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

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

51

52 **Review question**

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

54

55 **Keywords**

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

57

58 **Introduction**

59 Asthma is a chronic respiratory condition that is characterized by episodes of physiological airway
60 narrowing resulting in symptoms of wheeze, breathlessness and mucus production.¹ The trajectory of
61 symptoms varies from mild, moderate to severe episodes that can be fatal. The effects of this chronic
62 disease are known to impact on patients both physically, in restriction of activities, and psychosocially,
63 in terms of quality of life.² According to the World Health Organization (WHO), 235 million people suffer
64 from asthma, with 383,000 deaths occurring in 2015.³ Globally, the focus is on minimizing the morbidity
65 and mortality of asthma, recognizing the importance of providing asthma education to promote self-
66 management that may empower people with a diagnosis of asthma.⁴ Youths are identified as an at risk
67 cohort with specific education needs, as this group has a higher risk of life-threatening events.⁵

68 Self-management of a chronic illness, such as asthma, entails education about the condition,
69 symptom recognition and management including pharmacological interventions to negate the incidence
70 of asthma exacerbations.⁶ However, to effectively engage in self-management of a condition such as
71 asthma, personal commitment and an awareness of the consequence of poor adherence is required.⁶
72 Self-management education supports patients with chronic conditions to live their lives to the full.⁷
73 Achieving cognitive maturity entails psychological development, where awareness and understanding
74 to the cause and effect of actions is essential.⁸ This is essential for youths to achieve self-management
75 and successful disease associated outcomes.⁵ The World Health Organization⁹ uses the age
76 parameters of ten to 24 years to define adolescents, and the United Nations (UN) defines 'youth' as
77 those persons between the ages of 15 and 24 years.¹⁰ This is the age that cognitive maturity should
78 have been attained.

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

86 Decision-making skills in respect of disease management are tested and influenced through self-
87 regulation and experiences about asthma management plans⁵ A Cochrane review identified a range of

88 decision-making tools for people with asthma, indicating that self-management is linked to improved
89 clinical outcomes and quality of life, educating and empowering patients to become actively involved in
90 their own health management.¹³ Studies, although limited in adolescents and young adults, have
91 examined barriers to self-management of asthma¹⁴. These include restriction in participating in sporting
92 activities because of the diagnosis of asthma¹⁴ and concerns about the effectiveness and long-term
93 effects of medication, particularly in respect of inhaled corticosteroids.^{14,15} Self-management education
94 could help a young person to address these barriers. In addition, mental well-being and the stresses
95 of living with a chronic disease is reported as a concern for adolescents and young adults, particularly
96 those who had life-threatening hospital admissions in respect of uncontrolled asthma.^{14,15}

97 The perceived barriers to youth self-management of chronic health conditions is also influenced by
98 education.¹⁶ The development of asthma education varies internationally in terms of structure,
99 designated responsibility of educational delivery and follow-up on their effectiveness. A Cochrane
100 meta-analysis reviewed the effectiveness of asthma educational interventions in children, including
101 adolescents up to eighteen years of age, with a diagnosis of asthma, and reported positive benefits,
102 including decreased hospitalisations, returns to the emergency department and improved self-
103 efficacy.¹⁷ However, there is a lack of qualitative evidence specifically identifying youths' experiences
104 of self-management and asthma education. In addition, critiques of self-management programs identify
105 the adoption of adult models of education with chronic illness, as primarily healthcare practitioner driven
106 rather than programs that address the expressed needs of adolescents and young people.¹⁶ Successful
107 self-management education interventions, in one longitudinal study of young adults with Type 1
108 diabetes, focused on an individualized holistic approach to disease self-management, demonstrating
109 positive long-term health outcomes for study participants.¹⁸ Moreover, documented asthma diaries of
110 the physical, psychological and social impacts of the disease, indicate that an individualized approach,
111 supports health professionals in constructing appropriate self-management educational interventions
112 collaboratively with adolescents and young adults.¹⁹ Other studies, including random control trials and
113 qualitative studies, focus on the role of peers in providing guidance on self-management.^{2,15,16} These
114 indicate that young people's input into the development of self-care interventions is important and that
115 peer-led asthma educational intervention lends empathy about asthma experiences and those
116 challenges faced in adapting to living with the condition¹⁶.

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

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

129 **Inclusion criteria**

130 *Participants*

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

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

137 *Phenomena of interest*

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

139 *Context*

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

142 *Types of studies*

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

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

149

150 **Methods**

151 *Search Strategy*

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

161

162 **Information sources**

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

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

169 *Study Selection*

170 The results of the search will be collated and uploaded to EndNote X7 (Clarivate Analytics, PA, USA).
171 All duplicate studies will be removed. Titles and abstracts will be screened by two independent
172 reviewers and assessed against the inclusion criteria for the systematic review. Studies meeting the
173 inclusion criteria will be retrieved in full and the information imported into the Joanna Briggs Institute
174 System for the Unified Management, Assessment and Review of Information. Full text studies that do
175 not meet the inclusion criteria will be excluded and reasons for exclusion provided in an appendix in the
176 full systematic review. Included studies will be critically appraised by two independent reviewers. A
177 PRISMA²⁰ flow diagram will be used to present the results of the search. Any disagreements that arise
178 between the reviewers will be addressed through discussion, or with a third reviewer.

179 *Assessment of methodological quality*

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

188 *Data extraction*

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

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

197 *Data Synthesis*

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

203 *Assessing certainty in the findings*

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

211

212 **Acknowledgments**

213 None.

214

215 **Conflicts of Interest**

216 There are no conflicts of interest to declare.

217

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291 **Appendix I Search strategy (MEDLINE)**

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

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

297 Concept 1 AND Concept 2 AND Concept 3 AND Concept 4

298

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

299

300 **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:

301