Youths with asthma and their experiences of self-management education: a systematic review protocol of qualitative evidence

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Review question

What are the experiences of youths with asthma regarding self-management education?

Keywords

Adolescents; asthma; educational interactions; self-management; youths

Introduction

Asthma is a chronic respiratory condition that is characterized by episodes of physiological airway narrowing resulting in symptoms of wheeze, breathlessness and mucus production.[1] The trajectory of symptoms varies from mild, moderate to severe episodes that can be fatal. The effects of this chronic disease are known to impact on patients both physically, in restriction of activities, and psychosocially, in terms of quality of life.[2] According to the World Health Organization (WHO), 235 million people suffer from asthma, with 383,000 deaths occurring in 2015.[3] Globally, the focus is on minimizing the morbidity and mortality of asthma, recognizing the importance of providing asthma education to promote self-management that may empower people with a diagnosis of asthma.[4] Youths are identified as an at risk cohort with specific education needs, as this group has a higher risk of life-threatening events.[5]

Self-management of a chronic illness, such as asthma, entails education about the condition, symptom recognition and management including pharmacological interventions to negate the incidence of asthma exacerbations.[6] However, to effectively engage in self-management of a condition such as asthma, personal commitment and an awareness of the consequence of poor adherence is required.[6] Self-management education supports patients with chronic conditions to live their lives to the full.[7] Achieving cognitive maturity entails psychological development, where awareness and understanding to the cause and effect of actions is essential.[8] This is essential for youths to achieve self-management and successful disease associated outcomes.[5] The World Health Organization[9] uses the age parameters of ten to 24 years to define adolescents, and the United Nations (UN) defines 'youth' as those persons between the ages of 15 and 24 years.[10] This is the age that cognitive maturity should have been attained.

The overarching theme emerging from the literature regarding self-management and youths indicates issues around developmental maturity, risk taking and the young person's desire to be perceived as 'normal'.[11] Internationally, the management of young adults with asthma is a contentious issue.[9] Adolescence and young adulthood is a period of significant transition in cognition and psychosocial development. This transition period occurs for youth on the cusp of 'spectatorship' in their disease management, where parents are often concerned about handing over responsibility of self-management where health professionals are encouraging empowerment.[12]

Decision-making skills in respect of disease management are tested and influenced through self-regulation and experiences about asthma management plans[5] A Cochrane review identified a range of

decision-making tools for people with asthma, indicating that self-management is linked to improved clinical outcomes and quality of life, educating and empowering patients to become actively involved in their own health management.[13] Studies, although limited in adolescents and young adults, have examined barriers to self-management of asthma[14.] These include restriction in participating in sporting activities because of the diagnosis of asthma[14] and concerns about the effectiveness and long-term effects of medication, particularly in respect of inhaled corticosteroids.[14, 15] Self-management education could help a young person to address these barriers. In addition, mental well-being and the stresses of living with a chronic disease is reported as a concern for adolescents and young adults, particularly those who had life-threatening hospital admissions in respect of uncontrolled asthma.[14,15]

The perceived barriers to youth self-management of chronic health conditions is also influenced by education.[16] The development of asthma education varies internationally in terms of structure, designated responsibility of educational delivery and follow-up on their effectiveness. A Cochrane meta-analyses reviewed the effectiveness of asthma educational interventions in children, including adolescents up to eighteen years of age, with a diagnosis of asthma, and reported positive benefits, including decreased hospitalisations, returns to the emergency department and improved self-efficacy.[17] However, there is a lack of qualitative evidence specifically identifying youths' experiences of self-management and asthma education. In addition, critiques of self-management programs identify the adoption of adult models of education with chronic illness, as primarily healthcare practitioner driven rather than programs that address the expressed needs of adolescents and young people.[16] Successful self-management education interventions, in one longitudinal study of young adults with Type 1 diabetes, focused on an individualized holistic approach to disease self-management, demonstrating positive long-term health outcomes for study participants.[18] Moreover, documented asthma diaries of the physical, psychological and social impacts of the disease, indicate that an individualized approach, supports health professionals in constructing appropriate self-management educational interventions collaboratively with adolescents and young adults.[19] Other studies, including random control trials and qualitative studies, focus on the role of peers in providing guidance on self-management.[2,15,16] These indicate that young people's input into the development of self-care interventions is important and that peer-led asthma educational intervention lends empathy about asthma experiences and those challenges faced in adapting to living with the condition[16].

Therefore, in this systematic review, we aim to identify, appraise and synthesize the available evidence related to youths with asthma and their experiences of self-management education. This review will further consider the role of healthcare providers in developing asthma educational interventions, informed by the synthesis of evidence from the youths' viewpoint. This will provide insights which can be utilised by health care practitioners in the development of self-management education for this cohort. Consistent with Joanna Briggs methodology, this systematic review will highlight implications for practice and policy informed by the quality of the included studies and the contexts in which the studies have been conducted. In order to address the research objectives, we propose conducting a systematic review of evidence generated by qualitative research. A search of the Joanna Briggs Institute Database of Systematic Reviews and Implementations Reports, the Cochrane

Library, CINAHL and PubMed databases did not find any current or planned systematic reviews on this topic.

Inclusion criteria

Participants

The review will include studies involving youth with a diagnosis of asthma in primary care, hospital and community settings. For this review, we are adopting the UN definition of 'youth' as those persons between the ages of 15 and 24 years, without prejudice to other definitions by Member States. All UN statistics on youth are based on this definition.[8] If studies have an unclear age range or include those outside our age criteria, we will include the study if the mean age is between 15 and 24 years.[2]

Studies, where is it clear that participants are children under the age of 15 years, will be excluded.

Phenomena of interest

The phenomena of interest is youths with asthma and their experiences of self-management education.

Context

Primary care, hospital and community settings will include general practice, nurse-led clinics, public health services, all hospital settings.

Types of studies

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, action research, case studies and feminist research. Studies published in black or gray literature will be obtained through a comprehensive search strategy.

International studies published in the English language will be considered for inclusion in this review. No date limits will be set for the database searches.

Methods

Search Strategy

The search strategy will aim to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken to identify key texts, followed by an analysis of the text words contained in the title. These along with the index terms used to describe the articles will guide the development of an appropriate search strategy that will be constructed for each information source. A second search using all identified keywords and index terms will then be undertaken across all included databases. It will appear in an appendix of the completed full systematic review; a draft search for MEDLINE is detailed in Appendix 1. Thirdly, the reference list of all identified studies included in the review will be scrutinized for additional studies.

Information sources

The databases to be searched include: MEDLINE, CINAHL, Embase, PsycINFO, Scopus and Web of Science. The search for unpublished or gray literature will include: ProQuest Dissertations and Theses, Web of Science Conference Proceedings and Google Scholar.

The key terms that will inform the development of strategies for each database are derived from MEDLINE and will be revised and combined with free text terms before the full search is conducted in the relevant databases.

Study Selection

The results of the search will be collated and uploaded to EndNote X7 (Clarivate Analytics, PA, USA). All duplicate studies will be removed. Titles and abstracts will be screened by two independent reviewers and assessed against the inclusion criteria for the systematic review. Studies meeting the inclusion criteria will be retrieved in full and the information imported into the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information. Full text studies that do not meet the inclusion criteria will be excluded and reasons for exclusion provided in an appendix in the full systematic review. Included studies will be critically appraised be two independent reviewers. A PRISMA[20] flow diagram will be used to present the results of the search. Any disagreements that arise between the reviewers will be addressed through discussion, or with a third reviewer.

Assessment of methodological quality

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological quality prior to inclusion in the review using a standardized critical appraisal instrument from the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information.[20] Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The critical appraisal results will be reported in narrative form and in a table. A consensus process will be used to determine study inclusion, with blinded independent appraisal carried out by two members of the review team. Finally, the results will be discussed by the whole review team to determine the quality of each study.

Data extraction

One reviewer will extract qualitative data from the papers included in the review using the standardized data extraction tool from. Operational guidelines and definitions contained in the published JBI information regarding meta-aggregation will be used to guide data extracted.[21] In meta-aggregation, data extraction occurs in two phases. Phase one involves details about populations, context, culture, geographical location, study methods and the phenomena of interest. Phase two includes analytical data and an illustration of each finding from the included studies and are assigned a JBI level of

credibility.[21] Should relevant key data be missing from studies, additional information will be sought from study authors.

Data Synthesis

Qualitative research findings will be pooled using JBI-SUMARI with the meta-aggregation approach.[21] This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings based on similarity in meaning. These categories are then subjected to a synthesis to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.

Assessing certainty in the findings

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings table.[21,22] The Summary of Findings table includes the major elements of the review and details on how the ConQual score is developed. Included in the table is the title, population, phenomena of interest and context for the specific review. Each synthesized finding from the review is then presented along with the type of research informing it, a score for dependability, credibility, and the overall ConQual score.[21,22]

Acknowledgments

None.

Conflicts of Interest

There are no conflicts of interest to declare.

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Appendix I Search strategy (MEDLINE)

We have worked with a subject librarian to develop this draft search strategy and will have her ongoing input to finalise the strategy. The search is divided into key concepts based on the topic under review.

Concept 1: Self-management education; Concept 2: Asthma; Concept 3 Experiences; Concept 4 Youth

Concept 1 AND Concept 2 AND Concept 3 AND Concept 4

No	Query
1	(MH "Self Care") OR (MH "Self Medication") OR (MH "Self Administration") OR (educat*) OR (interact*) OR (program*) OR (setting*) OR (intervent*) OR (instruct*) OR (encounter*) OR (promot*) AND
2	(MH Asthma+) OR (MH Asthma, Occupational) OR (MH Asthma, Exercise-Induced) OR (MH Asthma, Aspirin-Induced) OR (MH Status Asthmaticus)
3	("Experience") OR ("experiences") OR ("experienced") OR ("view") OR ("views") OR ("viewpoint") OR ("viewpoints") OR ("perception") OR ("perceptions") OR ("perceive") OR ("perceived") OR ("attitude") OR ("attitudes") OR ("belief") OR ("beliefs") OR ("perspective") OR ("perspectives") OR ("opinion") OR ("opinions") OR ("thought") OR ("thoughts")
4	(youth) OR (young adult*) OR (adolescen*) OR (teen*)
5	1 AND 2 AND 3 AND 4
6	Limiters set to English language

Appendix II Data extraction template

Paper reference:
Title:
Authors:
Date and Year:
Aims and objectives:
Definitions included:
Study design:
Setting:

Participants:
Methods/methodology:
Findings:
Other comments:

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