The experiences of adolescents with juvenile idiopathic arthritis with transition programs to adult services: A systematic review protocol

Paula Mäkeläinen 1,3
Anne Korhonen 2,3

1. Mikkeli University of Applied Sciences
2. Oulu University Hospital
3. The Finnish Centre for Evidence Based Health Care: an affiliated Centre of the Joanna Briggs Institute

Corresponding Author:
Paula Mäkeläinen
paula.makelainen@mamk.fi

Review question/objective
The objective of this systematic review is to critically appraise, synthesize and present the best available evidence of the experiences of adolescents with juvenile idiopathic arthritis (JIA) with transition programs from pediatric to adult services.

Review question is: What are the experiences of adolescents with JIA relating to the transition programs from pediatric to adult services?

Background
Juvenile idiopathic arthritis (JIA) is a heterogeneous group of diseases characterized by arthritis of unknown origin. JIA is a clinical diagnosis made at age less than 16 years with continued arthritis of at least six weeks duration and with other identifiable causes of arthritis excluded. JIA is the most common chronic rheumatic disease in children being a significant cause of short- and long-term disability. Throughout the world, the incidence of JIA ranges from 1 to 22 new cases per 100,000 population per year with a prevalence of 8–400 per 100,000. In Europe and North America, the most common subtype of JIA is oligoarthritis (symptoms in one joint) accounting for approximately 50% of patients with JIA. In the Western world, girls are affected more often than boys. In Finland, 0.2% of children under 16 years suffer from JIA. The prognosis of the disease has been improved due to advances in medication however despite these advances, disease-related complications and side-effects of the medication occur. For example eye inflammation (uveitis) which may cause cataracts, glaucoma or blindness.
regardless of careful screening and care, occurs in approximately 10% of all cases. Adverse side-effects of medication relate mainly to the use of corticosteroids, which may inhibit growth. In addition, unsuccessful transition to adult services can result in poor health indicators and loss to follow-up.

Adolescence as a phase of life interposes between childhood and adulthood from 12 to 22 years consisting of specific physical, psychological and social development. Adolescents with chronic illness have special health needs, which are not fully recognized in health care. Chronic illness may impede the maturation process, which may impact on physiological, psychological and social maturation and vice versa. Understanding the complexity of the mutual relationship of the natural maturation process and chronic illness is urgent for health care professionals to contribute to both normal development task achievements and overall well-being for adolescents with JIA. For example, the experience of chronic illness can make adolescents feel uncomfortable in their body, or it disrupts their normal life.

Transition and transition care have been a research interest for over twenty years and practical models for organizing transition care have been developed. Regardless of this, local protocols and principles vary often causing fragmented and disease-centered care. Transition has been recognized as a key component of care. The Transition phase is defined as the multifaceted, active phase in care aimed at ensuring a seamless transition from pediatric to adult services for an adolescent patient. It is a continuous process lasting from early preparation, which starts in pediatrics until the young person with a chronic illness is settled in the adult services. Transition of care from pediatric to adult healthcare services is important and should be an age and developmentally appropriate process.

The Transition phase is challenging for all involved, including the patient, the family and health care organizations in terms of fostering adherence so as to avoid long-term complications. Success during this phase will be manifested as the patient’s adherence to self-care as well as gaining positive skills in order to cope with challenges in adulthood, such as integration of physical, psychological and social maturation.

Different transition programs have been developed with their goal being to ensure uninterrupted, comprehensive health care, which should be evaluated from the point of view of adolescents. According to the literature, the transition programs should be holistic by nature and address clinical, psychosocial and educational aspects as well as being simultaneously flexible and developmentally appropriate. It should not focus only on the young person but also the parents, as the parents may need help to lessen protectiveness, but increase the share of the responsibility of care and gradually proceed to give full responsibility to the young people with chronic illness.

Acceptance of the adolescents as active participants in their own transition process might strengthen their experience of an autonomous identity and enable participation socially and in society, thus enhancing the ability to achieve a meaningful adult life. Adolescents want to participate in decision-making, develop responsibility and subsequently take control in their lives.

For health care organizations, success in transition from pediatrics to adult services demands multi-professional collaboration with pediatric and adult services, clear transition schedules and preparation programs. In addition, health care personnel working in adult services need skills to cope with adolescents who are not adults but in a very salient phase in their lives.
It is important to collect all available evidence around JIA patients’ experiences with transition programs and adherence levels to care as these may be disturbed by intrinsic factors of adolescents and also by organizational inabilities to meet the needs of this population. This systematic review will collect and synthesize findings of all relevant studies in order to give valuable information for health care professionals to develop transition programs based on evidence for JIA patients. A preliminary search for existing systematic reviews was performed in the following databases: Cochrane Library of systematic reviews, JBI Library of systematic reviews, Medline, CINAHL, and PROSPERO. No existing systematic reviews are available on the topic. Existing systematic reviews are focused on health outcomes of transitional programs among children with chronic illness, mental illness or disability 6.

Keywords
Adolescence; adolescent*; adult services; arthritis rheumatism; chronic disease; chronic illness; confident; content analysis; continuity of patient care; counseling; experience*; grounded theory

Inclusion criteria

Types of participants
This review will consider studies that investigate 12 – 18 year-old adolescents suffering from JIA.

Phenomena of interest
This review will consider studies that are focused on experiences of adolescents undertaking transition programs from pediatric to adult health care services.

Context
This review will consider studies that include transition programs in any public healthcare setting.

Types of studies
This review will consider interpretative studies that draw on the experiences of young people with JIA, including but not limited to designs such as phenomenology, grounded theory, ethnography, action research and feminist research. In the absence of studies focusing on experiences of young people with JIA, the studies focusing on the experiences of young people with chronic illness will be accepted if they include JIA patients as a part of the target group. In the absence of research studies, other texts such as opinion papers and reports will be considered. This review will also consider academic dissertations that have been reported in Finnish or English.

This review will not consider research papers that study parents’ or health care providers’ experiences of transition programs. In addition, research papers that study transition programs organized by other than public health care organizations will be excluded. Studies which focus on adolescents’ experiences of the disease or their experiences of care and/or counseling without focusing on transition will also be excluded from the review.
Search strategy

The search strategy aims to find both published and unpublished studies in English or Finnish. A three-step search strategy will be utilized in this review. An initial limited search in MEDLINE and CINAHL will be undertaken followed by analysis of the text words contained in the title and abstract and in the index term used to describe the articles. A second search using all identified keywords and index terms will be performed across all indexed databases. Thirdly, the reference lists of all identified reports and articles will be search for additional studies. Studies published from January 1990 – May 2013 will be considered for inclusion in this review, as the first reports on transition programs were published in the 1990’s.

The databases to be searched include:

• CINAHL
• Cochrane Library
• DARE
• EBSCO (Academic Search Elite)
• Linda
• Medic
• Nelli (Finnish database portal)
• PsycINFO
• PubMed
• Science Direct

The unpublished studies will be searched from Eular (The European league against rheumatism) congress books from 2007 – 2012.

Initial keywords will be:

In English:
adolescence
adolescent*
adult services
arthritis rheumatism
chronic disease
chronic illness
confident
content analysis
continuity of patient care
counseling
experience*
grounded theory
health care
health care transition
juvenile
multidisciplinary collaboration
opinion*
out-patient clinic
paediatric
pediatr*
pediatric services
phenomenology
primary health care
program evaluation
rheumatoid
rheumatological clinic
rheumatology, juvenile idiopathic arthritis (JIA)
satisfact*
service
special health care
teenage
thought*
transfer
transition
transition care
unsatisfact*
view
young
In Finnish:

ajatukset, käsitys*
artriitti
erikoissairaanhoito
fenomenologia
grounded teoria
hoidon jatkuvuus
juveniili artriitti
kokemus, kokemuksen
lastenreuma
lastentautien klinikka
luottamus
moniammatillinen yhteistyö
nuori
nuoruus
näkemys*
ohjaus
palvelujen arviointi
pediatr
perusterveydenhuolto
pitkäaikaisairaus
reuma
reumatautien klinikka/yksikkö / poliklinikka
siirtymä* hoito
siirtymä vaihe
siirtymä vaiheen ohjaus
sisällön analyysi
teini*
teini-ikäinen
terveydenhuolto
transitio
Assessment of methodological quality

Qualitative 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).

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

Data collection

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

Textual data will be extracted from papers included in the review using the standardized data extraction tool from JBI-NOTARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Meta-synthesis will be carried out to provide an interpretation of qualitative data and aims to capture the essence of the phenomena of interest. Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorizing these findings on the basis of similarity in meaning (Level 2 findings). These categories will then be subjected to a meta-synthesis, in order to produce a single comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in a narrative form.

Textual papers will, where possible be pooled using JBI-NOTARI. This will involve the aggregation or synthesis of conclusions to generate a set of statements that represent that aggregation, through assembling and categorizing these conclusions on the basis of similarity in meaning. These categories will then be 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 conclusions will be presented in narrative form.

Conflicts of interest

None

Acknowledgements

None
References

16. Freed GL, Hudson EJ. Transitioning children with chronic diseases to adult care: Current


Appendix I: Appraisal instruments

QARI Appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

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<th>Question</th>
<th>Yes</th>
<th>No</th>
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<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>6. Is there a statement locating the researcher culturally or theoretically?</td>
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<td>7. Is the influence of the researcher on the research, and vice versa, addressed?</td>
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<td>8. Are participants, and their voices, adequately represented?</td>
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<td>9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
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<td>10. Do the conclusions drawn in the research report flow from the analysis, or interpretation of the data?</td>
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Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (including reason for exclusion)


Page 191
NOTARI Appraisal instrument

JBI Critical Appraisal Checklist for Narrative, Expert opinion & text

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

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

1. Is the source of the opinion clearly identified?  
   Yes ☐  No ☐  Unclear ☐  Not Applicable ☐

2. Does the source of the opinion have standing in the field of expertise?  
   Yes ☐  No ☐  Unclear ☐  Not Applicable ☐

3. Are the interests of patients/clients the central focus of the opinion?  
   Yes ☐  No ☐  Unclear ☐  Not Applicable ☐

4. Is the opinion's basis in logic/experience clearly argued?  
   Yes ☐  No ☐  Unclear ☐  Not Applicable ☐

5. Is the argument developed analytical?  
   Yes ☐  No ☐  Unclear ☐  Not Applicable ☐

6. Is there reference to the extant literature/evidence and any incongruency with it logically defended?  
   Yes ☐  No ☐  Unclear ☐  Not Applicable ☐

7. Is the opinion supported by peers?  
   Yes ☐  No ☐  Unclear ☐  Not Applicable ☐

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

_____________________________________________________________________

Method

_____________________________________________________________________

Phenomena of Interest

_____________________________________________________________________

Setting

_____________________________________________________________________

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 □
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Extraction of findings complete

Yes ☐

No ☐
NOTARI data extraction instrument

**JBI Data Extraction for Narrative, Expert opinion & text**

Reviewer ___________________________ Date ___________________________

Author ___________________________ Year __________ Record Number ______

**Study Description**

Type of Text: __________________________________________________________

Those Represented: ____________________________________________________

Stated Allegiance/ Position: ____________________________________________

Setting

Geographical

Cultural

Logic of Argument

Data analysis

Authors Conclusions

Reviewers Comments

Data Extraction Complete Yes ☐ No ☐
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