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Review article

What adolescents living with long-term conditions say about being involved in decision-making about their healthcare: A systematic review and narrative synthesis of preferences and experiences

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ABSTRACT

Objective: To understand the preferences and experiences of adolescents (age 10–19) with long-term conditions (LTCs) towards involvement in discussions and decisions regarding management of their condition.

Methods: A systematic review and narrative synthesis of mixed-methods, quantitative and qualitative and research was performed. Six databases were searched from inception to March 2017. The quality of the articles was assessed, and relevant data were extracted and coded thematically.

Results: The search yielded 27 articles which met the inclusion criteria. Decision-making involvement preferences and experiences were reported from the adolescents' perspectives. Adolescents often report that they do not have any choice of treatment options. Variability in preferences and experiences were found within and between individuals. Mismatches between preferences and experiences are common, and often with negative emotional consequences.

Discussion: Adolescent preferences for involvement in the decision-making process are situational and individualistic. Healthcare professionals can encourage involvement by ensuring that adolescents are informed of treatment options, and aware of the value of their contribution. Future research should explore adolescent perceived barriers and facilitators to SDM.

Practical implications: Interventions are needed to effectively train HCPs in the delivery of shared decision-making, and to support the participation of adolescents with LTCs in shared decision-making.

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1. Introduction

Adolescence is a critical period of psychosocial development in which people experience a change in interpersonal roles, responsibilities and identity [1,2]. Unsurprisingly, these years can be more complex for those living with a long-term health condition (LTC). Adolescents with LTCs increasingly take on self-management responsibility, sometimes doing the majority of self-care tasks by the age of 13 [3–7]. However, self-management and health outcomes of patients with LTCs often decline during adolescence, which can lead to increased likelihood health complications and hospital admissions [7–9].

Current recommendations state that adolescents should be encouraged and supported to participate in healthcare decisions [10,11], and the ability of adolescents with LTCs to make informed and thoughtful decisions about their healthcare has been documented [12,13]. Healthcare decision-making around LTCs has been described as a continual process, with no clear beginning or end; where numerous decisions are taken, evaluated and often reevaluated [14]. Montori et al. emphasise the need for patients to take a more active role in treatment decision-making in a long-term care setting, which offers a longer window of opportunity to make decisions, and to revisit and reverse them without important loss, compared to patients in acute care settings where decisions are often urgent and may be irreversible [15]. Shared decision-making (SDM) provides the opportunity for patients with LTCs to evaluate the risks, benefits and costs of various management options and procedures for their condition, while enabling a shared understanding of preferences and possible issues, such as difficulties with side-effects or in performing self-management tasks [16]. SDM interventions in paediatric medicine have been found to be associated with improved knowledge and reduced decisional conflict [17].

Previous research in decision-making in paediatrics has predominantly focused on interactions between the parent and healthcare professionals (HCPs) [17]. The presence of a triadic relationship is an important distinction between child and adult consultations, where parent involvement can prevent SDM from occurring between the young patient and HCP [18]. A review [19], which identified literature addressing adolescents', parents' and HCPs' experiences of decision-making in paediatrics, found that adolescents' views in health consultations were rarely sought or acknowledged. However, most of the studies in the review did not actually explore the patients' perspectives. This is reflective of the exchange during a paediatric consultation, where adolescents' voices are rarely heard, and they tend to act as bystanders [20,21]. It is important to understand how adolescents experience discussions and decision-making during consultations in a healthcare setting, as well as their preferences for involvement. Understanding the perspectives of adolescents with LTCs regarding their experienced and desired roles in the decision-making process can help us to further understand their support needs.

1.1. Aim & objectives

The aim of this review was to collect and synthesise published research data on adolescent perspectives towards involvement. The objectives were to: (a) understand the preferences of adolescents with LTCs towards being involved in the decision-making process about their condition management; (b) understand the experiences of adolescents with LTCs with involvement in the decision-making process and (c) make recommendations regarding how SDM with adolescents with LTCs can be implemented.

2. Methods

The review applied a systematic search methodology following the PRISMA statement [22] and in accordance with the guidance on the conduct of a narrative synthesis [23]. The protocol was prospectively registered on PROSPERO [24] (CRD42017055650).

2.1. Eligibility criteria

Included studies were English-language qualitative, quantitative and mixed-method papers which report empirical research about the preferences and/or experiences of adolescents living with one or more LTCs, from the patient perspective. No limitations were placed on the year of publication. An age range for adolescents of 10–19 years was stipulated in accordance with the WHO definition. Studies with participants of an age outside of the adolescent parameters were included if the measure of central tendency fell within the 10–19 year-old range. LTCs were defined as conditions requiring 'ongoing management over a period of years or decades' [25]; meaning conditions which require continuing clinical care and self-management. Examples include diabetes, asthma and cancer. Due to the small number of eligible papers, studies were not excluded if the sample also included acutely ill patients.

For inclusion, papers had to examine the decision-making process in a healthcare setting regarding decisions that are characteristic to LTC care. This means ongoing condition management discussions and decision-making, such as decisions about, diet, exercises, appointment scheduling, medication administration, or treatment plans. Papers which primarily examined other types of decisions such as research participation, fertility preservation, or end of life decisions, were excluded. Studies containing mixed samples (e.g. perspectives of adolescents, parents and HCPs) were included if the adolescents generated data were reported separately or could be separated by the reviewers. Data which made comparisons between adolescent and HCP/parent responses were retained. Papers which reported studies with wholly parent or HCP samples were excluded.

2.2. Systematic search

Six electronic bibliographic databases (Embase, Medline, Cochrane Library, CINAHL, PsycINFO and Scopus) were searched systematically from inception to March 2017 in order to identify

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