568)

Eligibility

Full-text articles assessed for eligibility (n=46)

Studies included in qualitative synthesis (n= 15)

Studies included in quantitative synthesis (meta-analysis) (n=0)

Included

Full-text articles excluded (n=31)

- No dedicated section to CCSM
- No developmental considerations
- Rescinded guidelines

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Guidelines by quality

The best quality guidelines overall were the Australian ‘National Asthma Handbook’\textsuperscript{18}, the ‘British Guideline on the Management of Asthma’\textsuperscript{23}, the Australian ‘National evidence-based guidelines for type 1 diabetes in children, adolescents and adults’\textsuperscript{28}, and the Scottish ‘Management of diabetes: a national clinical guideline’.\textsuperscript{32} These four guidelines ranked first in each of the iCAHE domains. See table 1 for all rankings.

Two guidelines did not grade the strength of the evidence and/or recommendations.\textsuperscript{24, 30} The other 13 guidelines used 12 different systems to do so: n=2 NHMRC\textsuperscript{20}, n=1 Global Initiative for Asthma\textsuperscript{35}, n=1 SIGN and NICE\textsuperscript{36}, n=1 Oxford\textsuperscript{37}, n=1 Department of Veteran Affairs and Department of Defence \textsuperscript{38}, n=1 Registered Nurses Association of Ontario (RNAO)\textsuperscript{9}, n=1 Canadian Diabetes Association\textsuperscript{27}, n=1 American Diabetes Association\textsuperscript{39}, n=1 National Collaborating Centre for Women’s and Children’s Health (UK) \textsuperscript{34}, n=1 Cystic Fibrosis Foundation\textsuperscript{19}, and n=1 the American Association of Clinical Endocrinologists.\textsuperscript{33} Grading of the strength of recommendations, depending on scale used, was heterogeneous. Levels given to similar recommendations ranged from the highest level of evidence available down to consensus opinion.

Guideline Recommendations

Together, the 15 guidelines provide 29 specific developmentally based recommendations for CCSM. One guidelines mentioned these considerations in the narrative text only \textsuperscript{35}. Some guidelines included multiple recommendations in the same grouping (e.g. two or three different recommendations for CCSM education). Practice recommendations centered on developmentally appropriate:

- **Collaboration** (n=15 recommendations)\textsuperscript{9, 18, 19, 23, 25-31, 33, 34}
  - All guidelines stated that CCSM support was the responsibility of the entire interdisciplinary team, with triadic collaboration between children, their adult caregivers and clinicians being routinely encouraged.
- **CCSM Education** (n=17 recommendations)\textsuperscript{9, 18, 19, 23, 25-31, 33, 34}
- **Clinicians’ CCSM support skills** (n= 4 recommendations)\textsuperscript{18, 24, 26, 28, 29}
- **Personalised action plans** (n=3 recommendations)\textsuperscript{18, 23, 24}
- **Problem-solving and decision-making** (n=2 recommendations)\textsuperscript{9, 32}
- **Assessment and monitoring of CCSM needs** (n=3 recommendations) (i.e., CCSM capacity assessment of the child n=1, and of the child-family dyad n =2)\textsuperscript{9, 26, 28}
Developmental transitions were highlighted as important time points in some guidelines (n=4/14); n=2 preschool, and n=3 adolescence.

Further analysis showed that developmentally appropriate CCSM recommendations lack a clear evidence base. Fifty-seven studies were provided as evidence for the 28 developmentally based CCSM recommendations and in-text comments. Only 14 (24.6%) of these studies, written in English, were found to be direct evidence for developmental considerations. Evidence was stronger for education (n= 6 concordant studies) and less so for all other areas for which each had less than two supporting studies (i.e. collaboration, clinicians CCSM support skills, action plans, and problem solving and decision making). In all guidelines, developmental considerations were only one part of multi-component recommendations.

Support tools available for clinicians
Two guidelines provided clinicians with practical tools to increase children’s participation in their healthcare. The RNAO asthma guideline included two tools: a summary of developmental theories and issues concerning health and illness; and, a practical guide of what are developmentally appropriate asthma CCSM behaviours, based on Piagetian concepts of cognitive development and Erikson’s theory of psychosocial development. A developmental psychologist was involved in the creation of the RNAO tools. The Medical Services Commission of British Columbia asthma guideline provided asthma action plans in two age groupings – i.e. less than six years old, and six to 18 years old.

Conversely, none of the three guidelines that recommended clinicians assessed CCSM and developmental capacity of the child and/or child-parent dyad provided any measures to do so.

Discussion
The most prominent finding of this review was that guidelines promoting developmentally appropriate CCSM lack a clearly articulated evidence base. Only 14 (24.6%) out of the 57 studies listed as evidence were concordant with the recommendations made, with the strongest evidence provided by guideline authors being for CCSM education.

Overall, 15 guidelines of various quality recommended that CCSM support be provided in a developmentally appropriate way. This finding was applicable and generalisable across a wide variety of conditions – asthma, T1DM and CF. The 29 clinical care recommendations within
these guidelines centered on developmentally appropriate: collaboration, CCSM education; clinicians’ CCSM support skills; personalised action plans; problem-solving and decision-making; and assessment of children’s and/or families’ knowledge about the condition and its treatment. Nonetheless, all 29 of these guideline recommendations were too vague to be of any practical relevance to clinicians.

Collaboration
The 15 included guidelines promoted the use of triadic partnerships without providing any supportive evidence. Children over the age of five years should be presumed competent to be involved in their own healthcare, in partnership with their adult caregivers and clinicians.45 Unfortunately, according to a good quality systematic review completed in 2007, children tend to have little meaningful healthcare involvement.45 Children are least likely to be active participants in the treatment planning and discussion parts of consultations when CCSM is often raised.45

For clinicians, three-way consultations are more complex than didactic consultations due to the need to contextualise health information in a way that both children and adults can understand, and the need to listen to children and adults equally and to consider any differences of opinions before planning ongoing healthcare.46, 47 Ways that clinicians can involve children more in consultations are to ensure that all adults in the room are supportive of their participation, and to engage children within the first half of a consultation.45

Education
All but one of the included guidelines (n=14/15) promoted the delivery of developmentally appropriate CCSM education to transfer knowledge, skills, and abilities necessary for children to look after their own healthcare needs. In these guidelines, six studies were quoted as evidence for providing developmentally appropriately CCSM education.10, 40-44 A further literature search by our research group (submitted for publication elsewhere)48, however, revealed that there are several additional randomised controlled trials in children with asthma, T1DM and CF (with statistically significant results) which were not referenced by the guideline authors.11, 49-60 Common themes for delivering developmentally appropriate education to children are:

- Age-appropriate stages of developmental psychology must be followed, with children being directly involved in CCSM from infancy through to adulthood
• Educational programs should be tailored specifically for infants, school-aged children, younger adolescents, older adolescents and adult caregivers
• CCSM should be facilitated in conjunction with self-efficacy
• Structured written curriculum is beneficial, with modular components building on CCSM skills that have been previously learnt by children
• Curriculum topics should include – knowledge of condition, impact of condition, symptom monitoring, responding to symptoms, actively participating in their own clinical care, being able to use a written action plan, lifestyle, and accessing support services
• Problem-solving and decision-making should be emphasised and
• Using play, role playing and arts based activities may facilitate the learning of infants and school aged children

These themes are consistent with proven adult self-management education programs.17

Clinicians’ CCSM support skills
The need for clinicians to have appropriate skills to support children to develop CCSM skills was articulated in four guidelines. Nonetheless, what these clinical skills would look like was not clearly articulated. Published in 2009, Flinders University CCSM capabilities resource outlines the skills that the healthcare workforce needs to deliver effective CCSM support across the lifespan.14, 61 Paediatric clinicians keen to improve their CCSM support skills should consider completing professional development in areas such as: communication, assessment of self-management capacity (understanding strengths and barriers), collaborative care planning, use of peer supports, psychosocial assessment and support, understanding of models of health behaviour change, motivational interviewing, and how to work better in an interdisciplinary environment.14

Tools, such as the developmentally based CCSM skill guide seen in RNAO 20089, may help with translation to practice.

Action plans
Three guidelines recommended that children and their families be provided with written instructions to manage the chronic condition/s in everyday life.18, 23, 24 Written instructions for CCSM in the home environment are commonly referred to as “action plans”, and their purpose is to help guide prevention, management of symptoms and when to seek medical
help. Only one out of three guidelines promoting action plans provided versions targeted at children of different ages – i.e. an asthma action plan for children aged <6 years, and a separate action plan for children aged 6 to 18 years. As mentioned in the Australian Asthma Handbook, the reason behind a lack of developmentally appropriate action plans for children may be related to there being no established guidance regarding the ideal format and the critical instructions that need to be included. However, research has shown that individuals with low health literacy can comprehend pictorial action plans.

**Problem-solving and decision-making**

Two guidelines recognised the importance of children being taught developmentally appropriate strategies for problem resolution. Structured problem-solving for children with chronic conditions appears to be a significant gap in the current literature base. Further research in this area is required before useful guideline recommendations can be made.

**Assessment and monitoring of CCSM needs**

Whilst three guidelines recommended that clinicians measure the CCSM capacity of children over time, neither of these guidelines cross-referenced any appropriate tools to do so. To date no systematic reviews have been completed looking at the validity of tools to assess children’s CCSM skills and thus this remains a gap in the knowledge base. Clinicians would benefit from having a clear go to research that articulates appropriate CCSM capacity tools for children.

**Translating guideline recommendations into practice**

Mere presence of high quality evidence in clinical guidelines does not necessarily result in translation to practice. As was highlighted in this review, despite most guidelines having been developed systematically, their recommendations supporting “developmentally appropriate CCSM” are vague and do not provide clinicians with practical advice.

An example of a difficult to implement recommendation is to “Assess patient and/or family for educational needs as well as for preferences and/or barriers to learning”. This recommendation requires clinicians to consider literacy, physical, developmental, emotional or psychological challenges as well as specific cultural and/or spiritual beliefs. Despite a level-A evidence ranking being assigned to this recommendation (i.e., there is strong evidence for this recommendation and clinicians should be applying this intervention to all eligible patients), none of the references included in this review support the assessment of a child’s
developmental stage. Clinicians may have difficulty interpreting the unclear evidence base of recommendations such as this.

A co- incidental finding, resulting from different methodologies used by the guideline development groups, was that multiple systems for grading evidence and recommendations were included in the guidelines. For clinicians, this creates unnecessary confusion. One guideline development group reported having previously trialed (twice) the international GRADE system in 2009; however, they ultimately decided to not adopt this methodology because of the major resource challenges it would present.25

Evidence-based recommendations need to be presented in a way that is both assessable and relevant, and integrated into strategies that are feasible for clinicians to use in their busy clinical practice.

**Strengths and limitations**

The strengths of our review include: a comprehensive guideline search which was supported by a medical librarian and conducted by an individual who has authored international guidelines; inclusion of only guidelines that were current and from six different countries; and the systematic summary of recommendations that promote developmentally based CCSM support. Moreover, each guideline was assessed for quality by two appraises; this approach meets the minimum standards for a systematic review.20

This review has limitations. Firstly, only guidelines written in English were included. Secondly, the exclusion of guidelines published as grey literature may have introduced biases. We excluded grey literature as a systematic and rigorous process to local guideline development processes could not routinely be ascertained. The risk of not including grey literature was mitigated through a search of professional association websites and by asking clinicians which guidelines they used to guide CCSM support. Thirdly, four older guidelines (i.e., still current but more than five years old) were included despite recommendations for guidelines to be updated every three to five years.20

**Conclusion**

Current guidelines articulate that developmentally appropriate CCSM is important; however, more work needs to be done to translate clinicians’ CCSM support for children into practice.
It will take the presence of a strong interdisciplinary clinical community to build nourishing environments within which families can successfully raise children with chronic conditions, and within which children can be equipped with developmentally appropriate CCSM skills.
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