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Transition to adult services for children and young people with palliative care needs: a systematic review

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ABSTRACT

Objective: To evaluate the evidence on the transition process from child to adult services for young people with palliative care needs.

Design: Systematic review

Setting: Child and adult services and interface between healthcare providers.

Patients: Young people aged 13 to 24 years with palliative care conditions in the process of transition.

Main outcome measures: Young people and their families' experiences of transition, the process of transition between services and its impact on continuity of care, and models of good practice.

Results: 92 studies included. Papers on transition services were of variable quality when applied to palliative care contexts. Most focused on common life threatening and life limiting conditions. No standardised transition programme identified and most guidelines used to develop transition services were not evidence based. Most studies on transition programmes were predominantly condition-specific (e.g. cystic fibrosis, cancer) services. Cystic fibrosis services offered high quality transition with the most robust empirical evaluation. There were differing condition-dependent viewpoints on when transition should occur but agreement on major principles guiding transition planning and probable barriers. There was evidence of poor continuity between child and adult providers with most originating from within child settings.

Conclusions: Palliative care was not, in itself, a useful concept for locating transition-related evidence. It is not possible to evaluate the merits of the various transition models for palliative care contexts, or their effects on continuity of care, as there are no long-term outcome data to measure their effectiveness. Use of validated outcome measures would facilitate research and service development.

INTRODUCTION

A growing number of children and young people with what were previously fatal conditions of childhood, such as cancer,¹ life-limiting conditions and other life-threatening conditions,² are now surviving into adulthood, due to advances in treatment. Transition to adult services for young people with palliative care needs is therefore a contemporary concern. Such transitions can be complicated by deteriorating physical health and/or cognitive abilities, alongside normal developmental changes.

Policy initiatives and developments around transition and palliative care have become increasingly common.³⁻⁵ The Department of Health (DH) recently launched their first Children's Palliative Care Strategy '*Better Care: Better Lives*.'⁶ The strategy reinforces many of the views expressed in the Independent Review of Children's Palliative Care, which acknowledges that there is: "*currently poor co-ordination of public services across the statutory and voluntary sectors, particularly transition between children's and adult services*."⁷ Identification of the unmet needs of this population resulted in the recent publication of a framework for Integrated Multi-Agency Care Pathways by the Association of Children's Palliative Care (ACT).⁸

The concepts of palliative care and transition which are central to this review are complex. Although there is considerable agreement between different definitions of palliative care, the absence of a universal definition means that, at the condition level, any definition is, to some degree, arbitrary and hence open to challenge.⁹⁻¹² In determining which conditions to include and exclude in this systematic review we were guided by the contemporary Association of Children's Palliative Care/Royal College of Paediatrics and Child Health (ACT/RCPCH 1997/2003) definition of life limiting conditions.⁹

Transition has been commonly described as "*The purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of young people and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems*."¹³ Health care providers require evidence on which to develop services that are appropriate and effective for young people so that their care should not be compromised or '*lost in transition*' by the transfer to an adult system.¹⁴ The scope of this systematic review was to evaluate the evidence on transition from child to adult services for young people with palliative care needs, exploring the impact of the transition process on continuity of care, young people and their families' experiences and to identify models of good practice.

METHODS

Search strategy

We used medical subject headings (MeSH) and key words to search systematically five databases (Medline, CINAHL, PsychINFO, British Education Index (BEI) and the International Bibliography of the Social Sciences (IBSS)) from January 1995 to February 2008. An initial search strategy was devised and subsequently revised through an iterative process

involving all members of the team (Appendix 1). Key words included “transition,” “child,” “young people,” “adolescent,” “palliative care,” “terminal care,” “nursing practice,” “life limiting conditions” (LLC) (such as “cystic fibrosis”) and “life threatening conditions” (LTC) such as “CHD” and “cancer.” We also searched the reference lists of included studies and sought additional literature through contact with experts in palliative care.

Study selection

We included studies if participants were: (a) young people aged 13 to 24 years with palliative care conditions, defined using our criteria (insert Table 1); and (b) relevant to situational transition, i.e. transition from child services to adult services, and/or between healthcare providers; (c) original articles, reviews, systematic reviews, consensus policies, guidelines and survey recommendations. Excluded from the systematic review were studies whose: (a) participants had chronic disorders which were not intrinsically life-limiting (e.g. diabetes, rheumatological and endocrine disorders); (b) developmental disorders (e.g. severe and profound learning disabilities); (c) transplant recipients; (d) *social status* transition (that is, from childhood to adulthood); (e) *health status* transition (that is, from relative health to illness, or to end of life care) and (f) articles that did not provide English language abstracts.

A shortlist of papers were initially identified using titles and abstracts. The steering group reached consensus on titles and/or abstracts for inclusion. Papers, whose abstracts provided insufficient information, were considered in full to decide on inclusion or exclusion.

Main outcomes

We focused on three outcomes: the experiences of transition and their impact on young people, their families, carers and service providers; the process of transition on continuity of care; and models of good practice for the transition process.

Quality Assessment

We used a validated scoring system for systematically appraising empirical studies with varied methodologies, including qualitative studies.¹⁵ Each study component (total eight) of the full text paper was given a quality score ranging from 1 (very poor) to 4 (good) which generates a maximum potential score of 32 (Appendix 2). Discrepancies were resolved by consensus.

Data Extraction

Two reviewers from a list of four (MD, YA, DK, RP) independently completed a standardised data extraction form for each included full text paper. Any differences were resolved by consensus.

Extracted information included items referring to citation details, reviewer initials, study design, setting and participants (palliative care condition, age), as well as interventions, outcome measures and a total quality score (if applicable).

Data Analysis

SPSS (version 15) was used to manage the data extraction process and perform frequency analyses of the search findings. Meta-analysis of the findings was not feasible due to the heterogeneity of papers and limited measures of effectiveness/outcomes. The findings are therefore integrated in a narrative synthesis.

RESULTS

Figure 1 describes the paper selection process. The searches identified 3493 citations of which 252 were potentially relevant and their abstracts reviewed. After second screening, 128 full text articles were examined in detail. Ninety-two papers met the inclusion criteria and were from a variety of countries around the world: United States (n=42);^{16-45 13 46-56}; UK (n=27);⁵⁷⁻⁸³; Australia (n=11);⁸⁴⁻⁹⁴ Canada (n=8);⁹⁵⁻¹⁰² Denmark (n=1);¹⁰³ Switzerland (n=1);¹⁰⁴ Germany (n=1)¹⁰⁵ and South Africa (n=1).¹⁰⁶

There were no studies reporting findings from randomised controlled trials, comparative trials or any economic evaluation of a transition programme and only one systematic review on transition but this was for a mixture of conditions to include a chronic condition (diabetes) and learning disability.⁸³ The most predominant transition model was the *condition-specific model*.^{94 48}

²⁶ Only one example of consumer involvement in any of the established programmes was found.⁹³ Three further models were described by Miller (1996): the *paediatric service to adult service direct*; the *paediatric service to transition clinic to adult service*; and the *paediatric service to adolescent clinic to young adults clinic to adult service*.⁷³

Methodological quality (empirical studies)

Only 31 out of the 92 articles (34%) were classified as empirical studies and could be fully quality assessed/scored according to the eight study components.¹⁵ These empirical studies varied in design with only a few high scoring ones ranging from 18-31 out of 32 (webappendix 3). The mean score for studies was 24, SD=3.4. The remaining articles (non-empirical) were reviews, descriptions of services, policy or position papers.

Description of included studies (Empirical and non-empirical)

Palliative care

Only three papers used the term 'palliative care' as an overall concept in relation to health care transition from child to adult services and were all non-empirical.^{57 61 69} Edwards (2001) described a model of palliative care for a young person with cancer (and this is included in the count of papers for cancer).⁶¹

Conditions and transitions

Most of the identified papers focussed on specific conditions that fall under the umbrella term of palliative care. We allocated these to the 'condition groups' detailed below (corresponding to table 1).

1. Life-Threatening Conditions (LTC)

There were a total of twenty-four papers on LTC.^{20 51 19 63 28 98 96 34 103 46 18 37 99 76 25 26 24 79 56 61 30 82 31 16}

Four predominant CHD transition models have been proposed: the *paediatric model* (care received from paediatric providers, facilities and programmes); the *adult model* (care received from adult providers); the *blended model* (care received from paediatric and adult providers, facilities and programmes); and the *'drop out' model* (no care received).¹⁹ As there remains controversy over the best model for CHD, the *'blended model'* of care was often used due to the fact that most young people remained with their paediatric cardiologist because adult congenital heart centres and adult cardiologists experienced in CHD were lacking.²⁸ It was often difficult for child health care providers, patients or parents to terminate their long-term relationships and, as a result, a transition to an adult program often does not occur and this was termed the *'drop-out'* model.

CHD papers indicated that there remains controversy on the age at which transition should occur. Proposed strategies for facilitating the CHD transition process include the *patient passport*⁴⁶ and the *patient transition tool*.⁹⁸

Four transition models were proposed for young people with cancer: a *condition/disease-specific model* (management of a specific condition by paediatric providers, working directly with adult providers, to ensure prioritisation of the management of the physical condition); a *generic adolescent model* (a young person's/adolescent health specialist coordinates developmentally-appropriate, holistic care, covering the young person's biological and psychological concerns); a *primary care model* (coordinated by the general practitioner, which has met considerable opposition because of a lack of integration between primary and specialist care) and a *single site model* (the same clinical environment is used, i.e. the young person moves from child to adult care within the same health care system).^{30 26}

None of the above cancer transition models alone seem adequate and a multidisciplinary, coordinated model, providing continuity of care throughout the disease course, from child to adult services, is proposed as optimal.²⁵ A good example is provided from the Living Well after Cancer (LWAC) programme in the United States.²⁶

2. Life-Limiting Conditions (LLC)

There were twenty papers on conditions requiring intensive treatment to prolong life and maximise functioning.^{86 58 59 60 87 21 22 29 89 66 67 68 41 105 101 106 55 65}

^{54 72} All HIV studies^{65 54 72} were empirical, promoting the development of individualised transition plans for each family, the provision of appropriate environments and continuity of care from a known provider. No studies were found of Duchenne Muscular Dystrophy as a single condition although it was included in three papers categorised under mixed palliative care conditions.⁸³
^{71 64}

Cystic fibrosis was the predominant condition in this category with the most empirical studies (eight),^{105 86 68 22 21 106 55 87} with some evaluation of transition

programmes.^{87 66 105} Cystic fibrosis was an example of a condition which had high quality transition services. However, there was also wide variation in policies and practices regarding the transition process for young people. Transition programmes were often based within established CF centres but were not standardised. Overall, transition was challenging when adult teams were separated from the paediatric teams with the majority of young people wanting to see the adult CF physician at the paediatric hospital (81%).⁸⁹ In addition, there were varying viewpoints on the ages when transition should occur.^{68 106 55 29} The experiences of young adults with CF showed that the successful elements of a transition programme were orientation tours, information provision and the presence of a familiar face at the adult clinics.⁸⁶

3. *Progressive conditions without curative treatments*

There were no published papers located that addressed this topic.

4. *Severe, non-progressive neurological disability*

Two empirical studies^{40 102} reported on numbers of young people with these conditions making the transition to adult care and their ages at transition. Mothers were key to managing the young person's personal health record on the transition from child to adult services.⁴⁰

5. *Mixed palliative care conditions*

A number of other papers could not be easily categorised under single 'condition groups' because they addressed mixtures of palliative care conditions (any combination of CF, CHD, muscular dystrophy, cancer, HIV, disability, spina bifida) under the label of (a) chronic illness (n=13)^{32 104 52 77 50 13 48 74 88 23 91 35 47} with five of these being empirical studies.^{88 74 48 50 77} The general themes from this cohort of papers were: strategies to facilitate transition; exploring barriers to the transition process; and the requirement for *individualised* transition plans providing multidisciplinary and collaborative care.^{77 50 35} Two main models were observed in a survey which identified and characterised transition programmes for young people with chronic conditions: a 'young person model' (38%) and the majority a condition-specific model (62%).⁴⁸

There were nine papers on (b) chronic illness and disability.^{83 64 85 100 71 92 93 81}

⁹⁴ In the only systematic review, four transition models promoting continuity of care were identified: the *direct transition model*, where continuity is achieved when the young person is transferred to adult care safely and efficiently with the focus on relations between services; the *sequential transition model*, which addresses the young person's changing needs, in which services are an extension of child provision or offered jointly between adult and child providers; the *developmental transition model*, with the main focus on personal growth and development; and the *professional transition model*, which is not focussed on the young person but on the professional responding to the young person's needs, i.e. it releases expertise from one service type to the other (either child or adult). This latter model was common in conditions with short life expectancies or where expertise is located heavily within one service e.g. CF or HIV. They also found very limited evidence showing good

practices which address continuity of care during the transition from child to adult services with regard to parents and carers.⁸³

Three main transition models have been proposed for young people with chronic illness and disability and these are similar to the cancer models described in the earlier section (but does not include the single-site model).⁹⁴ There were three established transition programmes for young people with a chronic condition or disability in Australia: Transition Care Program in Chronic Illness; Victorian Transition Project; Five Year Transition Plan and consumer participation was integral to all three.⁹³

Nine papers were identified on conditions classified as requiring (c) special health care needs^{43 49 39 17 38 36 42 95 44} and four of these were empirical studies.^{36 38 42 49} There were four predominating models of health care delivery described for young people with special health care needs and these are the same as those for CHD (paediatric, adult, blended and drop-out). The key factor was parental involvement during the transition process.^{49 36} High quality parent-provider relationships were strongly associated with addressing transition issues.⁴⁹

There were only two papers for (d) special health care needs and disability exploring young people's perspectives on strategies for successful transition.^{45 53} White, (2002) discusses the key elements of a successful transition programme with a selected list of helpful resources for health professionals, families, and young people.⁵³

There were three papers on (e) general disability^{84 97 90} and only one empirical study amongst these.⁹⁰ Both the process of transition and achieving transition were described as problematic for this group, although an evidence-based transition framework had been used in Canada to help families and young people with disabilities make the transition.⁹⁷

Two papers did not correspond with the definitions of palliative care outlined in table 1 and these were: epidermolysis bullosa;⁶² and paediatric illness (empirical).²⁷ Both highlighted the importance of having transition programmes because of the increasing numbers of young people surviving into adulthood and the role of the family in improving the transition process.

6. *Generic transition*

There were six papers on generic transition^{33 70 78 80 73 75} and two of these were empirical.^{70 73} The main themes resulting from this cohort were key elements considered important for effective transition programmes and the identification of effective strategies as well as barriers (see below).

Facilitators and barriers to transition programmes

Many of these papers described recurring themes. Three key principles that underpinned a successful transition process were *information, communication and planning/coordination*. Other elements considered helpful in successful transition programmes are listed in table 2 (insert). They apply at the levels of health care organisations, health care professionals (whether in paediatric or

adult health care settings); the young person themselves and, his/her parents/carers/families. Underlying factors which may impede transition from child to adult services included *service-based demands; restrictions in relation to service provision; and personal preferences* (table 3 - insert).

DISCUSSION

Our main finding was the lack of evidence of transition services that include 'palliative care' as the originating concept. The evidence base is primarily derived from the area of Life Threatening or Life Limiting Conditions rather than palliative care itself. This may reflect shifting constructions of palliative care away from end of life to include long term supportive care. Two main types of transition services existed for young people with such conditions: those underpinned by condition-specific models of transition (mainly for young people with cystic fibrosis, cancer or chronic conditions) and generic models of transition, such as holistic, developmentally-appropriate, young person's/adolescent health-focussed services.

There was a lack of standardised transition programmes and only a few models of good practice available in the literature. Good quality empirical evaluations of condition-specific or generic models of transition were sparse and outcome data mainly existed in relation to cystic fibrosis and CHD. One of the challenges facing health care providers is how to move forward with service developments in terms of transition given the diversity of the conditions and relatively small numbers of young people involved. These are key research and service evaluation challenges that will have to be addressed if responsive transition services are to be developed.

Most of the recommended guidelines for transition programmes lacked a robust evidence base. The majority of empirical studies had small sample sizes^{40 77 42 86 68 72 73} and the transferability and generalisability of findings were also limited as findings may only be relevant to the population under assessment. It is clear that gaps in service provision need to be considered alongside the current state of the evidence concerning transition.

Fragmentation also existed between child and adult providers, with evidence of poor continuity of care, which made it difficult and problematic for many young people to negotiate the transition period. Significant differences between child and adult providers have been noted.^{40 45} The role of the family in facilitating transition seems key and has some evidence-base.^{32 76 37} Individualised, flexible transition plans, that take into account the views of young people and their families, are advocated. There was also evidence emerging of specialists young people's clinics for cancer⁸² and HIV⁷² to facilitate the transition process.

Lack of access to, and availability of, appropriate comparable adult services for young people approaching transition was a key concern expressed by many young adults, families, carers and child health providers/organisations. Services need to be flexible and appropriate for chronological age and developmental stage. There seems little doubt that young people prefer same-age groupings and recognise the problem of moving away from the familiar

paediatric environment to an adult service. Having an intermediate service could be hypothesised as positive; however, generic or specialist adolescent transition services require further evaluation.

Appropriate education and training is essential for those providing care for young people making transitions from child to adult services. Ideally, a key-worker should guide young people through the process of transition and the young person and family/carers should be viewed as co-experts. As Olsen, 2004 stated 'developing an individualised transition plan (a life (not illness) plan) facilitates transition and improves continuity of care.'³⁹ Peer-led models of support are also open to further exploration.

Professional issues include paediatricians' reticence to initiate the transition process because of anxieties and concerns that adult colleagues may not be familiar with the young person's palliative care needs.^{29 41 86 22 24 30 67 92 45} The adult sector also has little experience of paediatric diseases that are now, with advances in medicine and technology, increasingly continuing into adult life. This represents a key challenge for the development of appropriate transition services for young people. The papers included in the review were, however, limited mainly to child health providers and settings. Research originating from adult services is therefore required. Findings from this systematic review should be used to identify the focus of further research that addresses which models of transition for young people, or components of differing models, can optimise outcomes. Use of evidenced-based facilitators, for example, as well as more nuanced knowledge of the barriers that impact negatively on the transition process, would aid in developing interventions that can be tested in the context of complex transitional care.

The development of validated outcome measures are also necessary to determine the effectiveness of transition programmes in the context of palliative care where health care needs may fluctuate more than in chronic conditions.

CONCLUSION

This review demonstrates a lack of available evidence comparing models of transition for young people with palliative care needs. Condition-specific transition programmes do dominate but little evaluation has been carried out into their effectiveness. Further empirical research is warranted to compare models of transitional care, including long-term evaluation of existing programmes, using validated measures to determine their effectiveness in relation to continuity of care, health and social care outcomes and cost effectiveness.

Table 1: Four areas of life-limiting conditions⁹

Areas	Examples of Conditions
1. Life-threatening conditions for which curative treatment may be feasible but can fail	<ul style="list-style-type: none">• Cancer• Cardiac anomalies• Irreversible organ failure
2. Conditions that may entail long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, although premature death is still possible or inevitable	<ul style="list-style-type: none">• Cystic fibrosis• Duchenne Muscular Dystrophy• HIV/AIDS
3. Progressive conditions without curative treatments, where intervention is exclusively palliative, although it may continue for many years	<ul style="list-style-type: none">• Batten disease• Mucopolysaccharidosis• Creutzfeldt Jacob Disease
4. Conditions associated with severe neurological disability that are not progressive but can entail weakness and susceptibility to health complications leading to premature death	<ul style="list-style-type: none">• Brain or spinal cord injuries

Figure 1 Flowchart for systematic review

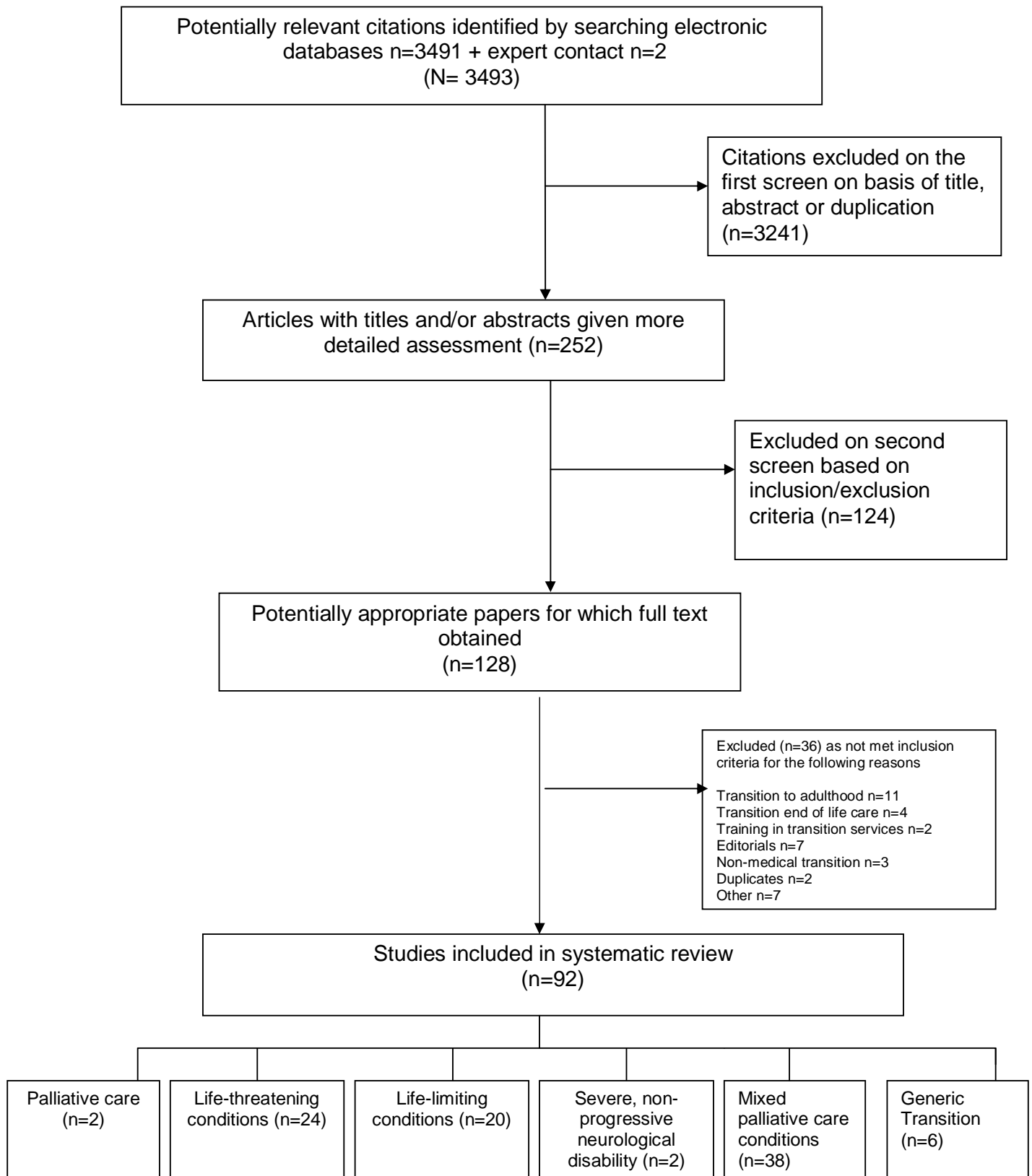


Table 2 Facilitators for a successful transition process between child and adult health care professionals, health systems, young people, families and carers

➤	Transition/adolescent clinic where patient is seen by the paediatrician and the general physician together is effective e.g. in CF ^{74 106}
➤	Adult orientated primary health care from appropriately trained and certified professionals in adult health care settings ^{54 48 88 47 46}
➤	Health care passports ^{28 18 46}
➤	Child and adult providers collaborate and agree on a workable written transition plan ^{74 81} at joint clinics ³⁵
➤	Communicate and share responsibility for transition between teams and with patients ^{61 40 92 39 97}
➤	Develop a medical summary transfer form 'transition note' ⁴⁰ and/or information pack about adult services ⁷⁴
➤	Adolescent autonomy checklists (assess patient readiness for transfer) ^{88 18}
➤	Continue the successful aspects of the paediatric plan at transition ^{44 33}
➤	To start transition years before the transfer date, ongoing communication and effective feedback from the adult care centre once transfer has occurred ⁸¹
➤	Individualise date of transfer for patients with special needs – 'social and medical stability' ⁸⁸
➤	Identify named professional (key worker) for contact point during transition for young people e.g. transition nurses, ⁴² transition workers/coordinators ^{13 75 74 81 86}
➤	Encourage patients as partners in their care ⁸¹
➤	Patients and families view as co-experts ⁴²
➤	Internet information of resources, website links & internet chat groups ^{18 42}
➤	Summer camps(CHD increasing- USA) ⁵¹
➤	Promote self care/management throughout the transition period ⁸⁸
➤	Young people and family involved in the transition process from beginning ^{29 72 77 50 62}
➤	Patients and families have visited adult teams and in patient centres/support groups/orientation tours ^{86 74 42}
➤	Attend mentor programmes to pair young people with successful adults with a similar condition ^{18 42}

Table 3 Barriers for child and adult health care professionals and health systems, young people, families and carers that effect the transition process

➤	Fragmentation of care between primary and specialty providers; paediatric and adult providers ^{25 64 90 41}
➤	Lack of available or appropriate/comparable adult services to provide consumer centred care that promotes autonomy ⁵⁰
➤	Paediatric providers unwilling or uncomfortable terminating relationships 'letting go' due to emotional attachments to the young person/family ^{44 19}
➤	Paediatric providers lack of confidence with adult providers and the adult system ⁸⁹
➤	Geographical issues related to location of available resources ^{33 45 48}
➤	Provider time constraints to address transition issues ^{92 49}
➤	Poor communication between paediatric and adult providers ^{24 59 92 41 74 90}
➤	Lack of condition-specific expertise in the adult system ²⁸
➤	Adult providers lack of awareness about or comfort with adolescent age group and the transition process ⁷⁷
➤	Lack of effective and evaluated models for transition ^{94 85 79}
➤	Patients or family unwilling to make transition ^{50 42}
➤	Medical insurance issues when reach adulthood(American) ^{49 16 29}
➤	Separation anxiety for patients and families leaving trusted and familiar health care providers ^{70 54 72}
➤	Lack of preparation/planning for successful participation in the adult health care system ^{45 42}
➤	Expectation of independence in negotiating and navigating the adult health care system ^{55 44}
➤	'Becoming burned out on healthcare.' this has only been described in one paper ⁴²

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CONFLICT OF INTEREST STATEMENT

None of the authors of this manuscript have any conflict of interest.

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WHAT IS ALREADY KNOWN ON THIS TOPIC

- The increased life expectancy of young people with life threatening and life limiting conditions has raised the importance of transition to adult services for young people with such conditions.
- There is increasing literature and attention around transition services for young people but this has mainly focussed on areas such as chronic illnesses and disabilities.

WHAT THIS STUDY ADDS

- There is no evidence of transition services that address 'palliative care' as an overall concept. Transition programmes that exist are mainly condition-specific.
- No long-term outcome data exist to compare the effectiveness/cost effectiveness of the condition-specific or generic transition models.
- Some consensus exists on what may facilitate or impede successful transition programmes. This suggests transition programmes should be multidisciplinary in nature, individualised in terms of addressing need and navigated with the help of a designated key worker.

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Appendix 1 Search strategy

MEDLINE (Ovid SP) 1995 to Feb week 2 in 2008

- 1 transition\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 2 child\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 3 adolescent\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 4 Young people.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 5 exp After-Hours Care/
- 6 exp "Delivery of Health Care, Integrated"/
- 7 exp Managed Care Programs/
- 8 exp Adolescent Health Services/
- 9 exp Community Health Centers/
- 10 Community Health Nursing/
- 11 nursing practice.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 12 social support/
- 13 exp School Health Services/
- 14 exp Home Care Services/
- 15 exp "Quality of Health Care"/
- 16 exp Pediatric Nursing/
- 17 exp Hospitals/
- 18 Hospice Care/
- 19 exp Palliative Care/
- 20 exp Neoplasms/
- 21 exp Terminal Care/
- 22 Cystic Fibrosis.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 23 exp Chronic Disease/
- 24 Cerebral Palsy/
- 25 Disabled Persons/
- 26 service evaluation.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 27 exp Program Evaluation/
- 28 exp Heart Defects, Congenital/
- 29 exp Leukemia, Myeloid/
- 30 exp Polycystic Kidney Diseases/
- 31 exp Neurodegenerative Diseases/
- 32 Terminally Ill/
- 33 life threat\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

34 life limit\$.mp. [mp=title, original title, abstract, name of substance word,
subject heading word]
35 or /2-4
36 or/5-34
37 1 and 35 and 36
38 limit 37 to (english language and humans and yr="1995 - 2008")

Appendix 2 Data Extraction/Assessment Form

Transition to adult services for children and young people with palliative care needs: a systematic review

Assessment form:

Author(s)	
REF ID	
Date of Publication	
Initials of reviewer	

1. Title and Abstract meets table of inclusion/exclusion criteria

Yes No

2. Study design

Quantitative Qualitative Combination Other

Please state:

3. Location of study

4. Sample Description

5. Aim

6. Research Questions/Hypothesis (If any)

7. Method and Analysis

8. Intervention (if applicable)

9. Results

10. Conclusions, Comments and Issues Raised

11. Summary:

	Good 4	Fair 3	Poor 2	Very poor 1	Comment
Introduction & aims					
Method & data					
Sampling					
Data Analysis					
Ethics & Bias					
Findings/results					
Transferability/generalisability					
Implications & Usefulness					

12. Total score (maximum 32)

Appendix 3 Characteristics of empirical papers with quality scores

Author, year of publication	Country	Research Focus	Design & Methods	Population & Setting	Key findings	Comments/ Implications	Quality assessment score (max 32)
Reid, Irvine, McCrindle, Sananes, Ritvo, Siu et al (2004) ⁹⁹	Toronto, Canada	To determine the percentage of young adults with CHD who successfully transferred from paediatric to adult care and examine correlates of successful transfer. Successful transfer would be associated with: 1. Health care system factors 2. Family factors 3. Individual factors	Qualitative and quantitative Cross-sectional study with prevalence data and qualitative interviews Eligible patients mailed a consent form, questionnaires and SAE. Two weeks later patients telephoned to address any difficulties with the questionnaire and schedule an interview. Interviews audiotaped and transcribed	360 patients aged 19-21yrs with complex CHD	47% patients transferred successfully to adult care. 27% reported having had no cardiac appointments since 18yrs. Successful transfer was significantly associated with more paediatric cardiovascular surgeries, older age at last visit, recommendations documented for follow up at the Canadian Adult Congenital Heart Network (CACH). Co-morbid conditions, not using any substances, dental antibiotic prophylaxis and attending cardiac appointments without parents/family members correlated with successful transfer	Multiple mechanisms such as referral letters and transition clinics are needed to facilitate successful transition. One of the first studies to show evidence of the percentage of young adults with a chronic illness who successfully transfer to adult care in a timely manner.	31
Steinkamp, Ullrich, Müller, Fabel, von der Hardt (2001) ¹⁰⁵	Germany	To evaluate patients opinion of the transition by analysing the results of two surveys performed before and after the transition	Quantitative Pre and post transition questionnaire surveys mailed anonymously and analysed using SPSS Intervention: adult CF clinic/unit	44 of 68 patients with cystic fibrosis aged 18 to 33 years replied to 1 st questionnaire and 56% of patients responded to 2 nd questionnaire Participants drawn from paediatric CF unit to a newly established CF clinic	Mean duration of treatment at paediatric centre was 7.5yrs. 12 supporters and 12 opponents of the transition, remainder intermediates. In 2 nd survey patients rated quality of care in the adult CF unit better than prior to the transition	Transition of a cohort of adult patients with CF from paediatric to internal medicine care (adult care) will be accepted by patients. The better the training of all internal medicine staff, the more positive the patient response will be.	29
Scal and Ireland (2005) ⁴⁹	USA	To investigate the opportunities for and barriers to addressing the transition from paediatric to adult providers among	Quantitative using parent self reports Explanatory variables: parental education, family poverty, status,	4332 young people (14-17yrs) from the 2000-01 National Study of Children with SHCN.	50.2% of parents reported they had discussed transition issues with their adolescent's GP and 16.4% discussed a plan for addressing those needs. Correlates of the	Young people with SHCN, those older and with more complicated needs were more likely to have addressed the transition	29

Author, year of publication	Country	Research Focus	Design & Methods	Population & Setting	Key findings	Comments/ Implications	Quality assessment score (max 32)
		young people with SHCN	race/ethnicity, measure of severity and complexity of conditions, health insurance status, personal doctor and the quality of parents relationship with the adolescent's GP entered into regression analysis	Adequacy of transition services determined by parent self report to 3 questions: 1. Have doctors or other providers talked about how healthcare needs might change when becomes an adult? 2. Has a plan for addressing these changes been developed with health care provider? 3. Have healthcare providers discussed eventually seeing a doctor who treats adults?	adequacy of transition services included, older age, female gender, complexity of healthcare needs and higher quality of the parent – doctor relationship.	from a paediatric to adult orientated system of care. Strong association between high quality parent provider relationships and extent to which transition issues addressed. Only cross-sectional data representing association but not causation	
Scal, Evans, Blozis, Ockinow, Blum (1999) ⁴⁸	USA	To identify and characterise programs providing transition health services for young people and young adults	Quantitative Postal survey	Nominated samples of programmes (277) that provide health care transition services to youth and adolescents with chronic conditions (includes CF). 155 programmes completed questionnaires with response rate 46%	2 models of transition organisation observed: 1. Adolescent model (38%) 2. Condition focussed (62%) Barriers to transition: <ul style="list-style-type: none"> Funding Access to adult providers 	Family and adolescent resistance was rarely reported despite previous literature indicating to the contrary that it was a major barrier to effective health care transition First empirical survey on organisation and financing of existing health care transition services and barriers they encountered	29
Reiss, Gibson, Walker (2005) ⁴⁵	USA	To identify key factors involved in successful transition between paediatric and adult services for young people with continuing health care	Qualitative Interviews and focus groups Content and narrative analyses using ATLAS-ti	34 focus groups and 143 interviews with: young adults (13-35yrs) with disabilities and SHCN; 44 family	3 major themes: 1. Transition services exploring chronological understanding of the transition process 2. Health care systems exploring differences between paediatric and	4 major factors impact transition process: 1. Transition developmental process 2. Significant differences between paediatric and	28

Author, year of publication	Country	Research Focus	Design & Methods	Population & Setting	Key findings	Comments/ Implications	Quality assessment score (max 32)
		needs and to assess the adequacy of such provision from the perspectives of service users, family members and healthcare providers		members and 50 health care providers.	adult providers and how differences between them inhibit transition 3. Transition narratives discussing transition experiences of patients and health care providers	adult providers 3. Resources 4. 'Trusting' relationships between C&YP and their providers in the evaluation of care. Predominance of providers from the paediatric setting and therefore the perspective of adult providers are not well presented. Fails to address the emergence of specialist clinics	
Scal (2002) ⁵⁰	USA	To describe the range of approaches that represent transition services as undertaken by primary care providers and to understand them in the context of the proposed models	Qualitative & quantitative including a postal survey of primary care providers Written responses reviewed for themes. Survey questions (forced response questions) were summarised as proportions and standard deviations – open ended questions reviewed for themes	Primary care providers (paediatricians, family physicians, internists, nurse practitioners, or others) who facilitated the transition of medical care from the paediatric to the adult health care system for chronic conditions	5 major themes identified: 1. Frustration with transition 2. Fear and ambivalence 3. Transition is a process not an event 4. Providers need to be geared towards the future 5. Family physicians see transition as integral to their practice Providing <i>individualised care</i> is key to the transition process rather than a uniform protocol	Chronic conditions not defined clearly but included CF Low response rate – indicative of primary care providers doing little in the area of transition? Additional training for primary care providers in behaviour and behaviour change, sexuality and reproduction and transition services Role of family in transition process integral Framework for developing institutional support created because lack of institutional support is a major barrier to providing transition services	28
Lotstein,	USA	To investigate social and	Quantitative	Parents of 13-17yr	50% of parents had discussed their		27

Author, year of publication	Country	Research Focus	Design & Methods	Population & Setting	Key findings	Comments/ Implications	Quality assessment score (max 32)
McPherson, Strickland, Newacheck (2005) ³⁶		health related factors associated with planning or receiving transition services in relation to 3 questions: 1. Do young people's parents discuss transition issues? 2. Do they have a plan to address these? 3. Have their children been advised they may have to see an adult doctor?	telephone surveys Bivariate analysis then multivariate logistic regression	olds as part of a National US survey of children with SHCN	child's changing health care needs. Of these 59% had a plan and 42% reported shifting care to adult providers. Hispanic or black youth less likely to - those in nursing homes more likely. Older age and having a nursing home place most closely associated with discussion and transition to adult care		
Craig, Towns, Bibby (2007) ⁸⁷	Australia	A preliminary evaluation of a transition programme for young people with CF	Quantitative Cross sectional data Self administered pre and post transition questionnaires SPSS data analysis	Pre and post transition questionnaires to young people with CF and their parents	137/220 (62%) participants completed questionnaires. In the pre-transition group. Parents had more concerns compared to young people. No difference between both groups regarding the degree of concern. Post-transition patients and parents who completed more steps in the transition program described the overall transition process more positively	First study in Australia to evaluate a transition program for C&YP with CF. Pre and post transition groups not identical and not matched for age, gender, or disease severity	26
While, Forbes, Ullman, Lewis, Mathes and Griffiths (2004) ⁸³	UK	To identify practices which address continuity during the transition from child to adult care To assess the merits of those practices, determining good practice. To identify any underlying mechanism or models which may be useful in developing continuity.	Systematic review focusing on the identification of good practice models	Five tracer conditions: - diabetes mellitus - learning disability - cystic fibrosis - congenital heart disease - muscular dystrophy	Components for better care: -Structural components -Process components -Outcome components were either disorder-specific or generic such as user satisfaction. -Components of practice regarding young people include -Components of practice regarding parents and carers • specific service provision; • development of skills of self-management and self-determination; • supported psychosocial		25

Author, year of publication	Country	Research Focus	Design & Methods	Population & Setting	Key findings	Comments/ Implications	Quality assessment score (max 32)
					<ul style="list-style-type: none"> development; involvement of young people; peer involvement; support for changed relationships with parents/carers; provision of choice; provision of information; Focus upon young person's strengths for future development. <ul style="list-style-type: none"> the evidence with regard to good practice with parents and carers was very limited Four models: <ol style="list-style-type: none"> 1. Direct transition model 2. Sequential transition model 3. Developmental transition model 4. Professional transition model 		
Young, McCormick, Mills, Barden, Boydell, Law et al (2006) ¹⁰²	Canada	Transition to adult health care	Multi methods <ol style="list-style-type: none"> 1. Postal survey 2. 15 adult and 15 youth qualitative interviews 3. Additional interviews with the 30 participants' caregivers 	100 adults (23-32.9yrs), 190 youth (13-17.9yrs) with spina bifida and acquired brain injuries. Also includes cerebral palsy in this sample. Identified from 6 children's rehabilitation centres (CRCs)	95% of youth and 61% adults were living with their parents; 23% youth and 55% adults employed; 60% youth and 42% adults reported 'excellent' or 'very good' health. Lowest health scores reported by adults with spina bifida	17.4% (33/190) reported making the transition with mean age at 12.5yrs 86% of the 100 adult participants' made the transition mean age 18.0yrs which is mandatory age of transition applied by the CRCs	25
Westwood, Henley, Willcox (1999) ¹⁰⁶	South Africa	To gain an insight into the perspectives of young people and adults with CF as well as their parents make the transition from paediatric to adult oriented health care	Qualitative – Cross sectional survey questionnaire 47/61 (77%) response rate	Young people with CF and their parents	'Autonomy' considered important to most young people with CF. Transfer at the age of 16-18yrs was preferred by respondents. Over 90% felt that a 'transition clinic' would be useful		24
Zack, Jacobs, Keenan, Harney, Woods, Colin, et al (2003) ⁵⁵	USA	How young people view preventative counselling and transition to adult care	Qualitative (patients experiences of transition) and quantitative (sources of medical care, receipt of	32 CF patients ≥ 16yrs	13-16yrs was thought the best age for transition, less than half had recalled preventive counselling and wanted to discuss more issues than they had. Decision making and		24

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			preventive counselling and desire to discuss health risks) Structured questionnaires with space for comments		promotion of independence emphasised and most viewed transition with caution – offered specific suggestions		
Brumfield and Lansbury (2004) ⁸⁶	Australia	Exploring the experiences of Australian adolescents with cystic fibrosis as they make transition from paediatric to adult care	Qualitative Focussed – in-depth interviews Thematic analysis	Six young adults with CF (19-34 years)	Four main areas found that affected the transition experiences of the participants: <ul style="list-style-type: none"> • paediatric health care • adult health care • elements included in the transition programme • psychosocial factors 	Relationship of patient with paediatric doctor and the doctors' attitude towards the transition and the delivery of age appropriate care appeared to influence the experiences of adolescents as they changed to adult care. The successful elements of a transition programme if it was offered were the orientation tours, information provision and presence of a familiar face at adult clinics	24
Wiener, Zobel, Battles, Ryder (2007) ⁵⁴	USA	HIV transition Barriers associated with transition were identified and addressed as well as transition readiness and state anxiety. Interventions utilised to assist with the obstacles identified in transition of care described	Qualitative and quantitative Two sets of interviews and administration of the Transition Readiness Scale (provides score for readiness and identifies barriers to successful transition to community based programs as well as to adult providers) and the State/Trait Anxiety Inventory for adults (STAI) Paired sample t-test compared readiness	39 caregivers of HIV infected youth (10-18yrs) and 12 youth over 18yrs interviewed at two time points transitioning from paediatric care to an adult or community based provider in response to a programme closure	Transition readiness improved and state anxiety decreased significantly from the first time point to the last visit (approx 7mths later). Not having a home social worker was the most reported concern/need identified.	To develop interventions to help young people and their families successfully transition to adult centred care and guide the development of an individualised 'transition plan' for each family	24

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			and state anxiety scores				
Por, Golberg, Lennox, Burr, Barrow & Dennard (2004) ⁷⁴	UK	To identify health care professionals' opinion of the main issues regarding the transition of care for young people with chronic conditions from children to adult services	Qualitative & quantitative Questionnaire postal survey anonymised. Content analysis	40 paediatric and adult health care professionals. CF included in majority of sample	Mental maturity cited as the most frequent in readiness to transfer 17-18yrs most frequent age Adult nurses felt unprepared to take over care and some felt parents were interfering 10% believed young people with chronic conditions prepared adequately Families/carers need more support Communication important factor	Clear multidisciplinary transfer plan required with a target transfer age useful to guide staff and C&YP but a flexible approach required. The clinical nurse specialist acts as important professional and advocate. Small study only undertaken in one Trust	24
Kennedy, Sloman, Douglass, Sawyer (2007) ⁸⁸	Australia	Experience from a transition programme from the Royal Children's Hospital, Melbourne and describes the preparation to ensure effective transition for young people with chronic illness to adult systems	Quantitative and qualitative	Young people with chronic illness transferring to adult systems	Most hospitals not actively involved in planning the transfer of patients from paediatric to adult providers. The quality of transition processes is variable. Transition coordinators are main drive towards a series of initiatives to support patients transferring to other hospitals	Adult physicians need to be aware of the 'developmental stage' of young people in order to provide appropriate and engaging care. A developmental model of adolescent healthcare needs to be taught at all adult physician training Experience from one hospital setting	24
McPherson, Weissman, Strickland, van Dyck, Blumberg, Newacheck (2004) ³⁸	USA	To provide baseline measures of the number of children meeting core outcomes of care – transition is one criteria out of six others	Quantitative – telephone surveys of families of children with SHCN Secondary analysis of national survey data and establishing measurable criteria for core outcomes of care	Two large national surveys of children with SHCN	15% aged 14-17yrs received medical support for transition, 25% some vocational training and only 5.8% met the criteria for successful transition		24
Judd, Doerholt, Tookey, Sharland, Riordan,	UK	To describe the changes over time in morbidity and mortality in cohorts of children in the UK and Ireland with perinatally	Quantitative Multivariate analysis of prospective cohort data reported to the National	1441 HIV infected children with 40% ≥ 10yrs old at most recent follow up visit	Morbidity and mortality rates among HIV infected children decreased over time. Specialist care is now provided in national clinical networks	Further development required of transition adolescent clinics aimed at ensuring successful transfer between paediatric	24

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Menson et al (2007) ⁶⁵		acquired HIV infection during 1996-2006.	Study of HIV in Pregnancy and Childhood (NSHPC) and the Collaborative HIV Paediatric Study			and adult services. Majority of children with a diagnosis of HIV infection expected to reach adulthood and will require support for a range of psychosocial issues.	
O'Connell, Bailey, Pearce (2003) ⁹⁰	Australia	Transition from paediatric to adult health care in relation to disability	Qualitative – 3 focus groups	Young adults with disability Carers of young adults with disability Health care service providers	Number of problems with the transition period identified. All participants acknowledged supportive, coordinating role of the paediatrician, without the paediatrician role carers felt they lacked the knowledge and support to manage the adolescent with a disability. Communication a problem. General lack of continuity of care between providers difficult for individuals to negotiate the transition period.		24
Goodman, Mendez, Throop, (2002) ²⁷	USA	Impact of adult survivors' of paediatric illness on: 1. Patterns of resource utilisation 2. Economic costs to hospitals	Quantitative Observational design analysis of routine data	10 US paediatric hospitals with data from 1994-1999 of adults receiving treatment in paediatric hospitals (21-64yrs)	Estimated upto 15 000 adult patients per annum at cost of \$556M	Importance of transition programmes highlighted	23
Flume, Taylor, Anderson, Gray, Turner (2004) ²²	USA	To investigate aspects of transition policy and practice and staff perceptions of patient concerns	Quantitative – survey of staff members Online survey	Directors in all CF centres (paediatric vs adult) (no. of centres 110). Number of staff unknown; 291 responses	Transition programmes not well developed from paediatric to adult systems. Paediatric directors felt patients and families and adult CF teams were less receptive to the concept of transition. Wide variation in policies and practices regarding transition	Need to develop standard programmes of transition and incorporate team members in the process	23
Miles, Edwards, Clapson (2004) ⁷²	UK	To explore experiences of transition from paediatric to adult HIV services	Qualitative Semi structured interviews – audiotaped, thematic analysis	7 young people (16-20yrs) who had transitioned to adult HIV services from Great Ormond Street Hospital paediatric	Degree of attachments to paediatric services correlated with anxiety about transition Participants welcomed the sense of independence and control in the decision making process that came	There is need for a 'young person's environment' and a need for continuity of care by a known physician	22

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				HIV service	with transition		
Zeback, Eshelman, Hudson, Mertens, Cotter, Foster, et al (2004) ⁵⁶	USA	To identify barriers and suggest ways to offer risk-based follow up care for young adult survivors of childhood cancer	Qualitative – Delphi method in three rounds using questionnaires and expert panel	19 young adult survivors of childhood cancer and one mother	Barriers identified relating to the: Survivors, psychological providers and system related. Preferred option was follow up clinic with experienced health care professionals and nurse practitioners. Expert panel suggested a more primary care based model		21
Patterson and Lanier(1999) ⁴²	USA	A grounded theory approach used to develop themes in teens or young adults with special health care needs in transition	Three qualitative focus groups	Young people or young adults with SHCN in three different geographical areas.	- health care providers must feel comfortable with disabilities -Barriers to successful transition -What helps or might have helped transition - Strategies for successful transition	Limited numbers of participants in each focus group, i.e.: Three, two, two.	21
Flume, Anderson, Hardy, Gray (2001) ²¹	USA	To assess status of transition programmes and problems of transfer to adult services	Quantitative – postal survey Descriptive statistical analysis	Directors of paediatric and adult CF centres in the USA (n=154)	67.5% response rate. Transfer was discussed at time of diagnosis in only 14% of programmes. Paediatricians reported higher patient, parent and staff concerns about transition than did adult programme directors	1. Lack of standardised transition programmes 2. Differences in perceptions of concerns by paediatric and adult program directors	21
Østerlund, Dosa & Arnott (2005) ⁴⁰	USA	A concise medical summary or 'transition note' i.e. the personal health record as a mechanism for improving health care transition To examine how young people with spina bifida and their families interact with their medical records during the transition from paediatric to adult orientated care	Qualitative Focus groups and semi-structured interviews Grounded theory NVIVO	6 patients, 6 family members and 1 private duty home nurse from population of 34 young adults 18-21yrs receiving comprehensive care at a regional referral centre for spina bifida and spinal cord injury	Mothers key to record keeping during transition from paediatric to adult orientated care. Information from healthcare providers greatly lacked detail and comprehensiveness.	Data findings from 4 questions: 1. Who is involved in record keeping? 2. How is the information stored? 3. What information is kept and shared among the different constituencies 4. When do patients and parents need the information?	21
Maynard, Rennie,	UK	How staff communicated with parents/families about	Quality Assurance Initiative/Service	Transition – general	Transition, both age and prognosis related caused concern with anxiety	Particularly difficult was children with profound	20

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Shirliffe and Vickers (2005) ⁷⁰		their child's care, their family support needs and how staff liaised with other professionals and organisations	Evaluation 6 'parent lunch' focus groups (n=29 parents) Thematic analysis	3 hospice sites with two focus groups at each site	about long-term future or loss of support when prognosis improved. Parents wanted better information about practical help and psychosocial supports as well as up-to-date information about their child's treatment and management from all care providers.	physical and learning disabilities.	
Soanes & Timmons (2004) ⁷⁷	UK	To examine the attitudes and needs of young people with chronic illness who are transferring to adult care	Qualitative Semi-structured interview audiotaped and transcribed. Interviews conducted in the hospital	Young people (14-17yrs) with chronic illness (1 cancer, 5 diabetes, 1 renal failure) transferring to adult care. Participants drawn from youth club service in a large teaching hospital	Five key themes: 1. Comfort and familiarity 2. Informality versus formality. Adult services were more serious and formal than paediatric facilities 3. Ready and prepared. Transition gradual process and importance of adequate preparation 4. Flexibility and support	To increase the likelihood of successful transition, strategies need to be informal, flexible, highly individualised and prepare young people steadily for adult services	19
Dore (2002) ⁹⁶	Canada	All new patients referred to adult CHD centres were asked to answer specific questions about diagnosis, needs, reasons for antibiophylaxis, and the risk of pregnancy	Questionnaire	104 patients were referred to the adult CHD centre	Poor level of knowledge about CHD in a large percentage of adults.	The questionnaire was not validated or standardised, only used in one region which prevents generalisations.	19
Madge and Bryon (2002) ⁶⁸	UK	To explore service users views on issues around transition. Transition from paediatric CF centre to adult CF centre	Quantitative Survey Descriptive statistics	21 teenagers with CF (14-17yrs) attending Great Ormond Street Hospital	1. Transition should occur between 14yrs and 19yrs 2. 91% felt discussion should involve all available sources 3. 81% felt discussion should involve themselves	Transition requires preparation and coordination	18
Miller (1996) ⁷³	UK	Transition of care in young people to adult services To investigate adolescent perceptions of a children's outpatient service and to discover what is important to them when attending an outpatient in one district	Qualitative Semi-structured interviews	Seven young people (12-19 years) with 'enduring' conditions who had been attending the children's outpatient for some time	Major themes: 1. Transition should be gradual 2. Familiar doctor retained and new adult doctor introduced 3. Good communication Three possible transition pathways : 1. Paediatric service to adult service	Adolescent and young adults prefer age grouping and recognise the problem of moving away from a familiar paediatric environment to an adult service if there are no intermediate phases. No details of	18

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		general hospital			direct 2. Paediatric service to transition clinic to adult service 3. Paediatric service to adolescent clinic to young adults clinic to adult service	methodological analysis provided and low number of participants No classification of conditions just described as 'enduring'	

