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Review article

Self-Reported Barriers to Medication Adherence Among Chronically Ill Adolescents: A Systematic Review

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ABSTRACT

Purpose: To investigate self-reported barriers to medication adherence among chronically ill adolescents, and to investigate whether barriers are unique to specific chronic diseases or more generic across conditions.
Methods: A systematic search of Web of Science, PubMed, Embase, PsycINFO, and CINAHL from January 2000 to May 2012 was conducted. Articles were included if they examined barriers to medication intake among chronically ill adolescents aged 13–19 years. Articles were excluded if adolescent's views on barriers to adherence were not separated from younger children's or caregiver's views. Data was analyzed using a thematic synthesis approach.
Results: Of 3,655 records 28 articles with both quantitative, qualitative, and *q*-methodology study designs were included in the review. The synthesis led to the following key themes: Relations, adolescent development, health and illness, forgetfulness, organization, medicine complexity, and financial costs. Most reported barriers to adherence were not unique to specific diseases.
Conclusion: Some barriers seem to be specific to adolescence; for example, relations to parents and peers and adolescent development. Knowledge and assessment of barriers to medication adherence is important for both policy-makers and clinicians in planning interventions and communicating with adolescents about their treatment.

IMPLICATIONS AND CONTRIBUTION

Insufficient adherence to medical treatment is a common health-threatening problem in chronic illness. This review contributes with adherence barriers across a range of chronic conditions from the adolescents' own perspective. Some barriers seem to be specific to adolescence and knowledge of these barriers may improve clinical interventions.

Chronic illness among adolescents is an important and increasing global public health concern. It is estimated that around 10% of adolescents suffer from a chronic disease affecting daily life [1].

Living with a chronic condition encompasses many complex behaviors that the patient has to add to daily routines including taking medication, following a diet, and/or executing lifestyle changes, as well as monitoring symptoms and attending outpatient clinical controls [2]. Insufficient adherence to long-term medical treatment is a major global health-threatening problem, and treatment adherence seems to be a larger challenge to chronically ill adolescents compared with children and adults [3,4].

Exploring barriers to medication adherence among chronically ill adolescents is important for several reasons. First of all, missing medical treatment can have serious consequences for health and result in increased morbidity and mortality [5]. Also, the economic burden of patient nonadherence is enormous [6,7]. Knowledge of barriers to medical treatment may improve the planning of interventions as well as an individual approach to young patients.

Disease-specific reviews have been undertaken to clarify adolescents' own perceptions of barriers to treatment; for example, in asthma [8,9], diabetes type 1 [10], and HIV [11]. To our knowledge, only a few reviews have focused on comprehensive insight of adolescents' perceptions of barriers to treatment. For example, Kyngäs [12] who included asthma, type 1 diabetes mellitus, arthritis, and epilepsy. Our systematic review seeks to address this gap by examining self-reported barriers to

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medication adherence among chronically ill adolescents among a broad range of chronic diseases. The review question was: Which barriers to medication adherence do chronically ill adolescents perceive? We also wanted to highlight the most common perceived barriers across chronic diseases in order to investigate whether they are unique to specific diseases or can be characterized as disease-independent. To emphasize the adolescents' voice we decided to focus on so-called "views studies," which look solely at the barriers perceived by the adolescents. Views studies can be characterized as "people's views in their own words, as well as questionnaires that use frequencies to quantify the proportion of people with a particular view or preference" [13].

Method

Search strategy

The following databases were searched for the period January 2000 to May 2012: Web of Science, PubMed, Embase, PsycINFO, and CINAHL. Google Scholar was searched for additional articles. Also, reference lists of all the identified articles were assessed for eligibility and reviews about adolescence and adherence were screened for additional relevant studies. The search strategy utilized both MeSH and non-MeSH terms. The following general search strategy was developed: Chronic disease OR chronic* AND adolescents OR adolescence OR teenage* OR youth AND adherence OR compliance OR self-management OR concordance. The full search strategy is available from the first author (S.H.) on request.

Inclusion and exclusion criteria

The inclusion criteria were: chronically ill adolescents aged 13–19 years. If a study had a wider age span, we decided to include the study if the mean age of the participants was between 14 and 18 years. Only somatic illness was included. Included studies had to have focused on exploring the views of adolescents, and had to have contained barriers to medication adherence in terms of medication intake as a main objective. Studies were only included if they were published in English and were of a western origin. To include the adolescent's views, only qualitative studies, survey studies, and *q*-methodology studies where barriers were presented either descriptive or in percentages were included. Epidemiologic studies, intervention studies, and reviews were not included. The exclusion criteria were: studies on children and adults (unless data on adolescents were also included), participants being mentally ill, and studies where barriers were reported by parents or healthcare providers, or studies that did not clearly separate answers given by parents/healthcare providers and adolescents, or between age groups, for example, children and adolescents. Studies focusing on adherence in terms of behavior such as adherence to treatment appointments, following special diets, and making lifestyle changes were not included except for studies also focusing on adherence to medication intake.

Quality assessment

It has been discussed whether it is meaningful to assess study quality of qualitative studies. Furthermore, there is a lack of guidance on quality criteria applicable to both quantitative and qualitative studies [14]. Thus, given that this review contains a significant portion of qualitative studies, we found it appropriate to use a quality checklist without a ranking score. S.H. and K.A.B. did the quality assessment individually and later discussed the results of the assessment together. We used a checklist developed by Mills [15,16] inspired by the Critical Appraisal Skills Program [17]. This quality assessment gives a thorough overview of the trustworthiness and transparency of each study. It is available from the authors on request.

Data extraction and synthesis

We used a thematic synthesis based on an interpretive, inductive approach in order to synthesize the findings. Included studies were extracted in a predesigned template (Table 1). In the qualitative studies, barriers were all presented descriptively, whereas barriers in the quantitative studies were presented as percentages. In the column "barriers" we reproduced outcome as it was presented in each article to strengthen the transparency of the synthesis. We were inspired by the tools and techniques for thematic synthesis to compare and contrast themes on barriers [18–20]. S.H. wrote the final synthesis, while all themes were continuously discussed with K.A.B until consensus was reached to ensure a common understanding of the themes. Then each article was reread to ensure that all barriers mentioned were included in the synthesis, so that all adolescent views were integrated.

Results

Study characteristics

Studies retrieved. The database search led to 3,486 published English-language titles and after identifying additional records through other sources, 3,655 records were ready for an initial screening (Figure 1). From these records, 293 abstracts were selected for an in-depth screening. S.H. and K.A.B. screened the abstracts individually and discussed inclusion until consensus was reached. Duplicates were identified, and studies that did not meet the inclusion criteria were excluded. Then 73 full-text articles were assessed for eligibility. Any disagreements about including or excluding a study were resolved by discussion until consensus was reached. In this stage of the process 45 articles were excluded for specific reasons, and 28 relevant articles were left for inclusion in the review: 11 qualitative, 15 quantitative, and two using a *q*-methodology [21].

Sample and participants characteristics. Sample sizes for the quantitative studies varied from 31 to 1,061, while the sample sizes in the qualitative studies varied from 4 to 49. Counting the participants of all studies, this review embedded 2,501 participants suffering from at least one of the following chronic conditions: diabetes, asthma, cystic fibrosis, inflammatory bowel disease, chronic kidney disease, epilepsy, rheumatoid arthritis, sickle cell disease, hemophilia, cancer, and Pierre Robin syndrome, or participants had undergone a solid organ transplantation (kidney, liver, or heart).

Barriers found

Synthesis. The synthesis led to the following key themes with subcategories in brackets: