

University of Dundee

Addressing education and employment outcomes in the provision of healthcare for young people with physical long-term conditions

Farre, Albert; Lunt, Laura; Lee, Rebecca; Verstappen, Suzanne; McDonagh, Janet E.

Published in:
Patient Education and Counseling

DOI:
[10.1016/j.pec.2023.107765](https://doi.org/10.1016/j.pec.2023.107765)

Publication date:
2023

Licence:
CC BY

Document Version
Publisher's PDF, also known as Version of record

[Link to publication in Discovery Research Portal](#)

Citation for published version (APA):

Farre, A., Lunt, L., Lee, R., Verstappen, S., & McDonagh, J. E. (2023). Addressing education and employment outcomes in the provision of healthcare for young people with physical long-term conditions: a systematic review and mixed methods synthesis. *Patient Education and Counseling*, 112, [107765].
<https://doi.org/10.1016/j.pec.2023.107765>

General rights

Copyright and moral rights for the publications made accessible in Discovery Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from Discovery Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain.
- You may freely distribute the URL identifying the publication in the public portal.

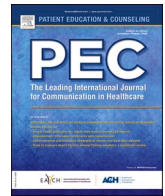
Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.



Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.journals.elsevier.com/patient-education-and-counseling

Addressing education and employment outcomes in the provision of healthcare for young people with physical long-term conditions: A systematic review and mixed methods synthesis

Albert Farre^{a,*}, Laura Lunt^{b,c}, Rebecca Lee^{b,c}, Suzanne Verstappen^{b,c}, Janet E. McDonagh^{b,c,d}

^a School of Health Sciences, University of Dundee, Dundee, UK

^b Centre for Epidemiology Versus Arthritis, University of Manchester, Manchester Academic Health Science Centre, Manchester, UK

^c NIHR Manchester Biomedical Research Centre, Manchester University NHS Foundation Trust, Manchester, UK

^d Department of Paediatric and Adolescent Rheumatology, Royal Manchester Children's Hospital, Manchester University NHS Foundation Trust, Manchester, UK

ARTICLE INFO

Keywords:

Adolescent health services
Chronic illness
Vocational guidance
Transition to adult care

ABSTRACT

Objective: To identify and synthesise the experiences and benefits of addressing vocational issues in the provision of healthcare for young people (YP) with long-term conditions (LTCs).

Methods: We searched 10 bibliographic databases. Restrictions were applied on publication date (1996–2020) and language (English). Two reviewers independently screened records against eligibility criteria. Articles reporting relevant qualitative and/or quantitative research were included. Quality appraisal was undertaken following study selection. Qualitative data were synthesised thematically, and quantitative data narratively. A cross-study synthesis integrated qualitative and quantitative findings.

Results: 43 articles were included. Thematic synthesis of qualitative studies (n = 23) resulted in seven recommendations for intervention (psychological support; information/signposting; skills training; career advice; healthcare-school/workplace collaboration; social support; flexible/responsive care). The narrative synthesis summarised results of 17 interventions (n = 20 quantitative studies). The cross-study synthesis mapped interventions against recommendations. Transitional care was the intervention type that most comprehensively met our proposed recommendations.

Conclusions: Evidence from YP perspectives highlights that vocational development is an important area to address in healthcare provision. Robust intervention studies in this area are lacking.

Practice implications: Our evidence-based recommendations for intervention can support health professionals to better address vocational issues/outcomes. With minimal adaptations, transitional care interventions would be particularly well suited to deliver this.

1. Introduction

Education and employment are two well-recognised social determinants of health which are relevant to all young people (YP) [1]. A much less studied but growing body of evidence also suggests that such associations have reverse implications too – i.e. health in childhood and adolescence is a determinant of poor education and employment outcomes in adulthood [2,3]. This evidence is of particular importance for YP living with physical long-term conditions (LTCs), who are more likely to experience poorer health, at critical times of their educational and career development and, therefore, be more at risk of not succeeding at mastering key vocational developmental milestones [4]. Vocational

development is a normal part of growing up, which starts in early childhood and is an integral component of adolescence. Several key vocational transitions occur during this stage of life [5–7]. In mid adolescence, YP are expected to have early notions of a future profession and will start to develop a vocational trajectory. In late adolescence, the formation of interests continues to evolve and YP develop vocational capability, including early work experiences. YP will make further vocational choices as they prepare to take on adult roles and responsibilities.

This raises an important question: can and should vocational issues be addressed in the provision of healthcare for YP with LTCs? Tensions between biomedical and psychosocial understandings of health and

* Correspondence to: School of Health Sciences, University of Dundee, 11 Airlie Place, Dundee DD1 4HJ, United Kingdom.

E-mail address: a.farre@dundee.ac.uk (A. Farre).

<https://doi.org/10.1016/j.pec.2023.107765>

Received 25 November 2022; Received in revised form 13 April 2023; Accepted 16 April 2023

Available online 17 April 2023

0738-3991/© 2023 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

illness, and with them, tensions around the role and importance of addressing non-physical aspects of illness as an integral part of clinical work and healthcare delivery, have historically been controversial [8]. A fundamental principle underpinning the practice of adolescent medicine, and the delivery of health services for YP more generally, is the provision of developmentally appropriate healthcare [9–11]. Developmentally appropriate healthcare is an approach to clinical work and healthcare delivery which is responsive to the dynamic nature of YP's development (understood as comprising biological, psychological, social and vocational aspects) and a defining characteristic of health services aimed at YP. Therefore, this would suggest that, at least philosophically, health services aimed at YP would consider the inter-relatedness of those domains and be prepared to address issues such as vocational development as integral to their role and a legitimate part of healthcare provision.

However, health providers' ability to enact such principles might be compromised by a range of limitations in practice such as service pressures, insufficient guidance and/or training, or lack of interventions available. In this context, it is important to bring together and critically examine the availability of existing interventions for health providers that can be used to help support and improve educational and employment outcomes for YP with LTCs. One example of such interventions are transitional care programmes. Transitional care is a well-recognised intervention [12], which is typically delivered in healthcare settings, to help prepare and support YP with LTCs to take on adult roles in relation to their health and successfully navigate adult-based healthcare. Although some studies have reported for some time that transitional care can successfully support vocational development [13], not all transitional care programmes explicitly address vocational issues [14,15]. Therefore, to help advance knowledge, research and practice in this area, it is important to examine if and how vocational issues have been addressed in healthcare settings to date.

The main overarching aim of this review was to identify and synthesise what is known about the experiences and benefits of addressing vocational issues in the provision of healthcare for YP with LTCs.

2. Methods

The protocol for this systematic review is registered on PROSPERO (CRD42016051359). We used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) to guide the current study report (see Appendix A) [16].

2.1. Search strategy

We systematically searched 10 electronic databases (MEDLINE; CINAHL; EMBASE; PsycINFO; Social Policy and Practice; Cochrane Library CDSR, DARE and CENTRAL; HMIC; Nursing and Allied Health Sources; ASSIA; and Sociological Abstracts) and one clinical trials register (ClinicalTrials.gov). Searches were conducted in January 2020 using combinations of index terms and free text words relating to 'young people' AND 'long-term conditions' AND 'vocational guidance' OR 'employment' OR 'educational attainment' (a sample search strategy for MEDLINE is provided in Appendix B). Restrictions were applied on publication date (1996–2020) and publication language (English). Reference lists of all included studies and relevant systematic reviews were scanned for eligible studies.

2.2. Eligibility criteria

Studies were included if they reported qualitative findings of primary research exploring the views and experiences of vocational issues/outcomes (either education or work related) of YP living with LTCs; or quantitative findings of primary research evaluating interventions addressing vocational issues/outcomes of YP with LTCs delivered in healthcare settings. Any types of healthcare settings were included.

YP were understood to be those in the age range of 10–24 years, in keeping with the definition by the World Health Organization (WHO) [17]. Where age ranges of participants were not provided by primary studies, only categories that can be associated with populations within the stipulated age range via identifiable definitions were included (e.g., adolescents, teenagers, young adults).

LTCs were understood as physical health conditions, therefore, study populations or interventions relating to mental health conditions only were excluded. The focus on physical health conditions was chosen to help address an evidence gap reported in a previous review [2] indicating that there was less evidence available for physical health conditions, compared with the evidence available for mental health conditions, on education and employment outcomes.

The perspectives of any stakeholders were included. (e.g. YP, parents/carers, doctors, nurses, allied health professionals, service managers).

2.3. Selection process

Two reviewers independently screened titles, abstracts, and relevant full texts against the predetermined eligibility criteria. Any discrepancies were resolved through discussion and consultation with a third reviewer.

2.4. Data extraction and quality appraisal

Data extraction was undertaken independently by two reviewers using a piloted data extraction form. Any discrepancies were resolved through discussion and consultation with a third reviewer.

Quality appraisal of qualitative studies was conducted using a piloted tool derived from a combination of items from the Standards for Reporting Qualitative Research [18] and the Critical Appraisal Skills Programme Qualitative Research Checklist [19]. Quality appraisal of quantitative studies was conducted using the Effective Public Health Practice Project Quality Assessment Tool (EPHPP) [20]. Quality appraisals were conducted independently by two reviewers. Any discrepancies were resolved through discussion and consultation with a third reviewer. Studies were not excluded based on the quality/adequacy of the reporting.

2.5. Data synthesis

We employed a mixed methods synthesis approach [21] comprising three interrelated syntheses: (1) a synthesis of qualitative data on stakeholders' views and experiences to develop a set of recommendations for interventions; (2) a synthesis of quantitative data on effectiveness of existing interventions; and (3) a cross-study synthesis to integrate qualitative and quantitative findings by mapping and summarising the effects of identified interventions against the set of recommendations arising from stakeholders' views and experiences.

For synthesis 1 (qualitative) we conducted a thematic synthesis [22] involving three stages: (1) line-by-line coding of the findings of the primary studies; (2) categorisation of codes into descriptive themes; and (3) development of analytical themes to develop a set of implications/recommendations for interventions. Primary research findings were understood to be all the text labelled as 'results' or 'findings' in the included papers. Included data therefore included both data extracts from participants and authors' descriptions, summaries and interpretations of primary data. Data were entered verbatim into QSR NVivo software and treated as qualitative data. To ensure the robustness of the findings, various techniques to enhance trustworthiness were used, including multiple coding and reviewer triangulation.

For synthesis 2 (effectiveness), given that the nature of included studies did not allow for a pooled analysis of primary data using statistical meta-analysis, we adopted a narrative approach to summarise the effects reported in included intervention studies. For all

interventions identified, we also aimed to examine any reported barriers/facilitators to their implementation.

For synthesis 3 (cross-study synthesis) we integrated qualitative and quantitative findings in two stages [21]. First, we assessed the identified interventions for the extent to which they addressed or incorporated the recommendations for interventions derived from the qualitative synthesis. Then, the narrative synthesis of intervention effects was organised according to how many recommendations were met by the evaluated interventions.

3. Results

The searches identified 5911 records, which were assessed against the inclusion criteria. Title and abstract screening resulted in 170 records considered eligible or inconclusive. Full-text articles were then retrieved and assessed for eligibility, resulting in 42 studies included in the final synthesis (Fig. 1).

3.1. Summary of included studies

A summary of key characteristics of included studies is presented in Table 1.

23 studies contributed qualitative data, including: interview studies (n = 10); focus group studies (n = 4); combined interview-focus group designs (n = 4); textual data from surveys (n = 2); combined interview-observation designs (n = 1); recorded video-calls (n = 1); and

ethnographic research (n = 1). Studies reported data from eight countries (UK, Canada, USA, Netherlands, Norway, Germany, Portugal, and Australia). Most studies focused on YP perspectives, with only a few including other stakeholders' views such as health providers, parents/carers, or teachers.

20 studies contributed quantitative data, including: randomised controlled trials (n = 5), non-randomised/quasi-randomised controlled trials (n = 3), uncontrolled/pseudo-controlled trials (n = 2), cohort studies (n = 8) and cross-sectional studies (n = 2). Studies reported data from seven countries (USA, Germany, UK, Netherlands, Australia, Saudi Arabia, and Portugal). Study samples in intervention groups ranged from 20 to 308 participants. Study settings included paediatric tertiary care hospitals, paediatric clinics/wards in general hospitals, combined paediatric-adult tertiary care hospitals, a behavioural medical centre and general practice.

3.2. Interventions

17 interventions were evaluated across the 20 quantitative studies included in this review. Most interventions were condition-specific (including chronic fatigue syndrome, chronic pain, juvenile idiopathic arthritis, chronic tension-type headache, and spina bifida), with eight interventions adopting a generic approach (i.e. targeting multiple LTCs) and one intervention combining both approaches.

The centrality of the vocational component/s of included interventions was assessed according to whether vocational issues were

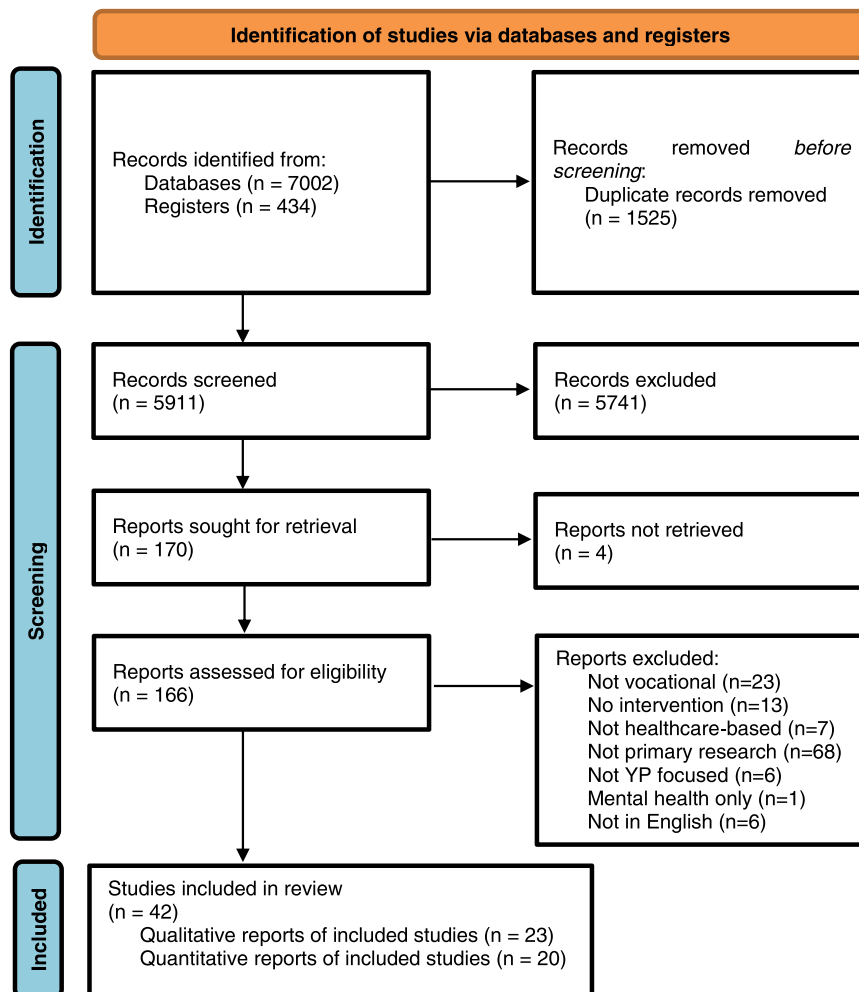


Fig. 1. : PRISMA Flow Diagram. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

Table 1
Key characteristics of the included studies.

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
Qualitative synthesis	Ahola Kohut et al. (2016)	Canada	Home (video-call)	Mixed sample (including Juvenile idiopathic arthritis and Chronic pain conditions)	Adolescents (12–17 years)	Qualitative	Qualitative content analysis of recorded video calls.	52 calls (representing 7 mentor–mentee pairings)	N/A	N/A	Peer mentorship program that provides modelling and reinforcement by young adult peer mentors who have learned to manage their chronic illness successfully to adolescents with the same chronic illness.	Evaluating topics discussed in a peer mentoring program for AYA with chronic illnesses	Topics of discussion during open-ended peer mentoring sessions	<ul style="list-style-type: none"> • <u>Intervention - indirectly addressed</u>: vocational issues considered but not targeted. • <u>Study - indirectly addressed</u>: no vocational specific aims, but outcomes included impact of chronic illness on school and work.
	Bomba et al. (2017)	Germany and Switzerland	Paediatric clinics	Mixed sample (including Type 1 diabetes, Cystic fibrosis, and Chronic inflammatory bowel disease)	Adolescents and young adults (15–27 years)	Qualitative	Individual and group interview. Qualitative content analysis.	Individual interviews (n = 11) Group interviews (n = 18)	N/A	N/A	A generic patient education programme for adolescents in transitional care.	(1) Investigation of experiences of and needs in transition of adolescents with chronic conditions, and (2) the integration of the findings into the design of a generic patient education programme for adolescents in transitional care.	Patient experiences and needs during transitional care period	<ul style="list-style-type: none"> • <u>Intervention - directly addressed</u>: explicit acknowledgment of vocational issues addressed in transitional care. • <u>Study - indirectly addressed</u>: no vocational specific aims, but outcomes included vocational issues.
	Burles and Thomas (2013)	Canada	Multiple settings	Mixed sample (including anorexia, breast cancer, depression, endometriosis, epilepsy, multiple sclerosis, primary hypoadrenalism and secondary hypothyroidism, and a malignant brain tumour)	Young adults (20–37 years)	Qualitative	Phenomenological and photovoice interviews. Data analysis informed by hermeneutic phenomenological approach.	10 participants (18 interviews and 111 photographs)	N/A	N/A	No intervention	To explore young adult women's experiences of having a life-threatening or chronic illness in order to better understand the role of life stage in serious illness experiences.	Experiences of living with a life-threatening or chronic illness.	<ul style="list-style-type: none"> • <u>Study - indirectly addressed</u>: no vocational specific aims, but outcomes included vocational issues (impact of being ill on education and employment goals).
	Dogba et al. (2014)	Canada	Hospital	Osteogenesis imperfecta (OI)	Adolescents and young adults (14–21 years) Parents Health Professionals	Qualitative	Case study approach including interviews, observations, and documents.	25 participants (including 6 patients, 4 parents, and 15 professionals)	N/A	N/A	Family-centred, transition focused care for adolescent and young adult patients with OI aged 14–21 years. In addition to transitional care, the program has links with external	To evaluate a transition program for adolescents and young adults with OI from the perspectives of the services users and staff.	Service users and staff views/ experiences (Strengths, Weaknesses, Opportunities and Threats) of the transition program.	<ul style="list-style-type: none"> • <u>Intervention - directly addressed</u>: explicit acknowledgment of vocational issues addressed in transition programme. • <u>Study -</u>

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
											organisations offering organised social events, such as camps and get-togethers, to help prepare young adults with special needs for adult life.			<u>indirectly addressed</u> ; no vocational specific aims, but outcomes included vocational issues.
	Farre et al. (2019)	UK	Hospital	Arthritis	Young people (10–29 years)	Qualitative	Narrative and semi-structured interviews. Thematic analysis.	39 participants	N/A	N/A	No intervention	To explore education and employment related aspects of the overall experiences of young people living with arthritis during early adolescence through to young adulthood.	Educational and early work experiences	• Study - <u>directly addressed</u> ; vocational specific aims/outcomes.
	Ferguson and Walker (2014)	Australia	Paediatric hospital	Mixed sample of LTCs (sharing the issue of resulting in significant school absences)	Adolescents (10–18 years)	Qualitative	Longitudinal case studies, using ethnography, semi-structured and open interviews. Interpretive and thematic analyses.	31 participants	N/A	N/A	No intervention	To investigate the social and educational experiences of young people whose schooling has been disrupted due to an ongoing health condition.	Strategies and relationships used by participants to help manage their LTCs and maintain or re-establish education and social connections.	• Study - <u>directly addressed</u> ; vocational specific aims/outcomes.
	Gee et al. (2007)	USA	Hospital	Diabetes	Young adults (19–26 years)	Qualitative	Semi-structured telephone interviews. Thematic analysis.	23 participants	N/A	N/A	No intervention	To highlight the issues that confront urban, underserved minority young people with diabetes as they enter adulthood.	Concerns about managing their disease.	• Study - <u>indirectly addressed</u> ; no vocational specific aims, but outcomes included vocational issues.
	Hanson et al. (2018)	UK	Hospital	Juvenile idiopathic arthritis	Young people (16–25 years) Adults (26–31 years) Health professionals	Qualitative	Semi-structured interviews and focus groups. Thematic analysis.	38 participants (26 young people, 3 adults, and 9 health professionals)	N/A	N/A	No intervention	To explore the expectations and experiences of employment among young people with JIA, and the actual and potential role of the multidisciplinary team in promoting positive employment outcomes.	Expectations and experiences of employment.	• Study - <u>directly addressed</u> ; vocational specific aims/outcomes.
	Hauser & Dorn (1999)	USA	Paediatric Sickle cell	Sickle cell disease	Adolescents (13–21 years)	Qualitative	Focus groups. Content analysis.	52 participants (22 adolescents,	N/A	N/A	No intervention	To develop a framework to guide the	Concerns, expectations, and	• Study - <u>indirectly addressed</u> ; no

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
			disease centres		Parents Health professionals			22 parents, and 8 practitioners)				transition of sickle cell disease patients from child-centred care to adult-centred care.	preparation needs the adolescent/ young adult and parents have about the move from child-centred to adult-centred care.	vocational specific aims, but outcomes included vocational issues.
	Holley et al. (2018)	UK	Primary and secondary care sites	Asthma	Adolescents (12–18 years) Parents Health professionals	Qualitative	Focus groups and interviews. Inductive thematic analysis.	54 participants (28 adolescents, 12 parents, and 14 health professionals)	N/A	N/A	No intervention	To explore views about barriers and facilitators to self-management of asthma from the perspective of adolescents, their parents and their health professionals.	Views and experiences of self-management.	• Study - indirectly addressed: no vocational specific aims, but outcomes included vocational issues.
	Jetha et al. (2018a)	Canada	Multiple settings	Arthritis	Young adults (18–34 years) Middle-aged adults (35–54 years) Older adults (>55 years)	Qualitative	Focus groups and interviews. Thematic analysis using a modified grounded theory approach.	45 participants (7 young adults, 13 middle-aged adults, and 25 older adults)	N/A	N/A	No intervention	To understand the similarities and differences in the employment participation of people living with arthritis across the life course.	Impact of arthritis on employment, experiences with health-related changes, career progression and social role involvement.	• Study - directly addressed: vocational specific aims/ outcomes.
	Jetha et al. (2018b)	Canada	Multiple settings	Arthritis	Young adults (18–34 years) Middle-aged adults (35–54 years) Older adults (>55 years)	Qualitative	Focus groups and interviews. Thematic analysis using a modified grounded theory approach.	45 participants (7 young adults, 13 middle-aged adults, and 25 older adults)	N/A	N/A	No intervention	To examine the need for and availability and use of formal and informal workplace resources and to uncover differences across the life course in adults with arthritis.	Employment experiences, formal and informal workplace resource needs, and availability and use of workplace resources.	• Study - directly addressed: vocational specific aims/ outcomes.
	Lewis and Arber (2015)	UK	Hospital	Renal failure	Young adults (16–30 years)	Qualitative	Semi-structured interviews. Modified grounded theory.	35 participants	N/A	N/A	No intervention	To explore how a serious chronic illness in childhood affects education and employment in early adulthood.	Views and experiences of education and employment.	• Study - directly addressed: vocational specific aims/ outcomes.
	Palmer and Boisen (2002)	USA	Large, metropolitan Cystic Fibrosis Centre	Cystic Fibrosis	Young adults (20–26 years)	Qualitative	Semi-structured interviews. Content analysis.	7 participants	N/A	N/A	No intervention	To examine the perceptions of young adults with Cystic Fibrosis regarding the impact the disease has had on their	Perceptions on the impact of disease in their lives.	• Study - indirectly addressed: no vocational specific aims, but outcomes

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
												lives, especially during the transition from adolescence to adulthood.		included vocational issues.
	Pini (2009)	UK	Hospital	Cancer	Young adults (13–25 years)	Mixed-methods	Focus groups and questionnaire	39 participants (29 patients, and 10 staff)	N/A	N/A	Teenage and young adult learning mentor. The role provides education support to oncology patients. It is a patient-led service, driven by the individual needs of patients.	To evaluate the impact of the learning mentor role.	Benefits of the role.	● Study - <u>indirectly addressed</u> : no vocational specific aims, but outcomes included vocational issues.
	Sen et al. (2017)	UK	Hospital	Juvenile idiopathic arthritis-associated uveitis	Children and young people (6–18 years) Parents	Qualitative	Semi-structured interviews. Inductive thematic analysis.	10 children and young people and their parents	N/A	N/A	No intervention	To explore the subjective experience of children and young people being treated for chronic, non-infectious uveitis associated with a systemic disease such as juvenile idiopathic arthritis.	Experiences of impact of illness/treatment/complications on health-related quality of life.	● Study - <u>indirectly addressed</u> : no vocational specific aims, but outcomes included vocational issues.
	Shaw et al. (2006)	UK	Hospital	Juvenile idiopathic arthritis	Adolescents (12–17 years)	Qualitative	Focus groups. Interpretive phenomenological analysis.	8 participants	N/A	N/A	No intervention	To explore the prevocational and early employment needs of adolescents with JIA from their own perspectives.	Perceptions about the meaning of juvenile idiopathic arthritis and vocation.	● Study - <u>directly addressed</u> : vocational specific aims/outcomes.
	Sluman et al. (2014)	Netherlands	Tertiary referral centre	Congenital heart disease	Young adults (22–35 years)	Qualitative	Semi-structured in-depth interviews. Directed content analysis.	15 participants	N/A	N/A	No intervention	To gain insight into current barriers and facilitating experiences at work among young adult patients with congenital heart disease.	Barriers and facilitators experienced at work.	● Study - <u>directly addressed</u> : vocational specific aims/outcomes.
	Taylor et al. (2010)	UK	Hospital	Liver transplant	Young people (12–18 years)	Qualitative	Semi-structured interviews. Framework analysis.	14 participants	N/A	N/A	No intervention	To explore young people's lived experience of life after transplantation.	Experiences of quality of life.	● Study - <u>indirectly addressed</u> : no vocational specific aims, but outcomes included vocational issues.
	Thomas and Taylor (2002)	UK	Hospital	Sickle cell disease	Adolescents and young adults	Qualitative	Focus groups. Phenomenological	25 participants	N/A	N/A	No intervention	To gain an understanding of the psychosocial	Views and experiences of sickle cell	● Study - <u>indirectly addressed</u> : no

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
					(15–35 years)		approach to data analysis.					impact of sickle cell disease.	disease impacts on the quality of life.	vocational specific aims, but outcomes included vocational issues.
	Twiddy et al. (2017)	UK	Hospital	Chronic pain	Young adults (18–30 years)	Qualitative	Focus groups. Thematic analysis.	18 participants	N/A	N/A	No intervention	To investigate the needs of young adults attending a tertiary level National Health Service Pain Management Programme Service in the United Kingdom; exploring how these needs may translate on to clinical assessment and the delivery of rehabilitation interventions.	Needs of young adults with chronic pain.	<ul style="list-style-type: none"> • <u>Study - indirectly addressed</u>: no vocational specific aims, but outcomes included vocational issues.
	Winger et al. (2014)	Norway	Hospital	Chronic fatigue syndrome	Adolescents (12–18 years)	Qualitative	In-depth interviews. Phenomenological, hermeneutical approach to data analysis.	18 participants	N/A	N/A	No intervention	To explore the experiences of living with chronic fatigue syndrome during adolescence.	Experiences of living with chronic fatigue syndrome.	<ul style="list-style-type: none"> • <u>Study - indirectly addressed</u>: no vocational specific aims, but outcomes included vocational issues.
Qualitative and Quantitative syntheses	Magalhães et al. (2018)	Portugal	General hospital	Mixed sample of paediatric ward inpatients	Parents/ caregivers and teachers of hospitalised children and adolescents (6–17 years)	Mixed-methods	Cohort study. Questionnaires. Descriptive statistics and thematic analysis.	231 participants (185 parents/ caregivers and 46 teachers)	185	N/A	Psychoeducational intervention programme delivered by educational psychologists and a hospital teacher, including psychoeducational activities tailored to the length of each individual hospital stay, and linkage to school to smooth the transition back to school and help to overcome the missed school-time.	To describe the experiences and perspectives of parents/caregivers and school teachers of patients who received the intervention.	Parents/ caregivers and teachers experiences.	<ul style="list-style-type: none"> • <u>Intervention - directly addressed</u>: dedicated intervention targeting vocational issues. • <u>Study - directly addressed</u>: vocational specific aims/ outcomes.
Quantitative synthesis	Al-Haggar et al. (2006)	Saudi Arabia	General practice, specialist clinic	Chronic fatigue syndrome	Adolescents (10–14 years)	Quantitative	Randomised controlled trial	92 participants	50	42	Cognitive behavioural therapy sessions guided by biofeedback. Sessions ran for a period of 18 months 40–60 sessions ranging for	To evaluate the efficacy of cognitive behavioural therapy aided with biofeedback machines in treatment of adolescents	Fatigue severity	<ul style="list-style-type: none"> • <u>Intervention - indirectly addressed</u>: vocational issues considered but not targeted. • <u>Study - indirectly addressed</u>:

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
	Ammerlaan et al. (2017)	Netherlands	Paediatric hospital	Juvenile idiopathic arthritis	Young adults (16–25 years)	Quantitative	Randomised controlled trial	72 participants	36	36	1–2 per week. Sessions included patients and family. Patient also told to keep a personal diary. Web-based self-management intervention guided by peer-trainers. Based on the self-efficacy theory of Bandura. The intervention is led by young peer trainers in the age range of 20–30 years who suffer from arthritis themselves.	suffering from chronic fatigue. To investigate the effectiveness of a web-based self-management intervention guided by peer-trainers.	Self-efficacy	secondary vocational outcomes included (school attendance). ● <u>Intervention - indirectly addressed:</u> vocational issues considered but not targeted. ● <u>Study - indirectly addressed:</u> secondary vocational outcomes included (absenteeism of school or work).
	Betz et al. (2010)	USA	Paediatric hospital	Spina bifida	Adolescents (14–18 years)	Quantitative	Randomised controlled trial	65 participants	31	34	A cognitive-behavioural program, Transition Preparation Training in combination with spina bifida management. A three-module, eight session program offered in a 2 day workshop format that involved the development of an adolescent-centred transition plan based on comprehensive assessment of the adolescent's goals for the future.	To examine whether a cognitive-behavioural program of Transition Preparation Training in combination with SB management, leads to improved transition subjective well being, role mastery, and self-care practice.	Subjective well-being, role mastery, and self-care practice.	● <u>Intervention - directly addressed:</u> explicit acknowledgment of vocational issues addressed by intervention components. ● <u>Study - indirectly addressed:</u> secondary vocational outcomes included (productivity as part of psychosocial adjustment, and interest-hobbies as part of community life skills).
	Chalder et al. (2010)	UK	General hospital	Chronic fatigue syndrome	Adolescents (11–18 years)	Quantitative	Randomised controlled trial	63 participants	32	31	Family-focused cognitive behaviour therapy, based on a previously developed model tailored to adolescents with chronic fatigue syndrome. Thirteen 1-hour sessions of cognitive	To compare the efficacy of family-focused cognitive behaviour therapy with a briefer, easier to deliver psycho-education intervention.	Attendance at school/college/work.	● <u>Intervention - indirectly addressed:</u> vocational issues considered but not targeted. ● <u>Study - directly addressed:</u> vocational primary outcomes.

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
	Claar et al. (2012)	USA	Paediatric hospital	Chronic tension-type headache	Adolescents (12–17 years)	Quantitative	Cohort study	47 participants	47	N/A	behaviour therapy were offered every 2 weeks. Multidisciplinary evaluation (by a neurologist and clinical psychologist, of approximately 1 h each) focusing on a return to functioning despite headaches. Families were provided with feedback by clinic nurse (approximately 20 min) that integrated the results of both evaluations and emphasised a return to functioning, especially school, despite headaches.	To examine (1) if school functioning/attendance improve after participation in a multidisciplinary headache evaluation that emphasises a return to function despite pain, and (2) if patients experience an improvement in headache frequency, severity, and duration 2–3 months after their initial evaluation and at 6 months follow-up.	School functioning, school attendance, and headache characteristics (frequency, severity, and duration).	<ul style="list-style-type: none"> • <u>Intervention - directly addressed:</u> explicit acknowledgment of vocational issues addressed by intervention components. • <u>Study - directly addressed:</u> vocational primary outcomes.
	Distelberg et al. (2014)	USA	Behavioural medical centre	Mixed sample (including type I diabetes, chronic kidney disease, rheumatoid arthritis, and cancer)	Adolescents (13–16 years)	Quantitative	Cohort study	22 participants	22	N/A	Mastering Each New Direction (MEND) is a biopsychosocial intensive outpatient program that provides mental health treatment for children (ages 8–18) diagnosed with a chronic illness and their family members. MEND uses individual and family therapy as well as peer group and multifamily group processes over the course of 21 sessions (three sessions a week for 7 weeks). The desired outcome of MEND is to increase treatment adherence as well as improve disease-specific outcomes.	To evaluate a family systems intervention for managing paediatric chronic illness.	Health-related quality of life	<ul style="list-style-type: none"> • <u>Intervention - directly addressed:</u> explicit acknowledgment of vocational issues addressed by intervention components. • <u>Study - indirectly addressed:</u> secondary vocational outcomes included (school functioning as part of paediatric health-related quality of life).
	Emerson et al. (2016)	USA	Behavioural medical centre	Mixed sample (including type I diabetes, nephrotic syndrome, transplant, and cancer)	Children and adolescents (8–18 years)	Quantitative	Cohort study	48 participants	48	N/A	over the course of 21 sessions (three sessions a week for 7 weeks). The desired outcome of MEND is to increase treatment adherence as well as improve disease-specific outcomes.	To investigate the role of social and physical functioning in reducing school absenteeism in youths participating in the MEND intervention.	Health-related quality of life and school absenteeism	<ul style="list-style-type: none"> • <u>Intervention - directly addressed:</u> explicit acknowledgment of vocational issues addressed by intervention components. • <u>Study - directly</u>

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
														<u>addressed</u> : vocational primary outcomes (school absenteeism) and secondary vocational outcomes (school functioning as part of paediatric health-related quality of life).
	Fernandes et al. (2014)	USA	Paediatric hospital	Mixed sample (including type I diabetes, Congenital heart disease, Juvenile rheumatoid arthritis, Hematologic disorder, Inflammatory bowel disease, Cystic fibrosis, Solid organ transplant, Genetic disorders, Renal disease requiring dialysis)	Young people (16–25 years)	Quantitative	Cross-sectional study	155 patients 104 parents (with 93 being patient-parent/guardian pairs)	N/A	N/A	Transition and self-management skills education provided across included clinics, departments and healthcare teams.	To assess the quality of transition education and identify deficiencies in the provision of transitioning education.	Patients' and parents' perceptions of transition education.	<ul style="list-style-type: none"> • <u>Intervention - indirectly addressed</u>: vocational issues considered but not targeted. • <u>Study - indirectly addressed</u>: secondary vocational outcomes included (impact of disease on patient's future education/career/vocation).
	Gauntlett-Gilbert et al. (2013)	UK	General hospital	Chronic pain	Adolescents (10–19 years)	Quantitative	Uncontrolled trial	98 participants	98	N/A	3-week Acceptance and Commitment Therapy (ACT) based residential pain management program. 90 h of treatment over 15 days. Parents attended with child to all sessions except for 4 day period of separate learning. The clinical team met three times per week to ensure consistency of approach and theoretical integrity.	To examine the effects of Acceptance and Commitment Therapy (ACT) treatment on a severely disabled group of adolescents with chronic pain, examining relationships between outcome and acceptance.	Functional disability	<ul style="list-style-type: none"> • <u>Intervention - indirectly addressed</u>: vocational issues considered but not targeted. • <u>Study - indirectly addressed</u>: secondary vocational outcomes included (school attendance).
	Hechler et al. (2009)	Germany	Paediatric hospital	Chronic pain	Adolescents (11–18 years)	Quantitative	Cohort study	167 participants	167	N/A	Multimodal Inpatient Pain Treatment. A multi-professional team including paediatricians, clinical psychologists,	To investigate the effectiveness of a 3-week multimodal inpatient pain program for children and	Pain intensity, pain-related disability, and emotional distress.	<ul style="list-style-type: none"> • <u>Intervention - indirectly addressed</u>: vocational issues considered but not targeted. • <u>Study - indirectly</u>

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
	Hirschfeld et al. (2012)	Germany	Paediatric hospital	Chronic pain	Adolescents (11–18 years)	Quantitative	Cohort study	167 participants	167	N/A	children and adolescent psychiatrists, paediatric nurses, physiotherapists, occupational therapists, and social workers delivered the inpatient program. Treatment duration was 3 weeks. Similar to the child, parents were actively engaged in the treatment process by initiating changes in daily routines (e. g., supporting the child to attend school despite pain). Reintegration into the adolescent's daily life was initiated from the second week onwards comprising of visits at home and school.	adolescents with chronic pain. To investigate the long-term effectiveness of a 3-week multimodal inpatient program for children and adolescents with chronic pain.	Pain intensity, pain-related disability, and emotional distress.	<u>addressed</u> : secondary vocational outcomes included (school absence). ● <u>Intervention - indirectly addressed</u> : vocational issues considered but not targeted. ● <u>Study - indirectly addressed</u> : secondary vocational outcomes included (school absence).
	Lim & Lubitz (2002)	Australia	Paediatric hospital	Chronic fatigue syndrome	Adolescents (10–19 years)	Quantitative	Cohort study	57 participants	57	N/A	Intensive multidisciplinary inpatient programme. The programme focuses on both the physical and emotional issues of adolescents with CFS and takes 4 weeks to complete, including a return to full-time school at the end of the programme with the cessation of home-based education.	To investigate the response to the programme and long-term outcome.	School attendance, physical activity, and social activity	● <u>Intervention - directly addressed</u> : explicit acknowledgment of vocational issues addressed by intervention components. ● <u>Study - directly addressed</u> : vocational primary outcomes.
	Maslow et al. (2013)	USA	Paediatric hospital	Mixed sample (including Celiac disease, Cerebral palsy, Cystic fibrosis, Diabetes, Ehlers–Danlos syndrome, Endometriosis,	Youth (13–19 years)	Quantitative	Cohort study	20 participants	20	N/A	Group mentoring program called The Adolescent Leadership Council (TALC) that brings together high school participants and college	To examine the outcomes of a group mentoring program for youth with chronic physical illness using the principles of PYD.	Loneliness, self-management competence, self-advocacy confidence, high school graduation,	● <u>Intervention - directly addressed</u> : dedicated intervention targeting vocational issues. ● <u>Study - directly</u>

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
				Epilepsy, Inflammatory bowel disease, Migraine, Nemaline myopathy, Peripheral neuropathy, Sickle cell disease, Stickler syndrome, Systemic lupus erythematosus, and Takayasu arteritis)							mentors, all with chronic illness. TALC uses a positive youth development (PYD) approach, emphasizing strong relationships between youth and adults in an environment where youth can learn important life skills and take a leadership role.		college attendance, influence on educational choices, employment status, career choice, influence on vocational choices, primary/specialist care attendance, health care transition mentor.	addressed : vocational specific aims and primary outcomes.
	McDonagh et al. (2007)	UK	Paediatric hospital	Juvenile idiopathic arthritis	Adolescents (11–18 years)	Quantitative	Pseudo-controlled trial	308 adolescents 303 parents	308	N/A	A programme of transitional care (PTC) centred on templates for individualized transition plans (ITP). The ITP templates were created for the young person and the parent to reflect both adolescent development as well as the components of the transition programme in terms of health, home and school.	To determine whether the quality of life of adolescents with JIA could be improved by a co-ordinated, structured multidisciplinary, evidence-based, transitional care programme.	Health-related quality of life	Intervention - directly addressed : explicit acknowledgment of vocational issues addressed by intervention components. Study - indirectly addressed : secondary vocational outcomes included (pre-vocational experience).
	Menrath et al. (2018)	Germany	Paediatric hospital	Mixed sample (including asthma, attention-deficit/hyperactivity disorder, T1D, phenylketonuria, IBD, CF, chronic kidney disease, epilepsy, liver or kidney transplantation, oesophageal atresia, juvenile idiopathic arthritis and Ehlers-Danlos syndrome)	Young people (15–24 years)	Quantitative	Quasi-randomised controlled trial	300 participants	166	134	The education program (ModuS-T) was designed as a compact workshop in a group setting for youth and their parents. The education program contained youth specific topics such as the transfer to adult care, the influence of disease on the daily life of YP, and other important issues like detachment from parents, occupational career, intimate	To demonstrate the efficacy of a modular transition education program (ModuS-T) for youth and their parents in regular health care services.	Satisfaction with the program, transition-specific knowledge, transition competencies, patient activation and health-related quality of life.	Intervention - directly addressed : explicit acknowledgment of vocational issues addressed by intervention components. Study - indirectly addressed : secondary vocational outcomes included (work-related preparedness).

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
											relationships and family planning. The program focused on improving competencies relevant for transition and self-management skills of the families.			
	Schmidt et al. (2016)	Germany	Paediatric hospital	Mixed sample (including type 1 diabetes, cystic fibrosis, inflammatory bowel disease)	Adolescents (15–21 years)	Quantitative	Quasi-randomised controlled trial	274 participants	142	132	A manualised two-day transition workshop carried out at 12 sites in Germany, focusing in standardized modules (eight modules, each of 60–90 min duration) on adjustment to adult care settings, organization of future disease management, career choices and partnership. The content of the curriculum is largely generic but some modules include integrated condition-specific aspects. A psychologist and a paediatrician led the transition workshop, for some modules a young adult with a chronic condition and a doctor practicing adult medicine were invited as experts.	To test the effects of a generic transition-oriented patient education program on adolescents' health service participation and quality of life.	Health-related transition competence, self-efficacy, satisfaction with care, patient activation, and quality of life.	<ul style="list-style-type: none"> • <u>Intervention - directly addressed</u>: explicit acknowledgment of vocational issues addressed by intervention components. • <u>Study - indirectly addressed</u>: secondary vocational outcomes included (work-related preparedness, and satisfaction with school/ educational services).
	Schmidt et al. (2018)	Germany	Paediatric hospital	Mixed sample (including inflammatory bowel disease, and diabetes)	Adolescents (14–20 years)	Quantitative	Quasi-randomised controlled trials	285 participants	149	136		To investigate the effects of a transition-oriented patient education program (PEP) on quality of life and self-management in young patients with IBD (PEP naive), compared to patients with diabetes.	Health-related transition competence, and quality of life.	<ul style="list-style-type: none"> • <u>Intervention - directly addressed</u>: explicit acknowledgment of vocational issues addressed by intervention components. • <u>Study - indirectly addressed</u>: secondary vocational outcomes included (work-related preparedness).
	Shaw et al. (2013)	UK	Paediatric and adult hospitals	Mixed sample (long-term condition of childhood/ adolescent onset)	Young people (11–21 years)	Quantitative	Cross-sectional study	457 young people 330 parents	N/A	N/A	Range of transitional care models translating guidance into routine clinical practice within a single paediatric	To examine the quality of transitional care in a paediatric and adult hospital by investigating (i) adherence to	Satisfaction with transitional care	<ul style="list-style-type: none"> • <u>Intervention - directly addressed</u>: explicit acknowledgment of vocational issues addressed

(continued on next page)

Table 1 (continued)

Contributing data to	Paper	Country	Study setting	Health condition (s)	Participants	Research type	Study design	Sample size	Int. group sample size	Control group sample size	Intervention description	Study aims	Primary outcomes	Centrality of vocational issues in interventions and studies
	Stulemeijer et al. (2004)	Netherlands	Paediatric hospital	Chronic fatigue syndrome	Adolescents (10–17 years)	Quantitative	Randomised controlled trial	71 participants	36	35	hospital and its neighbouring adult facility. Cognitive behaviour therapy, comprising 10 individual sessions over five months. Parents were actively involved. The aims of therapy took into account the specific developmental tasks of adolescents. Return to full time education was always a goal of treatment, and a plan for returning to school was discussed early with everyone involved. Four child therapists who were trained and supervised by an experienced cognitive behavioural therapist administered all therapy.	national transition guidance and (ii) whether implementation is associated with better patient/ carer experiences. To study the efficacy of cognitive behaviour therapy for adolescents with chronic fatigue syndrome by comparing outcome in those randomly assigned to immediate therapy with outcome in those who were assigned to the waiting list for therapy.	Fatigue severity, functional impairment, and school attendance.	by intervention components. • <u>Study - indirectly addressed:</u> secondary vocational outcomes included (transitional care models addressing educational/ vocational issues). • <u>Intervention - directly addressed:</u> explicit acknowledgment of vocational issues addressed by intervention components. • <u>Study - directly addressed:</u> vocational primary outcome included (school attendance).

directly/indirectly targeted by the intervention and whether vocational issues were part of primary aims/outcomes of intervention studies. Most interventions targeted vocational issues directly, but these were not always the primary aim/outcome, with only six interventions identified to both directly target vocational issues as well as to primarily expect vocational aims and outcomes. The remaining interventions did not target vocational issues directly but expected effects on vocational outcomes.

Intervention strategies relied on a wide range of approaches, including psychological/psychoeducational interventions; transitional care interventions; multidisciplinary/multimodal inpatient programmes; a self-management intervention guided by peer-trainers; a multidisciplinary clinic and treatment approach; and a group mentoring programme.

3.3. Quality appraisal

Our appraisal of included qualitative studies suggested that, overall, articles reported valuable research and credible findings (Table 2). However, a range of reporting issues were identified, most notably across three domains: (1) the comprehensiveness of descriptions and justifications of sampling and recruitment strategies; (2) the relationship between researchers and participants; and (3) the extent to which ethical issues were taken into consideration. Appendix C (Table C.1) provides further details of our appraisal for each included qualitative study.

Our appraisal of included quantitative studies suggested that, overall, the quality of currently available evidence on intervention effectiveness is at high risk of bias (Table 3). Most included studies were globally rated as 'weak', except for three studies which were rated as 'moderate', and no studies globally rated as 'strong'. Appendix C (Table C.2) provides further details of our appraisal for each included quantitative study.

3.4. Stakeholders' perceptions and experiences: recommendations for intervention

Stages 1 and 2 of our thematic synthesis resulted in the categorisation of primary qualitative data from the included studies into two overarching descriptive themes: 'Impact of living with a LTC on school and work' and 'Role of services in promoting positive education and employment outcomes'. Building on these findings, further analytical work and team discussion was undertaken to inform stage 3 of our thematic synthesis, which translated the descriptive themes and sub-themes arising from stakeholders' perspectives into a set of seven recommendations for interventions. Recommendations are described below. Appendix D illustrates the distribution of qualitative studies underpinning the developed recommendations (Table D.1) and provides exemplar data extracts from primary studies (Table D.2).

3.4.1. Recommendation 1 – provide psychological support

Some studies showed how the provision of vocational support encompasses an element of psychological support [23–27]. This was well illustrated by YP's experiences which highlighted a range of psychological implications associated with negotiating educational and vocational trajectories, including: anxiety tied to dilemmas/implications of disclosing their illness status to potential/current employers or teachers [24–26,28–32]; anxiety about their ability to cope with demands of education/work [24,25,33,34]; concerns about discrimination and negative experiences with others at school/work [24–26,31–35]; coping with the implications of illness-related disruptions to education/employment such as academic attainment or work performance [28–31,36–39]; coping with the financial ramifications of education/employment setbacks [29,31,36,38,40]; and adjusting to forced illness-related shifts in one's education/employment goals and expectations [29,30,36,39].

3.4.2. Recommendation 2 – provide information, signposting and facilitate access to supporting services

YP expressed the added proactiveness required from them to negotiate the journey towards attaining their future goals and the often-unknown rights and services that could support them in that journey, with some anxieties and insecurities associated with having to overcome issues such as: feeling the genuineness of their illness questioned by employers and financial ramifications of education and employment setbacks [29,31,36,40]; lack of optimised learning/work opportunities through disruptions to education and employment [24,29,31,33,36]; limited knowledge of rights and employers obligations [25,26,30,32,33,40]. Overall, included qualitative studies showed how YP with LTCs still retained clear goals, showed determination to carry on with their education and work [25,37] and were proactive in attaining that future [39]. Nevertheless, the importance of providing information and signposting about rights and services/resources that can support this journey, particularly during key education and employment transitions, was echoed by YP and healthcare providers [25,27,29,32,40–42].

3.4.3. Recommendation 3 – provide skills training

YP's views and experiences reflected the need for and importance of mastering key vocational skills relevant to the journeys of YP with LTCs in both education and employment, including: whether, when and how to disclose their illness status at school or to a prospective employer [24,25,28–30,32,33,39]; disease-specific individual work/learning competencies to accommodate aspects of one's condition into performance expectations or job/study requirements [25,42–44]; prevocational skills such as how to develop a CV, complete a job application and interview for a job [24,25,41]; managing relationships with peers, colleagues and teachers/employers [24,25,30,35,42]; and self-advocacy skills at school and work [24–26,29,30,34,39,44].

3.4.4. Recommendation 4 – provide specialist career advice

Planning one's future and career is a very important issue for every young person, however, for those with LTCs, this presented them with a range of additional challenges, restrictions, stress, insecurities and fears associated with having to consider their future life and career opportunities in light of their LTC [23,24,26,27,29,30,32,33,36,39–41,44]. Issues ranged from choosing an appropriate job, apprenticeship, or university to accommodate their condition through to specific concerns about entering the labour market, having to rethink one's career choice or rights and benefits entitlements. However, YP's experiences also indicate that appropriate advice and support can lead to positive vocational outcomes [23–27,30,32] and that, despite any forced career shifts and additional challenges due to their LTC, YP retain a strong determination to set and pursue goals to advance their careers, whether in education or employment, and irrespective of the nature and severity of their LTC [25,29,30,33,36,39,40].

3.4.5. Recommendation 5 – liaise with key stakeholders in educational or workplace settings

YP's experiences at school/work suggested that their needs were often misunderstood or insufficiently addressed. YP's early work experiences tended to be characterised by short-term, entry-level jobs often lacking support [25,26,35] with the physical load of their work being perceived as too high [25,31,35]. Similarly, the experiences of those in education were characterised by issues affecting their academic achievement and lack of understanding and appropriate support [24,27,28,31,37] often persisting even when adaptations were in place [34]. Therefore, ensuring appropriate resources and establishing a supportive environment in education/work settings are very important issues for YP [24,26,28,30,31,35,37,39,45]. Health professionals are uniquely placed to act as advocates for YP with LTC [24,25] by addressing education/employment transitions as part of transitional care [24,25,29,30,32] and offering to liaise between YP and their main places of education/work where needed [27,39,43].

3.4.6. Recommendation 6 – provide or facilitate access to social support

Participants recognised the provision of access to social support as an important part of promoting positive education and employment outcomes in the context of service provision [23–25,28,42]. Meeting other YP with the same LTC was reported as a positive experience, contributing to confidence and emotional well-being [25]; providing a space of discussion through shared understanding in terms of the impact of their LTC on their school and work lives [25,44]. However, some YP also suggested that social support was important beyond the circle of peers with LTCs, with friends and partners more broadly being perceived as equally key as sources of support [28].

3.4.7. Recommendation 7 – provide flexible care and optimal disease management to support education/employment transitions

The road to positive education and employment outcomes requires YP to overcome physical, psychological and social challenges which in turn requires optimal disease management [25] delivered in the context of flexible and convenient care [25,39,40,42,45] that is responsive to YP's school and work lives, particularly at key times such as school/work transitions, exams or job changes.

3.5. Mapping and effectiveness of interventions by recommendations arising from stakeholders' perspectives

The mapping of interventions against the set of recommendations arising from stakeholders' perspectives resulted in four groups of interventions, based on the number of recommendations met, which ranged from two to five. Table 4 presents a detailed distribution of the included interventions across the seven recommendations.

3.5.1. Interventions meeting two recommendations

Six interventions met two recommendations. Three of these studies were randomised controlled trials (RCTs), which evaluated different types of Cognitive Behavioural Therapy (CBT) based interventions but shared a focus on chronic fatigue syndrome (CFS), considering school attendance as either primary or secondary outcome:

- One study examined the efficacy of CBT by comparing outcomes between those assigned to waiting list and those randomly assigned to immediate therapy, and found a significant increase in school attendance (18.2% increase, with $P=0.040$) in the immediate therapy group [46].
- These findings were echoed by another RCT, which compared a family-focused CBT intervention with a psycho-education intervention, and found that improvements in school attendance following CBT were maintained up to a year after discharge. However, the study also found that psycho-education was as effective as family-focused CBT at 6 and 12 months follow-up for both the primary outcome (i.e. school attendance) and the secondary outcomes relating to education/employment (i.e. work and social adjustment). Therefore, suggesting a different pattern of improvement over time between interventions, with those receiving family-focused CBT improving more during treatment and at discharge, and those in the psycho-education group improving more from 3 months follow-up onwards, until becoming as effective as family-focused CBT at 6 and 12 months follow-up [47].
- Finally, a third RCT evaluated the effectiveness of an intervention employing CBT aided by biofeedback, which resulted in increased school attendance of 34.4% (CI 29.8–36.6 h/month, with $P < .001$) in the intervention group [48].

Two further studies were prospective uncontrolled cohort studies:

- One study evaluated the impact of a multidisciplinary clinic and treatment approach in adolescents with chronic tension-type headache, and found a significant change over time in adolescents' school

functioning ($F(2, 33) = 4.32, P < .05$) and school attendance ($F(2, 34) = 4.03, P < .05$) from baseline to follow-up [49].

- Another study examined the outcomes of a non-condition-specific group mentoring programme based on the principles of a positive youth development approach, and found that both educational and vocational outcomes of programme alumni were better than those generally reported in YP with LTC, particularly in terms of college attendance percentage [50].

Finally, one cross-sectional study examined adolescents and young adults (AYA) and parental perceptions of educational content in transitional care provision in a paediatric hospital setting, and found stated deficiencies in education regarding the impact of disease on future education and career/vocation [14].

3.5.2. Interventions meeting three recommendations

Five interventions met three recommendations. A retrospective uncontrolled cohort study examined the outcomes of adolescents with CFS following an intensive multidisciplinary inpatient programme, with participants reporting a decrease in school non-attendance (attending school never or only occasionally) and an increase in full-time school attendance with occasional absences only [51].

A RCT of a CBT-based transition preparation programme for adolescents with spina bifida (SB) in combination with disease management, showed no difference in education/employment-related outcomes when compared with a control group of adolescents who received SB management only. The authors considered that the one-month time frame of their intervention model was insufficient to address key education/employment-related transition plan goals (such as obtaining a high school diploma or seeking employment) which could have required months or years beyond the study's time frame [52].

An uncontrolled trial examined the effects of Acceptance and Commitment Therapy (ACT) treatment in severely disabled adolescents with chronic pain, reporting a decrease in the number of school sessions missed (1.5% change at 3-month follow-up; 95% CI 0.5–2.5; $P < .01$) [53].

Two included studies evaluated the impact of an intensive outpatient family therapy-based programme in a retrospective uncontrolled cohort study with a sample of adolescents with a range of LTCs [54] and a prospective uncontrolled cohort study with children and adolescents also with a range of LTCs [55], and both found the programme to be associated with a significant improvement in school absenteeism.

A RCT evaluated the effectiveness of a web-based self-management intervention guided by peer-trainers in young adults with JIA who were being treated at transition outpatient clinics. The vocational elements of this intervention included explicitly addressing communication skills at school or work as part of the intervention content and the evaluation considered absenteeism of school or work as a secondary outcome measure. The study found no differences between the control and intervention group on absenteeism of school or work, although additional qualitative analyses showed that the intervention was appreciated and valuable for the participants [56].

3.5.3. Interventions meeting four recommendations

Two interventions met four recommendations. A multimodal inpatient program for children and adolescents with chronic pain was evaluated by two prospective uncontrolled cohort studies using the same sample of adolescents at 3 months [57] and 12 months [58] from baseline, with both studies reporting significant reductions in school absences over time.

A psychoeducational intervention program for hospitalised school-aged children and adolescents, delivered regardless of length of hospital stay and with a focus on education-related skills, was evaluated in an uncontrolled cohort study using a survey of parents/caregivers and class teachers experiences, and found that the programme was perceived to have promoted self-regulated learning competences; facilitated

Table 2
Summary of quality assessment of included qualitative studies (n = 23).

	Yes	Partially	No	Unclear
1. Was the research problem and/or research question clearly reported/defined?	19 82.61%	4 17.39%	-	-
2. Was there a clear statement of the aims and/or objectives of the research?	18 78.26%	5 21.74%	-	-
3. Was a qualitative methodology appropriate?	23 100.00%	-	-	-
4. Was the research design appropriate to address the aims of the research?	19 82.61%	4 17.39%	-	-
5. Was the sampling and recruitment strategy clearly defined and justified?	11 47.83%	12 52.17%	-	-
6. Was the method of data collection well described?	15 65.22%	8 34.78%	-	-
7. Were any techniques to enhance trustworthiness used?	15 65.22%	1 4.35%	4 17.39%	3 13.04%
8. Has the relationship between researchers and participants been adequately considered?	5 21.74%	6 26.09%	7 30.43%	5 21.74%
9. Have ethical issues been taken into consideration?	6 26.09%	15 65.22%	2 8.70%	-
10. Was the data analysis/interpretation process well described and justified?	14 60.87%	8 34.78%	1 4.35%	-
11. Was there a clear statement of findings?	13 56.52%	9 39.13%	1 4.35%	-
12. Are the analysis and findings credible?	16 69.57%	7 30.43%	-	-
13. Was any conflict of interest reported?	1 4.35%	-	22 95.65%	-

Table 3
Summary of quality assessment of included quantitative studies (n = 20).

Quality assessment domains	Strong	Moderate	Weak
Selection bias	6 30.00%	5 25.00%	9 45.00%
Study design	8 40.00%	1 5.00%	11 55.00%
Confounders	5 25.00%	3 15.00%	12 60.00%
Blinding	-	-	20 100.00%
Data collection methods	8 40.00%	-	12 60.00%
Withdrawals and drop-outs	7 35.00%	9 45.00%	4 20.00%
GLOBAL RATING	-	3 15.00%	17 85.00%

communication and linkage with school life; provided academic, psycho-emotional and leisure-educational support; and smoothed the school re-entry process [43].

3.5.4. Interventions meeting five recommendations

Four interventions met five recommendations, all of them transitional care interventions.

One intervention was an evidence-based transitional care programme for adolescents with juvenile idiopathic arthritis, which was evaluated in a multicentre uncontrolled (pseudo-controlled) trial and reported significant improvements in two vocational secondary outcome measures (work experience and career advice) at both 6 months and 12 months follow-up [13].

A cross-sectional study examined characteristics of paediatric and adult based transitional care provision and patients/carers satisfaction, and found that better satisfaction was associated with attending clinics that provided transitional care defined as youth-friendly and holistic (i.e. addressing medical, psychosocial and vocational issues) [59].

Two further non-randomised controlled trials evaluated a group-based transition education programme in different patient groups. The first study included AYA diagnosed with type I diabetes (T1D), cystic fibrosis, and inflammatory bowel disease (IBD), and reported a significant improvement in the ‘work-related preparedness’ subscale of the ‘Transition Competence Scale’ for those in the intervention group [60]. The second study examined differential effects across AYA with T1D and IBD, and found again significant improvement in transition competence in both groups, but to a higher extent in subjects with IBD, although the study identified previous experience with the intervention as a potential confounder [61].

Finally, another group-based transition education programme for AYA and their parents was evaluated in a multicentre, prospective controlled study including AYA with 12 different conditions, and found that transition competence had improved significantly as measured by the Transition Competence Scale, including in the ‘work-related preparedness’ subscale, compared to usual care [62].

4. Discussion and conclusion

4.1. Discussion

The proposed set of recommendations for interventions from stakeholders’ perspectives identified in this review highlights important issues for YP with LTC that have continued to emerge in recent literature, for example: work-related goals are both challenging and changing following diagnosis [63]; difficulties with disclosure are a barrier to successful transition into employment [64]; mental health and emotional wellbeing are important component of transitional care provision and integral to successful achievement of vocational development milestones for YP with LTCs [65]; the importance of proactive and continued engagement from healthcare providers with educational settings to support positive educational outcomes [66]. Also, engagement of healthcare professionals at the interface of healthcare and workplace settings has been shown to be an important factor for interventions delivered in workplace settings [67]. However, there were also notable omissions, such as the lack of explicit recognition of the role that mobile/digital technologies could play in enabling health services/professionals to better support the vocational development of YP with LTCs [68], which is in contrast with a growing interest in research on the use of mobile/digital technologies to interact with YP with LTC and support disease self-management and transitional care [69–71].

The perspectives and experiences of YP with LTCs are the primary views underpinning our recommendations. This is an important strength. However, it is also important to acknowledge the need for further research into the views and experiences of other stakeholders such as carers, healthcare providers, and teachers. These recommendations can inform adaptations for interventions to better address vocational issues, or they could enable the identification of potentially crucial implementation factors. The latter were notably lacking in the qualitative evidence identified in this review, with only one mixed-methods study [43] contributing to both syntheses – i.e., exploring views and experiences relating to vocational issues in the context of one of the interventions included. Given that healthcare-based interventions addressing vocational issues for YP with LTCs can be considered complex interventions [72] such limited qualitative and process evaluation data available on existing interventions is a particularly important evidence gap. Robust mixed-methods designs should be a priority for future intervention studies in this area.

This review also found that unclear/insufficient reporting of intervention procedures made it challenging to establish how interventions addressed vocational issues/outcomes, with some interventions addressing them explicitly/directly (reporting vocational intervention components) and others implicitly/indirectly (reporting vocational outcomes only). Similarly, such reporting limitations made it difficult to establish whether interventions met our recommendations specifically in relation to vocational needs or in relation to more generic LTC-related issues (i.e. the extent to which intervention components such as

Table 4
Mapping of interventions against recommendations.

Recommendations for interventions generated from stakeholders' experiences reported in included qualitative studies	Intervention studies																		Number of interventions meeting each recommendation
	Al-Hagggar et al. (2006)	Ammerlaan et al. (2017)	Betz et al. (2010)	Chalder et al. (2010)	Claar et al. (2013)	Distelberg et al. (2014) / Emerson et al. (2016)	Fernandes et al. (2014)	Gauntlett-Gilbert et al. (2013)	Hechler et al. (2009) / Hirschfeld et al. (2013)	Lim & Lubitz (2002)	Magalhães et al. (2018)	Maslow et al. (2013)	McDonagh et al. (2007)	Menrath et al. (2018)	Schmidt et al. (2016) / Schmidt et al. (2018)	Shaw et al. (2013)	Stulemeijer et al. (2004)		
1. Provide psychological support	●	●	●	●	●	●	○	●	●	●	●	○	○	●	●	○	●	13	
2. Provide information, signposting and facilitate access to supporting services	○	○	●	○	●	○	●	○	○	●	●	○	●	●	●	●	○	9	
3. Provide skills training	●	●	○	○	○	○	○	●	●	○	●	●	●	●	●	●	●	11	
4. Provide specialist career advice	○	○	○	○	○	○	○	○	○	○	○	○	○	●	●	○	○	2	
5. Liaise with key stakeholders in educational or workplace settings	○	○	○	●	○	○	○	○	●	●	●	○	●	○	○	●	○	6	
6. Provide or facilitate access to social support	○	●	○	○	○	●	○	○	●	○	○	●	●	●	●	●	○	8	
7. Provide flexible care and optimal disease management to support education/ employment transitions	○	○	●	○	○	●	●	●	○	○	○	○	●	○	○	●	○	6	
Number of recommendations met by each intervention	2	3	3	2	2	3	2	3	4	3	4	2	5	5	5	5	2		

psychological support or skills training were specifically tailored to vocational development issues). Although, in relation to the latter, it could be argued that some of the targeted generic LTC issues are transferable to the more specific domain of vocational development (e. g., intervention components such as self-management education, communication skills, or goal setting used in pain management or transitional care programmes can promote the development of skills which are transferable to the world of education and work). To enable this level of insight into existing published evidence, the reporting of how intervention procedures are expected to lead to vocational outcomes should be improved either in results papers or as part of linked registered protocols or intervention development papers.

Vocational outcomes used by included interventions were varied and tended to be self-reported, but limitations in study designs meant that changes in outcome measures were difficult to confidently attribute to intervention effects. Many interventions focused on outcomes relating to educational attainment, while other important educational/vocational outcomes received less attention. Educational attainment is only one aspect of vocational readiness, which includes other aspects such as communication skills, work experience, self-esteem, expectations of self and others, knowledge of resources and rights, and societal attitudes towards illness/disability. Outcome measures in future research should consider more of these rather than just focus on educational attainment related measures.

5. Conclusions

Existing evidence from YP's perspectives highlights that vocational development is an important area to address in healthcare provision for YP with LTCs.

The evidence-based set of recommendations for intervention resulting from our thematic synthesis can inform further research and intervention development/adaptations to better address vocational outcomes for YP with LTCs in healthcare settings and help ensure consistency across interventions/studies.

Robust intervention studies in this area are notably lacking. The reporting of intervention procedures and pathways leading to expected vocational outcomes should be improved in future research reports and protocols to enable better quality evidence.

Practice implications

The proposed recommendations for intervention can support health professionals to better address the vocational development for YP with LTCs in healthcare settings.

The types of intervention identified in this review were significantly wide-ranging, with important limitations in the evaluation of their effectiveness. Transitional care interventions were the type of intervention that most comprehensively met our proposed recommendations. This is an important finding with relevance to the policy and practice implications of this review's findings, for two key reasons:

Firstly, because vocational development is integral to the definition of transitional care [7,73] and, therefore, the philosophical and conceptual underpinnings of such interventions are already largely in line with the recommendations for intervention proposed by this review. This minimises the need for high-level adaptations to relevant policies and intervention approaches/strategies, as well as the implications in terms of training and buy-in from professionals delivering such interventions. Therefore, required intervention adaptations to ensure that vocational development is sufficiently and consistently addressed as part of transitional care might as simple as including transition readiness checklists [14,15].

Secondly, the importance of providing developmentally-appropriate transitional care for YP with LTCs has been well recognised in policy documents in a wide range of healthcare systems [12], with many well-established programmes delivering developmentally-appropriate

transitional care for years. Therefore, not only transitional care interventions are particularly well placed to address the distinct vocational development needs of YP with LTCs in keeping with their views, but also, they can provide a potentially cost-effective platform to improve vocational outcomes for this population.

Conversely, the various transitions experienced during adolescence and young adulthood, including social and vocational transitions, are particularly vulnerable times for health and therefore important to specifically consider in the provision of developmentally appropriate healthcare for YP. The seven recommendations reported in this paper reflect the key domains of developmentally appropriate healthcare [10, 11].

CRediT authorship contribution statement

Albert Farre: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Validation, Writing – original draft, Supervision. **Laura Lunt:** Conceptualization, Investigation, Data curation, Formal analysis, Validation, Writing – review & editing. **Rebecca Lee:** Formal analysis, Validation, Writing – review & editing. **Suzanne Verstappen:** Formal analysis, Validation, Writing – review & editing. **Janet E. McDonagh:** Conceptualization, Methodology, Formal analysis, Validation, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendices A–D. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2023.107765](https://doi.org/10.1016/j.pec.2023.107765).

References

- [1] Viner RM, Ozer EM, Denny S, Marmot M, Resnick M, Fatusi A, et al. Adolescence and the social determinants of health. 1641–52 *Lancet* 2012;379. [https://doi.org/10.1016/S0140-6736\(12\)60149-4](https://doi.org/10.1016/S0140-6736(12)60149-4).
- [2] Hale DR, Bevilacqua L, Viner RM. Adolescent health and adult education and employment: a systematic review. 128–40 *Pediatrics* 2015;136. <https://doi.org/10.1542/peds.2014-2105>.
- [3] Hale DR, Viner RM. How adolescent health influences education and employment: investigating longitudinal associations and mechanisms. *jech-2017-209605* *J Epidemiol Community Health* 2018. <https://doi.org/10.1136/jech-2017-209605>.
- [4] Pinquart M. Achievement of developmental milestones in emerging and young adults with and without pediatric chronic illness—a meta-analysis. *J Pediatr Psychol* 2014. <https://doi.org/10.1093/jpepsy/jsu017>.
- [5] Zimmer-Gembeck MJ, Mortimer JT. Adolescent work, vocational development, and education. 537–66 *Rev Educ Res* 2006;76. <https://doi.org/10.3102/00346543076004537>.
- [6] Malanchuk O, Messersmith EE, Eccles JS. The ontogeny of career identities in adolescence. *N Dir Child Adolesc Dev* 2010;2010:97–110. <https://doi.org/10.1002/cd.284>.
- [7] Farre A, McDonagh JE. Helping health services to meet the needs of young people with chronic conditions: towards a developmental model for transition. *Healthcare* 2017;5:77. <https://doi.org/10.3390/healthcare5040077>.
- [8] Farre A, Rapley T. The new old (and old new) medical model: four decades navigating the biomedical and psychosocial understandings of health and illness. *Healthcare* 2017;5:88. <https://doi.org/10.3390/healthcare5040088>.
- [9] Sawyer SM. Developmentally appropriate healthcare for young people with chronic illness: questions of philosophy, policy, and practice. *Pedia Pulmonol* 2003;36:363–5. <https://doi.org/10.1002/ppul.10369>.
- [10] Farre A, Wood V, Rapley T, Parr JR, Reape D, McDonagh JE. Developmentally appropriate healthcare for young people: a scoping study. *Arch Dis Child* 2014. <https://doi.org/10.1136/archdischild-2014-306749>.
- [11] Farre A, Wood V, McDonagh JE, Parr JR, Reape D, Rapley T, et al. Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. *Arch Dis Child* 2016;101:628–33. <https://doi.org/10.1136/archdischild-2015-309473>.
- [12] National Institute for Health and Care Excellence (NICE). NICE guidelines [NG43] Transition from children's to adults' services for young people using health or social care services 2016. (<https://www.nice.org.uk/guidance/ng43>).

- [13] McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology* 2007;46. <https://doi.org/10.1093/rheumatology/ke1198>.
- [14] Fernandes SM, O'Sullivan-Oliveira J, Landzberg MJ, Khairy P, Melvin P, Sawicki GS, et al. Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective. *J Pediatr Rehabil Med* 2014;7:43–51. <https://doi.org/10.3233/PRM-140269>.
- [15] Clemente D, Leon L, Foster H, Carmona L, Minden K. Transitional care for rheumatic conditions in Europe: current clinical practice and available resources. *Pedia Rheuma* 2017;15:49. <https://doi.org/10.1186/s12969-017-0179-8>.
- [16] Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. <https://doi.org/10.1136/bmj.n71>.
- [17] World Health Organization. The second decade: improving adolescent health and development. Geneva: 2001.
- [18] O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51. <https://doi.org/10.1097/ACM.0000000000000388>.
- [19] Critical Appraisal Skills Programme (CASP). Qualitative Research Checklist 2013.
- [20] Thomas B h, Ciliska D, Dobbins M, Micucci S. A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. 176–84 *World Evid Based Nurs* 2004;1. <https://doi.org/10.1111/j.1524-475X.2004.04006.x>.
- [21] Kavanagh J, Campbell F, Harden A, Thomas J. *Mixed Methods Synthesis: A Worked Example*. In: Hannes K, Craig L, editors. *Synth. Qual. Res. Choos. Right Approach*. Chichester, UK: Wiley-Blackwell; 2012. p. 113–36.
- [22] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Method* 2008;8:45. <https://doi.org/10.1186/1471-2288-8-45>.
- [23] Bomba F, Herrmann-Garitz C, Schmidt J, Schmidt S, Thyen U. An assessment of the experiences and needs of adolescents with chronic conditions in transitional care: a qualitative study to develop a patient education programme. 652–66 *Health Soc Care Community* 2017;25. <https://doi.org/10.1111/hsc.12356>.
- [24] Shaw KL, Hackett J, Southwood TR, McDonagh JE. The prevocational and early employment needs of adolescents with juvenile idiopathic arthritis: the adolescent perspective. *Br J Occup Ther* 2006;69:98–105. <https://doi.org/10.1177/030802260606900302>.
- [25] Hanson H, Hart RI, Thompson B, McDonagh JE, Tattersall R, Jordan A, et al. Experiences of employment among young people with juvenile idiopathic arthritis: a qualitative study. 1921–8 *Disabil Rehabil* 2018;40. <https://doi.org/10.1080/09638288.2017.1323018>.
- [26] Jetha A, Gignac MAM, Bowring J, Tucker S, Connelly CE, Proulx L, et al. Supporting arthritis and employment across the life course: a qualitative study. 1461–8 *Arthritis Care Res* 2018;70. <https://doi.org/10.1002/acr.23523>.
- [27] Pini S. Education mentoring for teenagers and young adults with cancer. 1316–9 *Br J Nurs* 2009;18. <https://doi.org/10.12968/bjon.2009.18.21.45363>.
- [28] Gee L, Smith TL, Solomon M, Quinn MT, Lipton RB. The clinical, psychosocial, and socioeconomic concerns of urban youth living with diabetes. 318–28 *Public Health Nurs* 2007;24. <https://doi.org/10.1111/j.1525-1446.2007.00640.x>.
- [29] Lewis H, Arber S. Impact of age at onset for children with renal failure on education and employment transitions. *Health (N Y)* 2015;19:67–85. <https://doi.org/10.1177/1363459314539773>.
- [30] Farre A, Ryan S, McNiven A, McDonagh JE. The impact of arthritis on the educational and early work experiences of young people: a qualitative secondary analysis. *Int J Adolesc Med Health* 2019;0. <https://doi.org/10.1515/ijamh-2018-0240>.
- [31] Thomas VJ, Taylor LM. The psychosocial experience of people with sickle cell disease and its impact on quality of life: qualitative findings from focus groups. *Br J Health Psychol* 2002;7:345–63. <https://doi.org/10.1348/135910702760213724>.
- [32] Jetha A, Bowring J, Tucker S, Connelly CE, Martin Ginis KA, Proulx L, et al. Transitions that matter: life course differences in the employment of adults with arthritis. *Disabil Rehabil* 2018;40:3127–35. <https://doi.org/10.1080/09638288.2017.1378387>.
- [33] Taylor RM, Franck LS, Dhawan A, Gibson F. The stories of young people living with a liver transplant. *Qual Health Res* 2010;20:1076–90. <https://doi.org/10.1177/1049732310368405>.
- [34] Sen ES, Morgan MJ, MacLeod R, Strike H, Hinchcliffe A, Dick AD, et al. Cross sectional, qualitative thematic analysis of patient perspectives of disease impact in juvenile idiopathic arthritis-associated uveitis. *Pedia Rheuma* 2017;15:58. <https://doi.org/10.1186/s12969-017-0189-6>.
- [35] Sluman MA, de Man S, Mulder BJM, Sluiter JK. Occupational challenges of young adult patients with congenital heart disease. *Neth Heart J* 2014. <https://doi.org/10.1007/s12471-014-0540-1>.
- [36] Burles M, Thomas R. 'But they're happening to you at the wrong time': Exploring young adult women's reflections on serious illness through photovoice. *Qual. Soc Work* 2013;12:671–88. <https://doi.org/10.1177/1473325012450484>.
- [37] Winger A, Ekstedt M, Wyller VB, Helseth S. 'Sometimes it feels as if the world goes on without me': adolescents' experiences of living with chronic fatigue syndrome. *J Clin Nurs* 2014;23:2649–57. <https://doi.org/10.1111/jocn.12522>.
- [38] Twiddy H, Hanna J, Haynes L. Growing pains: understanding the needs of emerging adults with chronic pain. *Br J Pain* 2017;11:108–18. <https://doi.org/10.1177/2049463717709641>.
- [39] Ferguson P, Walker H. 'Getting on with life': resilience and normalcy in adolescents living with chronic illness. *Int J Incl Educ* 2014;18:227–40. <https://doi.org/10.1080/13603116.2012.676082>.
- [40] Palmer ML, Boisen LS. Cystic fibrosis and the transition to adulthood. *Soc Work Health Care* 2002;36:45–58. https://doi.org/10.1300/J010v36n01_04.
- [41] Hauser ES, Dorn L. Transitioning adolescents with sickle cell disease to adult-centered care. *Pedia Nurs* 1999;25:479–88.
- [42] Dogba MJ, Rauch F, Wong T, Ruck J, Glorieux FH, Bedos C. From pediatric to adult care: strategic evaluation of a transition program for patients with osteogenesis imperfecta. *BMC Health Serv Res* 2014;14:489. <https://doi.org/10.1186/s12913-014-0489-1>.
- [43] Magalhães P, Mourão R, Pereira R, Azevedo R, Pereira A, Lopes M, et al. Experiences during a psychoeducational intervention program run in a pediatric ward: a qualitative study. *Front Pedia* 2018;6:124. <https://doi.org/10.3389/fped.2018.00124>.
- [44] Ahola Kohut S, Stinson J, Forgeron P, van Wyk M, Harris L, Luca S. A qualitative content analysis of peer mentoring video calls in adolescents with chronic illness. *J Health Psychol* 2018;23:788–99. <https://doi.org/10.1177/1359105316669877>.
- [45] Holley S, Walker D, Knibb R, Latter S, Liossi C, Mitchell F, et al. Barriers and facilitators to self-management of asthma in adolescents: an interview study to inform development of a novel intervention. *Clin Exp Allergy* 2018;48:944–56. <https://doi.org/10.1111/cea.13141>.
- [46] Stulemeijer M, Jong LWAM de, Fiselier TJW, Hoogveld SWB, Bleijenberg G. Cognitive behaviour therapy for adolescents with chronic fatigue syndrome: randomised controlled trial. *BMJ* 2004;330:14. <https://doi.org/10.1136/bmj.38301.587106.63>.
- [47] Chalder T, Deary V, Husain K, Walwyn R. Family-focused cognitive behaviour therapy versus psycho-education for chronic fatigue syndrome in 11- to 18-year-olds: a randomized controlled treatment trial. *Psychol Med* 2010;40:1269–79. <https://doi.org/10.1017/S003329170999153X>.
- [48] Al-Haggar MS, Al-Naggar ZA, Abdel-Salam MA. Biofeedback and cognitive behavioral therapy for Egyptian adolescents suffering from chronic fatigue syndrome. *J Pedia Neurol* 2006;04:161–9. <https://doi.org/10.1055/s-0035-1557320>.
- [49] Claar RL, Kaczynski KJ, Minster A, McDonald-Nolan L, LeBel AA. School functioning and chronic tension headaches in adolescents: improvement only after multidisciplinary evaluation. *J Child Neurol* 2013;28:719–24. <https://doi.org/10.1177/0883073812450945>.
- [50] Maslow G, Adams C, Willis M, Neukirch J, Herts K, Froehlich W, et al. An evaluation of a positive youth development program for adolescents with chronic illness. *J Adolesc Health* 2013;52:179–85. <https://doi.org/10.1016/j.jadohealth.2012.06.020>.
- [51] Lim A, Lubitz L. Chronic fatigue syndrome: successful outcome of an intensive inpatient programme. *J Paediatr Child Health* 2002;38:295–9. <https://doi.org/10.1046/j.1440-1754.2002.00786.x>.
- [52] Betz CL, Smith K, Macias K. Testing the transition preparation training program: a randomized controlled trial. *Int J Child Adolesc Health* 2010;3:595.
- [53] Gauntlett-Gilbert J, Connell H, Clinch J, McCracken LM. Acceptance and values-based treatment of adolescents with chronic pain: outcomes and their relationship to acceptance. *J Pedia Psychol* 2013;38:72–81. <https://doi.org/10.1093/jpepsy/jss098>.
- [54] Distelberg B, Williams-Read J, Tapanes D, Montgomery S, Pandit M. Evaluation of a family systems intervention for managing pediatric chronic illness: mastering each new direction (MEND). *Fam Process* 2014;53:194–213. <https://doi.org/10.1111/famp.12066>.
- [55] Emerson ND, Distelberg B, Morrell HER, Williams-Read J, Tapanes D, Montgomery S. Quality of life and school absenteeism in children with chronic illness. *J Sch Nurs* 2016;32:258–66. <https://doi.org/10.1177/1059840515615401>.
- [56] Ammerlaan J, van Os-Mendendorp H, de Boer-Nijhof N, Scholtus L, Kruize AA, van Pelt P, et al. Short term effectiveness and experiences of a peer guided web-based self-management intervention for young adults with juvenile idiopathic arthritis. *Pedia Rheuma* 2017;15:75. <https://doi.org/10.1186/s12969-017-0201-1>.
- [57] Hechler T, Dobe M, Kosfelder J, Damschen U, Hübner B, Blankenburg M, et al. Effectiveness of a 3-week multimodal inpatient pain treatment for adolescents suffering from chronic pain: statistical and clinical significance. *Clin J Pain* 2009;25:156–66. <https://doi.org/10.1097/AJP.0b013e318185c1c9>.
- [58] Hirschfeld G, Hechler T, Dobe M, Wager J, von Lützap P, Blankenburg M, et al. Maintaining lasting improvements: one-year follow-up of children with severe chronic pain undergoing multimodal inpatient treatment. *J Pedia Psychol* 2013;38:224–36. <https://doi.org/10.1093/jpepsy/jss115>.
- [59] Shaw KL, Watanabe A, Rankin E, McDonagh JE. Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. *Child Care Health Dev* 2013. <https://doi.org/10.1111/cch.12110>.
- [60] Schmidt S, Herrmann-Garitz C, Bomba F, Thyen U. A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults. *Patient Educ Couns* 2016;99:421–8. <https://doi.org/10.1016/j.pec.2015.10.024>.
- [61] Schmidt S, Markwart H, Bomba F, Muehlan H, Findeisen A, Kohl M, et al. Differential effect of a patient-education transition intervention in adolescents with IBD vs. diabetes. *Eur J Pedia* 2018;177:497–505. <https://doi.org/10.1007/s00431-017-3080-z>.
- [62] Menrath I, Ernst G, Szczepanski R, Lange K, Bomba F, Staab D, et al. Effectiveness of a generic transition-oriented patient education program in a multicenter, prospective and controlled study. *J Transit Med* 2018;1. <https://doi.org/10.1515/jtm-2018-0001>.
- [63] Ghazal LV, Merriman J, Santacroce SJ, Dickson VV. Survivors' Dilemma: young adult cancer survivors' perspectives of work-related goals. *Workplace Health Saf* 2021;69:506–16. <https://doi.org/10.1177/21650799211012675>.

- [64] Jetha A, Bowring J, Furrrie A, Smith F, Breslin C. Supporting the transition into employment: a study of Canadian young adults living with disabilities. *J Occup Rehabil* 2019;29:140–9. <https://doi.org/10.1007/s10926-018-9772-z>.
- [65] Palman J, McDonagh JE. Young minds: mental health and transitional care in adolescent and young adult rheumatology. *Open Access Rheuma Res Rev* 2020;12:309–21. <https://doi.org/10.2147/OARRR.S228083>.
- [66] Broholm-Jørgensen M, Tjørnhøj-Thomsen T, Pedersen PV. Development of an intervention for the social reintegration of adolescents and young adults affected by cancer. *BMC Public Health* 2022;22:241. <https://doi.org/10.1186/s12889-022-12611-4>.
- [67] Jetha A, Shaw R, Sinden AR, Mahood Q, Gignac MA, McColl MA, et al. Work-focused interventions that promote the labour market transition of young adults with chronic disabling health conditions: a systematic review. *Occup Environ Med* 2019;76:189–98. <https://doi.org/10.1136/oemed-2018-105454>.
- [68] Blower S, Swallow V, Maturana C, Stones S, Phillips R, Dimitri P, et al. Children and young people's concerns and needs relating to their use of health technology to self-manage long-term conditions: a scoping review. *Arch Dis Child* 2020;105:1093–104. <https://doi.org/10.1136/archdischild-2020-319103>.
- [69] Huang JS, Terrones L, Tompane T, Dillon L, Pian M, Gottschalk M, et al. Preparing adolescents with chronic disease for transition to adult care: a technology program. *Pediatrics* 2014;133:e1639–46. <https://doi.org/10.1542/peds.2013-2830>.
- [70] Virella Pérez YI, Medlow S, Ho J, Steinbeck K. Mobile and web-based apps that support self-management and transition in young people with chronic illness: systematic review. *J Med Internet Res* 2019;21:e13579. <https://doi.org/10.2196/13579>.
- [71] Shamambo L, Niemann M, Jonas R, Douglass LM. Mentorship for youth with chronic neurological conditions in the digital era: an innovative approach to supporting transition. *Semin Pediatr Neurol* 2020;36:100857. <https://doi.org/10.1016/j.spen.2020.100857>.
- [72] Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ* 2021;374:n2061. <https://doi.org/10.1136/bmj.n2061>.
- [73] Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the society for adolescent medicine. *J Adolesc Health* 2003;33:309–11.