Review

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Chronic illness and transition from paediatric to adult care: a systematic review of illness specific clinical guidelines for transition in chronic illnesses that require specialist to specialist transfer<https://doi.org/10.1515/jtm-2020-0001>

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Abstract

Introduction: A quarter of a century has passed since the importance of transition from paediatric to adult care for chronically ill adolescents was highlighted by the American Society of Adolescent Health and Medicine. Despite discussions, the development of generic guidelines and some cohorting of age groups in paediatric speciality care, adolescents continue, unacceptably, to fall through the care gaps with negative clinical outcomes. Government bodies and international organisations have developed clinical practice guidelines (CPGs) for specific chronic physical illness although it remains unclear as to what extent these discuss transition from paediatric to adult care. This study systematically reviewed scientific and grey literature to determine how effectively transition has been incorporated into chronic illness specific CPGs.

Methods: Five bibliographical databases; Medline, Embase, PsycINFO, CINAHL and Web of Science plus an extensive grey literature search from the internet were

used to identify published guidelines between 2008 and 2018 using key words adolescents, transition, guidelines, together with the names of over 20 chronic physical illnesses which require specialist to specialist care after transitioning from paediatric care. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed. In addition a measure of trustworthiness for CPGs was included. Guidelines were benchmarked against a published set of Australian transition principles embodying the comprehensive recommendations from National Institute for health and Care Excellence (NICE) transition guidelines discussing key transition aspects on: a systematic and formal transition process; early preparation; transition coordinators, good communication and collaboration between health professionals; individualised transition plan, enhancing self-management and active follow up after transition.

Results: Initially, 1055 articles were identified from the literature searches. Eight hundred and sixty eight articles were selected for title and abstract review. One hundred and seventy eight articles were included for full text review. Ultimately, 25 trustworthy CPGs were identified and included across 14 chronic physical illnesses. Five articles exclusively discussed illness specific transition recommendations and two included all the seven key transition principles. Three provided a minimal discussion of transition to adult care due to lack of high level evidence. Follow up and evaluation was the least addressed principle with recommendations in only seven CPGs.

Conclusions: A limited number of chronic physical illnesses have illness specific CPGs that address transition from paediatric to adult care. The CPGs' content emphasises the need for empirical data in order to develop quality transition recommendations for adolescents with chronic physical illness to ensure long term engagement and retention within health services.

Keywords: adolescents and young adults; chronic physical illness; clinical practice guidelines; transition.

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Introduction

A quarter of a century ago the American Society of Adolescent Health and Medicine highlighted the critical importance of a comprehensive transition care process from paediatric to adult care for Adolescents and Young Adults (AYAs) with chronic and complex paediatric conditions. Transition was defined as the “The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems” [1]. Since transition was first thus defined, much has been written about the challenges AYAs face during transition and the need to develop innovative transition programs to strengthen the transition and transfer process [2, 3]. These proactive approaches are necessary, especially when the increasing numbers of young people with chronic illness transitioning from paediatric to adult care is considered. This increase is occurring both as a result of advances in medical and surgical treatment management and increasing life expectancy [4–10] and the increased prevalence of chronic illnesses such as diabetes and inflammatory bowel disease (IBD) [11–14].

During the adolescent years, young people undergo major physical, psychosocial and neurocognitive development. Additionally, AYAs with chronic and complex conditions face multiple other challenges in life during transition from paediatric to adult care. These include acquiring knowledge and autonomy to take on self-management responsibilities [15, 16], decreasing parental involvement and support [17], disengagement with health services [18], socio-economic challenges like income support and transport [19] and lack of illness specific knowledge and education [20]. On the other hand, the scarcity of services to attend [21], poor coordination between health services [22] and insufficient staff training on adolescent health transitions [23] are other factors to be addressed. With discontinued care, AYAs with chronic illness also confront the risk of developing adverse outcomes of their chronic conditions that can lead to both acute and chronic morbidity [24–27].

Despite the increasing rates of survival for AYAs with chronic illness as well as the global increase in the prevalence of chronic illnesses, generic issues in the transition of paediatric to adult care such as clear guidance on where, when and how they can continue their health management are not always addressed, partly due to the general lack of empirical evidence [28]. Expert opinion suggests the importance of having internationally accepted CPGs for all age groups (children, adolescent and adults) on

the management and treatment of chronic illness [29–31]. CPG development is instituted by scientific organizations and professional societies at both national and international levels and CPGs generally target a specific clinical condition.

The aim of this systematic literature review of CPGs was to provide for the first time an understanding of how many specific chronic illness CPGs mention transition and how well key transition principles have been incorporated into these CPGs. This systematic review will thus provide a better understanding of how comprehensive these CPGs are for transition management and allow individual specialist groups to consider how to improve transition care through communication in illness specific guidelines.

Methods

We implemented a systematic literature reviews approach. The review was conducted as both a traditional bibliographical database search using peer reviewed literature following PRISMA guidelines and a broad based search of the grey literature as it appears on the internet. The search was limited by publication dates 2008–2018 to ensure currency of the CPGs. With the assistance of an academic librarian, five bibliographic databases (Medline, Embase, PsycINFO, CINAHL and Web of Science) were searched. The grey literature was searched from the internet using Google, Google.gov, Google scholar, TRIP and Informit. Both methods of literature search shared the aim of identifying published CPGs for transition in adolescence from paediatric to adult care in chronic illness.

The bibliographic databases and the internet databases were searched using the key words or similar MESH terms to: adolescent, transition to adult care practice, guidelines and chronic illness [diabetes mellitus, polycystic ovary syndrome, congenital adrenal hyperplasia, Klinefelter syndrome, Turner syndrome, juvenile idiopathic arthritis (previously known as juvenile rheumatoid arthritis), systemic lupus erythematosus, haemophilia, thalassemia, sickle cell, Marfan syndrome, osteogenesis imperfecta, inflammatory bowel disease, Crohn's disease, ulcerative colitis, epilepsy, neurofibromatosis, spina bifida, cystic fibrosis, muscular dystrophy, neuromuscular diseases, Phenylketonuria] (see Supplementary Figure 1: search terms). While not an exhaustive list of chronic physical illnesses, these represent the most common [32] or the more complex conditions requiring specialist to specialist transition.

Inclusion criteria

CPGs: Guidelines, consensus, standards, statements or recommendations for any of the above listed chronic illness that discuss transition from paediatric to adult care were included. Guideline development bodies such as government health departments, professional health organisations and other associations have established their own guideline development standards [33]. The diversity of these standards raises questions about how best to determine ‘trustworthiness’ of any CPG. Clear trustworthy CPGs addressing relevant transition criteria would support clinicians to take necessary actions to support AYAs leaving paediatric care. The Institute of Medicine (IOM) defines CPGs as follows: “Clinical practice guidelines are statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.” [34]. Standards of CPG trustworthiness recognized by the IOM and Guidelines International Network (GIN), CPG quality appraising tools such as the Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument and International Centre for Allied Health Evidence (iCAHE) checklists were used as guides to determine the eligibility of the CPGs for this review [33–36].

The above standards identify the characteristics that a trustworthy CPG should have. These standards include whether the guideline: (1) specifies the scope; (2) describes a targeted population; (3) discloses any conflict of interest of the guideline development group; (4) details the funding source; (5) involves a multidisciplinary development group; (6) includes public involvement in the decision making process; (7) contains systematically reviewed evidence; (8) evaluates the quality of evidence which is used to formulate the recommendations; (9) uses a grading system to rate the strength of recommendations; (10) ensures recommendations are clearly stated with potential benefits, risks, side effects, costs; (11) is externally reviewed by experts and public; (12) includes a future review date or procedure for updating and (13) is publicly available and/or freely accessible to allow global access. For the purposes of the review, CPGs were scored one point for each of the above standards they possessed. None of the trustworthiness assessment tools provided a score, and no literature guidance on a cut point for trustworthiness was identified. The authors came to a consensus of a 50% threshold, indicating that the CPGs fell onto the positive side of the trustworthiness scale. This criterion was useful for early inclusion/exclusion screening at the eligibility

stage using the PRISMA method. The selected final articles had 60%–100% of criteria addressed.

Chronic illness: As per the key words above, 22 chronic physical conditions were included.

Language – Only English language publications were included as there was no capacity for translation of full CPGs.

Exclusion criteria

CPGs were excluded if these: (1) were adult specific guidelines; (2) were not addressed to a specific age group; (3) were generic guidelines for transition (i.e. not condition-specific); (4) made no mention of transition from paediatric to adult care; (5) contained no clear grading of the evidence and recommendations; (6) were written by an individual author; or, (7) were internet identified guidelines that required payment to access. Mental health conditions, developmental disabilities or lifestyle/health risk behaviours which may or may not require specialist to specialist care but predominantly require primary care, nursing and/or allied health care were excluded because the review was targeting chronic physical illnesses requiring specialist to specialist transition. Cancer, either in acute or survivorship state, was excluded as transition is avoided in acute cancer care and survivorship would require consideration of different cancer types and transition to adult care is often dependent on the organ system(s) involved.

Document selection and data extraction

Titles and abstracts were screened by one author (SS) against the eligibility criteria. Full text articles were selected against the inclusion criteria by SS and KS. Consensus was always reached by discussion. Eligible final records were further analysed using CPG criteria standards and were given a score out of 13 (See Supplementary Table 1).

Final records were then qualitatively synthesised with a high level comparison to understand how these accorded with the consensus derived transition principles developed by the Agency of Clinical Innovation (ACI- a statutory health body that reports to the New South Wales (NSW) State Minister for Health) and Trapeze (the transition support service of the Sydney Children’s Hospital Network) in NSW Australia [37]. These principles embody the later developed comprehensive transition recommendations published by the NICE in 2016 [38]. The key elements of

the ACI principles include: (1) a systematic and formal transition process; (2) early preparation, (3) identification of a transition coordinator, (4) good communication strategy and collaboration between health professionals, (5) individualised transition plan, (6) enhancing self-management and (7) active follow up after transition. Each CPG was given a score out of seven indicating how many of these recommended principles were included. Scores were reviewed and confirmed by KS and JH.

Results

The two search strategies (see methods, first paragraph) yielded a combined total of 1055 publications (Figure 1). Of these, 868 publications were retained after removing duplicates. Screening by publication title and abstract excluded 690 records, leaving 178 publications for full text screening. Of these, 153 records did not meet eligibility criteria, and were accordingly excluded for the following reasons:

- Not meeting CPG standards (including reviews, statements, reports, expert opinions, surveys etc.) $n = 94$.

Among these excluded full texts, five chronic conditions, muscular dystrophy, Klinefelter syndrome, spina bifida, Marfan syndrome and osteogenesis imperfecta had publications that did not reach 50% of the CPG standards score (see methods, fourth paragraph).

- guidelines that did not mention transition from paediatric to adult care $n = 40$ (among these were haemophilia and neuromuscular guidelines)
- generic transition guidelines $n = 1$
- superseded versions of guidelines published by International Society for Paediatric and Adolescent Diabetes (ISPAD) $n = 2$, Canadian Diabetes association $n = 2$
- adult specific guidelines $n = 8$
- non-English languages (Spanish and Dutch) $n = 3$
- other $n = 3$ (including spina bifida that had no guideline grading information and neurofibromatosis guidelines that were inaccessible requiring an authority to access.)

Twenty-five publications met inclusion criteria and were selected for qualitative synthesis (Table 1).

The selected publications originated from England ($n = 5$) United Kingdom ($n = 2$), European collaborations

Figure 1: PRISMA study selection flow diagram.

Table 1: Summary data for included publications.

Title	Year	Authors	Organisation	Guideline country of origin	Chronic illness
Children and Adolescents: Standards of Medical Care in Diabetes 2018 [39]	2018	American Diabetes Association	American Diabetes Association (ADA)	United States of America	Diabetes
ISPAD Clinical Practice Consensus Guidelines 2018 [40]	2018	International Society for Paediatric and Adolescent Diabetes	International Society for Paediatric and Adolescent Diabetes (ISPAD)	Multinational collaboration	Diabetes
Epilepsies in children and young people: Investigative procedures and management-draft [41]	2018	Scottish Intercollegiate Guidelines Network. (SIGN)	The Scottish Intercollegiate Guidelines Network (SIGN)	Scotland	Epilepsy
Recommendations from the International evidence-based guideline for the assessment and management of polycystic ovary syndrome (PCOS) 2018 [42]	2018	Teede et al.	The Centre for Research Excellence in Polycystic Ovary Syndrome (CREPCOS) research ^b	Multinational collaboration	Polycystic ovary syndrome
Diabetes Canada 2018 Clinical Practice Guidelines [43]	2018	Diabetes Canada	Diabetes Canada	Canada	Diabetes
UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care [44] ^a	2017	Brooks et al.	Clinical Services and Standards Committee of the British Society of Gastroenterology under the auspices of the Adolescent and Young Persons (A&YP) Section	United Kingdom	Chronic digestive diseases including inflammatory bowel disease
EULAR/PreS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases [45] ^a	2017	Foster et al.	European League Against Rheumatism (EULAR), Paediatric Rheumatology European Society (PreS)	European collaboration	Juvenile idiopathic arthritis
Clinical practice guidelines for the care of girls and women with Turner syndrome: Proceedings from the 2016 Cincinnati International Turner Syndrome Meeting [46]	2017	Gravholt et al.	European Society of Endocrinology and Paediatric Endocrine Society ^c	Multinational collaboration	Turner Syndrome
European evidence-based recommendations for diagnosis and treatment of childhood-onset systemic lupus erythematosus (SLE): the SHARE initiative [47]	2017	Groot et al.	Single Hub and Access Point for Paediatric Rheumatology in Europe (SHARE)	European collaboration	Systemic lupus erythematosus

Table 1 (continued)

Title	Year	Authors	Organisation	Guideline country of origin	Chronic illness
Cystic fibrosis: Diagnosis and management [48]	2017	NICE	National Institute for health and Clinical Excellence (NICE)	England	Cystic fibrosis
The complete European guidelines on phenylketonuria: diagnosis and treatment [49]	2017	Van Wegberg et al.	European Society of Phenylketonuria and Allied Disorders (ESPKU)	European collaboration	Phenylketonuria
Consensus of the Spanish society of pediatric rheumatology for transition management from pediatric to adult care in rheumatic patients with childhood onset [50] ^a	2015	Calvo et al.	Spanish Society of Paediatric Rheumatology	Spain	Juvenile idiopathic arthritis
Transition of gastroenterological patients from paediatric to adult care: A position statement by the Italian Societies of Gastroenterology [51] ^a	2015	Elli et al.	Italian Gastroenterological Societies ^d	Italy	Inflammatory bowel disease
Diabetes (type 1 and type 2) in children and young people: diagnosis and management [52]	2015	NICE	National Institute for health and Clinical Excellence (NICE)	England	Diabetes
Nonclassical Congenital Adrenal Hyperplasia: Targets of Treatment and Transition [53]	2014	McCann-Crosby et al.	Texas Children's Hospital	United States of America	Non classical congenital adrenal hyperplasia
Ulcerative colitis: Management in adults, children and young people [54]	2013	NICE	NICE. Published by National Clinical Guideline Centre	England	Ulcerative Colitis
The Epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care [55]	2012	NICE	NICE. Published by National Clinical Guideline Centre	England	Epilepsy
Crohn's disease: Management in adults, children and young people [56]	2012	NICE	NICE. Published by National Clinical Guideline Centre	England	Crohn's disease
Management of Pediatric Ulcerative Colitis: Joint ECCO and ESPGHAN Evidence-based Consensus Guidelines [57]	2012	Turner et al.	European Crohn's and Colitis Organization (ECCO) and European Society for Paediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN)	European collaboration	Ulcerative Colitis

Table 1 (continued)

Title	Year	Authors	Organisation	Guideline country of origin	Chronic illness
National Evidence Based Clinical Care Guidelines for Type 1 Diabetes in Children, Adolescents and Adults [58]	2011	Craig et al.	Australasian Paediatric Endocrine Group (APEG) and the Australian Diabetes Society (ADS), on behalf of the Australian Government Department of Health and Ageing	Australia	Diabetes
Diabetes care for emerging adults: recommendations for transition from paediatric to adult diabetes care systems [59] ^a	2011	Peters et al.	ADA ^e	Multinational collaboration	Diabetes
Sickle cell disease in childhood: standards and guidelines for clinical care [60]	2010	National Health service	NHS Sickle Cell and Thalassaemia Screening Programme Sickle cell society	United Kingdom	Sickle cell
Management of diabetes – A national clinical guideline [61]	2010	SIGN	The Scottish Intercollegiate Guidelines Network	Scotland	Diabetes
Congenital Adrenal Hyperplasia Due to Steroid 21-hydroxylase Deficiency: An Endocrine Society Clinical Practice Guideline [62]	2010	Speiser et al.	Endocrine society	Multinational collaboration	Congenital adrenal hyperplasia
Guidelines for the Clinical Care of patients with Thalassaemia in Canada [63]	2009	Sayani et al.	Thalassaemia Foundation of Canada, Anemia Institute for Research and Education	Canada	Thalassaemia

^aIllness specific transition CPGs.

^bIn partnership with the European Society of Human Reproduction and Embryology (ESHRE) and American Society of Reproductive Medicine (ASRM), and in collaboration with professional societies and consumer advocacy groups.

^cIn collaboration with the European Society for Paediatric Endocrinology, the Endocrine Society, the European Society of Human Reproduction and Embryology, the American Heart Association, the Society for Endocrinology, and the European Society of Cardiology. The guideline has been formally endorsed by the European Society of Endocrinology, the Pediatric Endocrine Society, the European Society for Paediatric Endocrinology, the European Society of Human Reproduction and Embryology and the Endocrine Society.

^dItalian Society of Paediatric Gastroenterology, Hepatology and Nutrition (SIGENP), Italian Association of Hospital Gastroenterologists and Endoscopists (AIGO), Italian Society of Endoscopy (SIED), Italian Society of Gastroenterology (SIGE).

^eWith representation by the American College of Osteopathic Family Physicians, the American Academy of Paediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Paediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Paediatric Endocrine Society (formerly Lawson Wilkins Paediatric Endocrine Society).

($n = 4$), Spain ($n = 1$), Italy ($n = 1$), multinational collaboration ($n = 5$), United States of America ($n = 2$), Canada ($n = 2$), Scotland ($n = 2$) and Australia ($n = 1$).

As shown in Table 1, CPGs were found for 14 chronic illnesses. Diabetes had seven CPGs published [39, 40, 43, 52, 58, 59, 61]. There were two each for juvenile rheumatic arthritis (currently agreed term ‘juvenile idiopathic arthritis’) (JIA) [45, 50], congenital adrenal hyperplasia (CAH) [53, 62] and epilepsy [41, 55], IBD had five CPGs (two general [44, 51], two ulcerative colitis (UC) [54, 57], one Crohn’s disease [56]) and one CPG each for Turner Syndrome [46], polycystic ovary syndrome (PCOS) [42], cystic fibrosis (CF) [48], sickle cell disease (SC) [60] thalassemia [63], phenylketonuria (PKU) [49] and systemic lupus erythematosus (SLE) [47].

Twelve of the 25 CPGs scored 100% of the CPG criteria standards with a maximum score of 13 [39, 41–44, 48, 52, 54–56, 58, 61]. The remainder reached 62% of the CPG standards (See Supplementary Table 1). Of these, seven did not mention involving the public in the decision making process for the guideline development [40, 47, 49, 51, 53, 57, 62], ten did not include information on updating the guidelines [45–47, 50, 51, 53, 57, 59, 60, 63] and three were not freely accessible through the internet [47, 50, 53]. As per inclusion criteria, all guidelines used a grading system to rate the recommendations. The search did not yield any published illness specific CPGs specifically for AYAs.

All the 25 guidelines mentioned the word ‘transition’ from paediatric to adult care. Five CPGs exclusively discussed transition care management for the specific illness: IBD [44, 51], JIA [45, 50] and diabetes [59]. Fifteen articles discussed “transition from paediatric to adult care” in a separate chapter within the guideline, whilst another five did not have a separate chapter to discuss transition care [42, 47, 49, 54, 56]. Two had no graded recommendations for transition from paediatric to adult care due to scarce evidence [42, 54].

The evidence levels for grading these recommendations varied from ‘no evidence’ to ‘limited evidence’, ‘low evidence’ and ‘moderate evidence’ levels. Only the draft available for epilepsy guidelines from the Scottish Intercollegiate Guidelines Network (SIGN) at the time of writing had recommendations based on high quality evidence [41]. Two CPGs on IBD and CF discussed all the seven ACI transition principles with graded recommendations as well as fulfilled all trustworthy CPG standards [44, 48]. Seventeen CPGs recommended good communication and collaboration between health teams and AYAs [40, 41, 43–48, 50, 51, 55, 57, 59–63]. Follow up and evaluation post transition was the least adhered to principle [41, 44, 45, 48, 50, 59, 63] followed by individual transition plan

[40, 41, 44, 45, 48, 52, 53, 59] and identification of a transition coordinator/facilitator [40, 41, 43–48, 50, 55, 59] respectively.

Table 2 provides the total score out of seven for the number of ACI transition principles addressed for each publication.

Evidence based recommendations related to transition from paediatric care from each of the CPGs with the grading system used are provided in detail as these appear in the CPGs themselves in Supplementary Table 2. Summary data for these two tables are provided below.

A systematic and formal transition process: Among the sixteen publications that recommended having a systematic formal transition process, eleven guidelines discussed structured, planned, youth focused processes or programs in detail [40, 44–51, 53, 57].

Early preparation: Sixteen guidelines had recommendations for early transition preparation of which five mentioned an age to start the actual transition process; Diabetes, CF and SC CPGs stating as early as 12–14 years [43, 48, 60] and two IBD CPGs from age 16–18 [51, 57]. Four guidelines further suggested that transition preparation age depends on individual development and that the age should be a flexible factor even though there is a virtual age limit [40, 44, 52, 57]. Several guidelines also recommended that the transition process should be planned and initiated several years in advance, allowing sufficient time for transition preparation [45, 46, 52, 62, 63]. Three others stated that preparation of at least one year before transition is necessary [39, 53, 59]. Diabetes CPGs recommend a varied age range from 12 years [43] to an optimum of one year before transition [39]. IBD CPGs’ recommended age range was from 16 to 18 years [51, 57].

Identification of a transition coordinator/facilitator: Eleven guidelines contained clear recommendations for a coordinator’s role or coordinated care. Five mentioned a named coordinator/care ambassador [43, 44, 46, 55, 59] while another specified the need of a transition coordinator within the multidisciplinary team [45]. Another five CPGs stated that transition processes need to be coordinated between the various health care professionals involved in patient care [40, 41, 47, 48, 50].

Good communication and collaboration: Seventeen publications discussed the need for good communication between paediatric and adult specialists as well as patients/families/carers and professionals involved in the care for a smoother transition process. These guidelines recommended open and transparent collaboration between the binary health facilities, especially with joint or overlapping clinics across paediatric and adult settings.

Table 2: Comparison of included publications with key ACI transition principles [37, 38].

Title	Systematic and formal transition process	Early preparation	Transition coordinators	Good communication and collaboration	Individualised transition plan	Enhance self-management	Follow up and evaluation post transition	Score (Max 7)	Chronic illness
American Diabetes Association [39]	N	Y	N	N	N	Y	N	2	Diabetes
ISPAD Guidelines [40, 64–66]	Y	Y	Y	Y	Y	Y	N	6	Diabetes
SIGN [41]	Y	N	Y	Y	Y	Y	Y	6	Epilepsy
Teede et al. [42]	N	N	N	N	N	N	N	0	PCOS
Diabetes Canada [43, 67, 68]	Y	Y	Y	Y	N	Y	N	5	Diabetes
Brooks et al. [44]	Y	Y	Y	Y	Y	Y	Y	7	IBD
Foster et al. [45]	Y	Y	Y	Y	Y	N	Y	6	JIA
Gravholt et al. [46]	Y	Y	Y	Y	N	Y	N	5	Turner
Groot et al. [47]	Y	N	Y	Y	N	N	N	3	SLE
NICE [48]	Y	Y	Y	Y	Y	Y	Y	7	CF
Van Wegberg et al. [49]	Y	Y	N	N	N	N	N	2	PKU
Calvo et al. [50]	Y	N	Y	Y	N	Y	Y	5	JIA
Ellr et al. [51]	Y	Y	N	Y	N	Y	N	4	IBD
NICE [52]	Y	Y	N	N	Y	Y	N	4	Diabetes
McCann-Crosby et al. [53]	Y	Y	N	N	Y	Y	N	4	CAH
NICE [54]	N	N	N	N	N	N	N	0	UC
NICE [55]	N	N	Y	Y	N	N	N	2	Epilepsy
NICE [56]	N	N	N	N	N	Y	N	1	Crohns'
Turner et al. [57]	Y	Y	N	Y	N	Y	N	4	UC
Craig et al. [58]	N	N	N	N	N	N	N	0	Diabetes
Peters et al. [59]	N	Y	Y	Y	Y	Y	Y	6	Diabetes
National Health service England [60]	Y	Y	N	Y	N	Y	N	4	SC
SIGN [61]	Y	N	N	Y	N	N	N	2	Diabetes
Speiser et al. [62]	N	Y	N	Y	N	N	N	2	CAH
Sayani et al. [63]	N	Y	N	Y	N	Y	Y	4	Thalassaemia

“Y” is given a score of one if the publication recommendations mention the transition principle and “N” is given a score of zero when not.

Individual transition plan: Eight guidelines emphasised the need for a tailored, youth focused, developmentally appropriate individual plan that is responsive to the young person's preferences. Two of these further described involvement of family in regard to preparation of this written plan [40, 45].

Enhance young people to self-manage: Sixteen guidelines recommended developing self-management skills: with the focus on assessing readiness for transition [44, 48, 60]; educating the young patient with age related condition specific knowledge [41, 44, 53, 59, 63]; use of various resources and transition readiness tools [39–41, 43, 50, 56, 59]; psychological support, peer to peer support and other educational information to build up confidence and independence to facilitate transition preparation such as understating the disparities in the binary health system in terms of approaches to patient care [46, 51, 52, 57, 59].

Follow up and evaluation after transition: Only seven guidelines discussed follow up and evaluation. Recommendations included: routine follow ups and feedback on the patient transfer success rate [63]; monitoring adherence to treatments and visits [50]; developing a measurable follow up process that can be evaluated [41]; providing AYAs with links and resources to re-engage with adult services after lapses in care [59]; direct communication between paediatric and adult healthcare services at least once after the transition was finalised [45]. Two other CPGs recommended evaluating and auditing the transition service as opposed to patient follow up [44, 48].

Diabetes had the greatest number of CPGs addressing transition care. Among the seven included diabetes CPGs, one exclusively focussed on recommendations for transition to adult diabetes care, with a focus on all key principles apart from a systematic transition process [59]. Three other guidelines minimally discussed transition principles, scoring zero to two [39, 58, 61]. Follow up and evaluation was the least discussed transition principle, with only one CPG from the group [59] including recommendations. One CPG did not have graded recommendations or practice points as to scarce evidence [58]. However, in this CPG, the key transition elements were discussed based on evidence from earlier published international guidelines. This CPG further discussed additional transition elements such as identifying a transition case manager for each person, a choice of adult provider, accessible medical documentation, general practitioner involvement and responsibilities. Further topics highlighted the importance of finding adult diabetic services that have adopted transition practices such as good communication with the patient in terms of appointments, seeing the same

clinicians for consultation, patient centred care, providing resources and maintaining a feedback process.

IBD including UC and Crohn's disease CPGs discussed all principles except for one UC CPG that did not have graded recommendations and transition was minimally discussed [54]. However, this CPG emphasised the use of self-monitoring over the transitioning period. The two general IBD CPGs focussed solely on transition to adult care, although they recommended varied age ranges for optimal age for transfer. One recommending early years with flexible timing [44] whilst other from 16 years [51].

The two CPGs for CAH addressed two to four principles each, but excluded any recommendations for coordinated care and follow up post transition [53, 62]. Epilepsy CPGs lacked recommendations for an age to start the transition process, but discussed coordinated care and good communication. CPGs included for JIA focussed exclusively on transition to adult care and between them provided recommendations to cover all the seven ACI key transition principles [45, 50].

Of those chronic illnesses that each had one CPG included in the study (PCOS, PKU, Turner syndrome, SLE, SC and thalassaemia, CF) the PCOS CPG had no recommendations due to limited models of care and evidence for adolescents transitioning to adult care. However, this CPG suggested that multidisciplinary care and condition specific education would support the transition process [42]. The PKU CPG discussed a systematic transition process and recommended early preparation for transition [49]. CPGs for Turner syndrome, SLE and SC did not have recommendations for individualised transition plans and follow up care [46, 47, 60]. The SLE CPG further lacked recommendations for early preparation and self-management, while the thalassaemia CPG focused on these plus recommendations for good communication and follow up care [63]. The NICE CF CPG addressed all seven ACI key transition principles [48] through reference to their generic transition guidelines [38].

Of those five guidelines that exclusively discussed transition for the specific chronic illnesses [44, 45, 50, 51, 59], good communication and collaboration was discussed the most extensively, whilst individualised transition planning was recommended by only three [44, 45, 59].

Discussion

Clinical management guidelines are important to both health professionals and patients in managing a chronic

and often complex condition. The transfer of care from paediatric to adult services is an important aspect in the patient's care management and the process of this transition may be challenging, particularly if clinicians do not have expertise in the condition and/or if there is no similar ambulatory care team in adult institutions. To date, there has been no systematic review that we could identify which described to what extent these CPGs in chronic illness that need specialist to specialist care explicitly discuss the practicalities of transition from paediatric to adult care. To address this, in addition to conducting a traditional database literature search, this study also examined internet based grey literature that included published documents from international scientific organisations.

Our aim was to identify whether and to what extent aspects of accepted transition principles were included in the published, illness specific CPGs and to determine what areas of transition need more evidence based research, using guidelines that included grading of evidence. One of the most important clinical practice goals is to develop clear, detailed, illness specific CPGs which are relevant to both paediatric and adult health care. Our systematic review suggests that there is still a way to go before we have a fully developed evidence base on how to achieve the goals of successful transition as first clearly described by Blum and colleagues 25 years ago [1].

The majority of CPGs recommend a systematic formal transition process and good communication, while relatively few guidelines mentioned follow up and evaluation. However, research indicates that transfer to adult care is not always effective, hence follow up and evaluation post completed transition are particularly important [18, 20, 69–71]. These processes are resource intensive, and to date the data on effectiveness of published programs remain limited. This situation might be improved by not relying on patient report but through use of data linkage with routinely collected institutional data. In general, the recommendations across all of the selected CPGs were based on limited/low or moderate evidence strengths or based on a high level of expert agreement from the guideline developers. Some of the selected CPGs mentioned aspects of the key transition principles in general discussion without grading them as recommendations, suggesting that guideline development groups are aware of these transition principles but lack the empirical evidence required to support the development of formal recommendations.

It is known that even before transition programs are developed it is beneficial to understand AYAs' preferences for what and how information/resources and support services are delivered to continue their care [72].

While transition recommendations in CPGs offer a promising start, implementation is more complicated and AYAs are still falling through gaps. This raises concerns about whether: AYAs actually get the opportunity to be involved in establishing the transition plan; institutions and services have sufficient funding to initiate these plans; care coordination between paediatric and adult services is consistent and robust; paediatric and adult health care systems are equipped with measures to monitor adherence [31]; and, sufficient training is taking place in the binary (child/adult) health settings for patients and professionals [23]. This is particularly relevant to current clinical practice in the context of greater numbers of young patients transitioning to and/or disengaging from adult health services [73].

It is also evident that the study did not identify sound CPGs for a number of chronic illnesses that would benefit from such guidelines such as: Klinefelter syndrome, spina bifida, Marfan syndrome and osteogenesis imperfecta. Further, identified CPGs for haemophilia and neuromuscular disorders did not mention any key transition principles on transition to adult care. CPGs have a much broader clinical reach than do clinical research publications, and it is therefore particularly useful if CPGs include recommendations for all key transition principles, while of course acknowledging that the evidence base is not always strong.

A major strength of this review is that the search was not limited to traditional database literature review, instead including also a broad internet search across high-quality websites that included organisational guidelines available to the public and published in the last decade. We also considered a number of less prevalent chronic illnesses that require specialist to specialist care, as taken together rarer chronic illnesses make up a significant proportion of transitioning patients. Additionally, this study used several standards and tools such as IOM, GIN, AGREE II and iCAHE to assess the quality of the CPGs.

A limitation around numbers is that illness specific CPGs only were considered and much of the transition literature is generic. Some guidelines were also excluded because they required a payment or authority to access and these may have contributed additional, important information had they been accessible.

Conclusion

In conclusion a number of chronic illnesses have illness specific guidelines that have recommendations for

transition from paediatric to adult care. Based on low and moderately low evidence quality, only two illness specific guidelines covered all the key transition principles. Additionally, key principles were mostly those initiated by paediatric care and only a few mentioned these as also being a responsibility of the adult providers. A challenge is to apportion responsibility to AYAs after leaving paediatric care in order for them to continue their long term health management, which is one of the most crucial steps in transition care although the least discussed key principle in the CPGs. The overall absence of high quality evidence around transition care means that policy makers must rely on low evidence levels or on expert opinion and practitioners do not have the evidence to request additional resourcing. A quarter of a century on from Blum and colleagues' key statement, evidence based transition care remains limited.

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