

## Parents' experiences of the transfer from pediatric to adult care for their adolescent or young adult children with chronic conditions: a systematic review protocol

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### Review question/objective

The objective of this systematic review is to identify parents' experiences of adolescents and young adults (AYA) health care transfer from pediatric to adult care.

1. How do parents experience being prepared for the transfer from pediatric to adult care of their AYA with a chronic condition?
2. How do parents experience the event of transfer?
3. How does the type of chronic condition influence parents' experiences of AYAs' transfer from pediatric to adult care?

## Background

The prevalence of chronic conditions in adolescence is increasing and it is estimated that between 7.5% and 15% of adolescents suffer from a chronic disease depending on the diversity in methodology and definitions used.<sup>1</sup> Advances in medical technology are resulting in that more children are diagnosed with severe and chronic conditions; they are surviving childhood and likely to overcome adolescence and reach adulthood.<sup>2</sup> Thus an increasing number of parents are faced with preparing AYAs for managing and taking over responsibility for their chronic disease. The parental role is changing regarding monitoring and supervision, in setting boundaries and limits and in regulating homework and spare time.<sup>3</sup> Issues such as confidentiality in relation to medical treatment may leave parents at a loss, leading to lowered parental self-confidence, increased anxiety and less effective parenting.<sup>3</sup> Parents are documented to worry about their child's ability to manage their disease themselves.<sup>4</sup> This may activate reluctance to letting go of the AYA.<sup>5-7</sup>

Adolescence is characterized by physical (puberty, changes in the brain, growth and sexual maturation), as well as mental (thinking and reasoning, and the self and identity) and social changes (relationships, family, peers and friends).<sup>3</sup> In this period, AYA's parents cope with the chronic condition together with worries about sexuality, mood, mental health, substance abuse, risk-taking behavior and decisions about their own health.<sup>8</sup> In the adolescence health transition, AYAs themselves highlight issues such as independence, relationship with professionals, differences in ward cultures and process and timing of transfer.<sup>9</sup>

Parents' physical and emotional support plays an important role in the process of AYAs' transition to adulthood. AYAs need their parents for support, comfort, reassurance, feedback and guidance. The influence of the family, especially of the parents, on the development of a child and adolescent is important in relation to quality of life of the AYAs.<sup>10</sup>

AYAs with chronic conditions rely on their parents to manage their care, such as scheduling appointments and communication with health care professionals.<sup>11</sup> Even when they have successfully transitioned to independence in the care for their own disease, some continue to regularly consult their parents regarding their care and/or live with their parents.<sup>12</sup> Parents appear to favor attending appointments together with AYAs before transfer in contrast to what the AYAs favor.<sup>13</sup> In addition, parents seem concerned whether they will become less involved in the care following transfer.<sup>13</sup> Parents seem to prefer older age at transfer from pediatric to adult care. While dedicated AYA services were described as beneficial by patients and their parents, only 50% of AYAs preferred to have medical appointments joint with their parents.<sup>13</sup>

In addition, to cooperate and support AYAs, health care professionals also have to cooperate with and support parents during their transition into adulthood as their role as parents is also transitioned.

The concept of transition has been developed for more than 30 years.<sup>14-15</sup> A transition is characterized by an unstable passage between two more stable life periods; a time span with an endpoint, a period of instability and confusion and an ending with a new beginning of stability.<sup>15</sup> Transition denotes a change in health status, or in role relationships, expectations, or abilities. Transition requires the person to incorporate new knowledge, to alter behavior and therefore to change the definition of self in social contexts.<sup>15</sup> In this review, transfer is defined as a professional act where the organization reassigns adolescents from pediatric to adult care and the personal experience of the transfer is defined as

transition.<sup>16-17</sup>

Most definitions of chronic condition address duration and limitations in functional level, although there is currently no existing common definition.<sup>18</sup> This review defines a chronic condition as a condition having a biological basis, lasting for a minimum of 12 months and necessitating compensatory assistance (e.g. medication).<sup>19</sup>

There is no longer any clear or well defined moment when an individual reaches adulthood.<sup>20</sup> Adolescence has been defined as a phase of life between childhood and adulthood from 12 to 22 years, characterized by a specific physical, psychological and social development.<sup>21</sup> For the purpose of this review, adolescence is defined as 13-18 years of age and young adulthood is defined as 19-24 years of age.

Parents are defined as fathers and mothers or significant others such as grandparents and close relatives who act on behalf of the parents.

In a previous published meta-synthesis, the perspective of AYA's experiences during transfer from child centered to adult centered care was explored using similar transfer and transition definitions.<sup>9</sup> The two reviews are expected to be part of a future umbrella review concerning AYAs, professionals (nurses) and parents' experiences of AYAs transfer from child centered to adult centered care.

In addition the author team of the current review forms a research group exploring transition in various ways and populations.<sup>9, 22-25</sup>

Systematic, stepwise approaches including metasynthesis of parents' perspectives could, together with the perspectives of AYAs and health care professionals, be used for developing clinical, educational and health care policies. By conducting this review, the authors wish to contribute knowledge which professionals in health care can include in their clinical work when making a professional assessment of the transitional needs concerning parents of AYAs during their continuing encounters with the health care system. A preliminary search of the JBI Database of Systematic Reviews and Implementation Reports, CINAHL, PubMed and PROSPERO revealed that there is no available systematic review or protocol on this topic.

## **Keywords**

Adolescents; chronic conditions; parents; pediatrics; qualitative; transition; young adults

## **Inclusion criteria**

### ***Types of participants***

This review will consider studies that include parents of AYAs (adolescents aged 13-18 years and young adults aged 19-24 years) living with a chronic condition. No limit considering the AYA's type of chronic condition, as long the AYA is not under residential accommodation or institutionalized care.

### ***Phenomena of interest***

This review will consider studies that investigate how parents of AYAs with chronic conditions experience and manage the AYA's transfer from pediatric to adult care.

## Context

Transfer from pediatric to adult care for AYAs.

## 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, action research and feminist research. In the absence of research studies, other texts such as opinion papers and reports will be considered.

## Search strategy

The search strategy aims 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 has been undertaken and was followed by analysis of the text words contained in the title and abstract and of the index terms used to describe the articles. The following initial keywords were used: Adolescent/Teenager/Young adult, Parent/Transition/Transfer and identified a number of keywords (Table 1).

<b>Population</b>	<b>Phenomenon of Interest</b>		<b>Context</b>	
parent*	experience*	transition *	adolescent*	chronic*
mother*	comprehension*	transfer*	young adult*	chronic disease*
father*	attitude*	discharge*	teenager*	chronic condition*
relative*	emotion*		young people	special health care need*
client*	view*		paediatric*	long term illness*
next of kin	opinion*		pediatric*	
single-parent*	perception*		young person*	
famil*	belie*			
step-parent*	feeling*			
step parent*	know*			
stepparent*	understanding*			
	adaptation*			

A systematic search at the second step, using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles will be searched for additional studies. All identified research reports will be subject to forward citation searches to reach as complete as possible inclusion of studies in the review. Studies published in English, German, Danish, Swedish and Norwegian will be considered for inclusion in this review.

Studies published between 1999 and 2014 will be considered for inclusion in this review. Time limitations are related to the fact that this review is to be linked to a previous review exploring the AYA's experiences of transfer.<sup>9</sup> The current review follows the same date limits, which were set because it is considered the situation for parents of AYAs to have changed considerably through this period of time, as well as to enable a future umbrella review including both reviews.

The databases to be searched include: PubMed, CINAHL, PsycINFO, EMBASE, Scopus, Web of Science SveMed+, and MedPilot.

Grey literature is a core component in a systematic review. In the context of this review grey literature such as theses and dissertations will be considered for inclusion because they presumably report findings relevant for this review. The search for unpublished studies will include: Google Scholar, Mednar and ProQuest Dissertations and Theses.

Journals publishing in Danish, Swedish and Norwegian relevant for this systematic review are all indexed in the above mentioned databases.

Systematic searches will be developed for each database and conducted in cooperation with a research librarian.

### **Assessment of methodological quality**

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

### **Data collection**

Data will be extracted from individual studies independently using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

### **Data synthesis**

Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

### **Conflicts of interest**

None

### **Acknowledgements**

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## Appendix I: Appraisal instruments

### QARI appraisal instrument

#### JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer ..... Date .....

Author ..... Year ..... Record Number .....

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:  Include  Exclude  Seek further info.

Comments (Including reason for exclusion)

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## Appendix II: Data extraction instruments

### QARI data extraction instrument

#### **JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year .....

Journal ..... Record Number .....

#### **Study Description**

Methodology

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Method

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Phenomena of interest

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Setting

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Geographical

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Cultural

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Participants

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Data analysis

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Authors Conclusions

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Comments

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Complete

Yes

No

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete      Yes       No