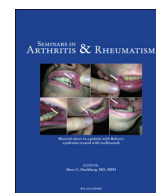




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Systematic review and critical appraisal of transitional care programmes in rheumatology ☆☆☆

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ABSTRACT

Objectives: Identify existing models of transitional care in rheumatic and musculoskeletal diseases (RMD), describe their strengths and weaknesses, and provide support to a consensus initiative to develop recommendations for transitional care.

Methods: A systematic review was conducted to identify publications describing transition programmes in RMD. Eligibility for inclusion required detailed description of the programme. Descriptive information was collected, including country of the programme, target diseases and ages of the patients, resources, elements of the transition process and, when described, outcomes and quality indicators. Quality assessment of the programmes included: level of definition and the evidence base for the programme, availability of quality indicators and evidence of effectiveness.

Results: Overall, 27 articles were identified and evaluated, related to 8 programmes in 6 countries: 4 covered all RMDs, 3 specific for patients with juvenile idiopathic arthritis (JIA) and 1 programme generic for chronic diseases and adapted for RMD. Core elements of these transition programmes included the following: a written transition policy; patient individualised planning and flexibility of transitional care; designation of transition coordinator role; acquisition of knowledge and skills in self-management of care; decision making, shared care and communication between paediatric and adult health care provider teams and a planned transfer to adult rheumatology. Only 2 provided evidence of effectiveness according to previously specified outcome measures.

Conclusions: Transitional care programmes in RMDs are variable in their structures, staffing and processes. There are no standardised measures of outcome or effectiveness. This information provides important valuable insights and strategies to develop transitional care in RMD.

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Abbreviations: RMD, rheumatic and musculoskeletal diseases; jRMDs, juvenile onset rheumatic and musculoskeletal diseases; JIA, juvenile idiopathic arthritis; MAGICC, moving on in adolescence: growing up in collaboration and coping; DON'T RETARD, devices for the Optimisation of TRAnsfer and transition of adolescents with rheumatic disorders; YARD, young adult with rheumatic diseases; BTP, Berlin transition programme; PReS, paediatric rheumatology european society; EULAR, European league against rheumatism.

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Introduction

Transitional care, as defined by the Society for Adolescent Medicine, is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems” [1]. Transition is a multidimensional, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents and young adults with special health care needs. In contrast, transfer is the administrative event in which the patient moves from the paediatric or adolescent clinic to the adult office and its medical information pass from one specialist to another [2,3]. A variety of transitional care programmes

have been developed to guide patients with chronic diseases and their families through the transition process. Some studies evaluating transition care programmes in other chronic conditions, mainly diabetes, has been published in the last years, but there is a lack of evidence regarding standardized practices in transition care [4,5]. Transition is especially important in youth with juvenile onset rheumatic and musculoskeletal diseases (jRMDs) as approximately 50% will continue to have ongoing active disease. Many patients will require treatment or have significant sequelae of their rheumatic disease into adult life [6] and there is evidence of worse physical and psychosocial functioning in adults with jRMDs [7]. Although transitional care programmes have been described, their reproducibility and effectiveness in clinical practice remain unclear. There is an urgent need to move the agenda forward to implement evidence-based transitional care into practice and identifies effective measures of transitional care and quality indicators to measure success [3]. With this in mind, the objective of this review was to identify, describe and critically appraise the existing transitional care programmes in jRMDs.

Methods

As a part of a European League Against Rheumatism (EULAR)/Paediatric Rheumatology European Society (PRES) working group, a systematic review was performed to select studies that contained validated transitional care programmes, from paediatric to adult health care. Once selected, articles were analysed using standard methods for systematic review (<http://www.prismastatement.org/>). The information obtained was used to support a consensus initiative to define potential standards and best practice recommendations for transitional care.

Search strategy

The searches were carried out by L.L. and L.C. in Medline, Embase and PsycINFO (all from inception until October 2014). These included free text and MeSH terms synonyms of “RMD”, “transitional care” and “outcomes” (discussed in [Appendix for full search](#)). The search was limited to adolescents, children and young adults and to studies published in English, German and Spanish. In addition, we scanned the reference lists and the “Related articles” function on PubMed (www.pubmed.gov) of the included articles, and searched the abstracts of the ACR, EULAR and PRES meetings available on their official websites.

Study selection

Studies were selected if they described valid transition programmes in jRMDs. The term valid referred to programmes that had been described in sufficient details as to be reproducible and had been implemented and tested in real life conditions). Two reviewers (D.C. and L.L.), who had not participated in any of the transition programs published and thus had no conflicts of interest, independently examined the results captured by the searches for articles potentially relevant; first by scanning the title and abstract, and then by detailed review of the full text. Those articles that fulfilled the inclusion criteria were critically and independently appraised by the reviewers, extracting the following information on the transition programmes: country and setting of the programme, diseases and ages of the patients, resources—staff, transition coordinator, office—transition process, available indicators and effectiveness results. Any discrepancies were resolved by consensus with a methodologist (L.C.).

Quality assessment

In the absence of an available appropriate tool for systematic reviews of health services, we developed an *ad hoc* scale, based on the work of Campbell [8], to grade the quality of the programmes based on the following dimensions: level of definition/reproducibility, whether the programme was based on previous evidence-based benchmark research, availability of quality indicators and results/evidence of effectiveness of the programme ([Fig. 1](#)). Quality was assessed independently and then discussed to reach a consensus, by the reviewers and the methodologist.

Results

The electronic search yielded 521 articles (404 from PubMed, 116 from Embase and 1 from PsycInfo), plus 6 abstracts from congresses. In addition, a total of 10 references were obtained by reviewing the references of the included articles. The selection by title and abstract left 52 articles plus 6 abstracts for detailed review. Only 26 articles remained for critical appraisal, after excluding duplicated publications and articles not describing or signposting to a programme; these articles corresponded to 8 transition programmes. Another article, presenting results of the evaluation of one of these programmes, was available after the search was finished. [Figure 2](#) shows the flow chart to describe the literature search process.

[Tables 1](#) and [2](#) describe the programmes identified by the search process and the analysis to focus on the following areas.

Diseases and age of inclusion

All jRMDs were considered in 4 programmes, 3 of them were only applied to patients with juvenile idiopathic arthritis (JIA) and there was one generic programme for patients with various diseases, including a specific adaptation for RMD. Age at inclusion to the transition programme varied, starting as early as 11 years old and not later than age of 17 years. The patient's final transfer to an adult rheumatologist was variable and up to the age of 25 years.

Staff and setting

All the transition programmes began in the paediatric setting and continued into adult health care, sometimes with the development of transition clinics specifically designed for adolescents and young adults with RMD. Transitional care teams were composed of paediatric and adult rheumatologists with interest and training in adolescent rheumatology plus a clinical nurse specialist(s) as a minimum. Other health care professionals that could be part of the transition teams included physiotherapists, occupational therapists, psychologists, social workers and adolescent medicine specialists. Participation of the general practitioner was advocated not only for routine care—specific advice on contraception or intercurrent illnesses—but also for emotional support to patients and family [10,29–31]. All the programmes identified had a transition coordinator, namely a health care professional who was responsible to guide and support young persons and their families during the transition process. In most cases the transition coordinator was a clinical nurse specialist.

Transition processes

All transitional care programmes had a written transition policy and protocol agreed by the paediatric and adult teams that described in detail the transition process. Two components of these programmes were of particular importance: (1) information and education of both young persons and parents and (2) building-up of

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