

## Accepted Manuscript

Title: Title: Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences

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PII: S0738-3991(16)30353-6  
DOI: <http://dx.doi.org/doi:10.1016/j.pec.2016.08.011>  
Reference: PEC 5429

To appear in: *Patient Education and Counseling*

Received date: 10-4-2016  
Revised date: 28-7-2016  
Accepted date: 8-8-2016

Please cite this article as: Heath Gemma, Farre Albert, Shaw Karen. Title: Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling* <http://dx.doi.org/10.1016/j.pec.2016.08.011>

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Manuscript: Patient Education and Counseling

**Title: Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences**

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**Competing Interests:** The authors declare they have no competing interests.

**Author contributions:** All authors contributed to the review design and analysis of papers. GH conducted the searches. GH and AF conducted data extraction and coding. GH drafted the manuscript. All authors revised the manuscript and approved the final version.

## Highlights

- Parents view young person progression to self-care as an incremental process.
- Parent perceptions of child readiness and wellness impact on healthcare autonomy.
- Parents are concerned about a lack of transitional healthcare.
- Parents **can** adjust their behaviour to support their child's independence.
- **Healthcare professionals can support parents to facilitate adolescent autonomy.**

## Abstract

**Objective:** To understand how parents view and experience their role as their child with a long-term **physical health** condition transitions to adulthood and adult healthcare services. **Methods:** Five databases were systematically searched for qualitative articles examining parents' views and experiences of their child's healthcare transition. Papers were quality assessed and thematically synthesised. **Results:** Thirty-two papers **from** six countries, **spanning** a 17-year period were included. Long-term conditions were diverse. Findings indicated that parents view their child's progression toward self-care as an incremental process which they seek to facilitate through up-skilling them in self-management practices. Parental perceptions of their child's readiness, wellness, competence and long-term condition **impacted on the child's progression to healthcare autonomy**. A lack of transitional healthcare and differences between paediatric and adult services **served as barriers to effective transition**. Parents were required to adjust their role, responsibilities and behaviour to support their child's growing independence. **Conclusion:** Parents **can** be key facilitators of their child's healthcare transition, supporting them to become experts in their own condition and care. To do so, they require clarification on their role and support from **service** providers. **Practice**

Manuscript: Patient Education and Counseling

**Implications:** Interventions are needed which address the transitional care needs of parents as well as young people.

**Keywords:** Parents; Child health; Long-term conditions; Transition; Qualitative research

## **Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences**

### **1. Introduction**

Long-term physical health conditions (LTCs) affect significant and increasing numbers of adolescents in the UK [1]. Advances in treatment/technology mean that these young people are now more likely than ever to reach adulthood [2]. This will at some point, require them to assume a greater degree of independence and self-care than previously encountered [3], in addition to transferring from paediatric to adult services for ongoing healthcare [4]. The need for effective transitional care and the benefits this provides in terms of maintaining engagement with healthcare throughout the life course and improving health outcomes is well established [5]. However, transition cannot be conceptualised as young person-only phenomenon. Parents and adolescents together create the emotional environment necessary for the adolescent's adaptation to the demands of young adulthood [6,7]. Healthcare transition therefore also requires parents to adjust their care giving role, gradually relinquishing control of their child's LTC and supporting progression to young person autonomy [8,9]. Studies examining the role of family members during the transitional period [8,10,11] suggest parents face a range of new care challenges associated with their and their child's development, including adaptation to a changing role, allocation of treatment responsibilities and anxiety regarding their child's illness trajectory [12].

Despite recognition of the systemic nature of transition [7] and the effect of this developmental phase on shifting roles within family systems, previous reviews have focused on the perspectives of patients [13-15], transitional models [16,17] and healthcare practices [18,19]. Reviews have been carried out on the experience of parenting a child with a LTC [20] and on the effectiveness of interventions for parents of children and adolescents with chronic illness [21,22], however, these do not consider the experience of parenting a child with a chronic condition during their transition to adulthood and adult-services.

It is important to understand how parents experience their child's transition to adulthood because how parents manage and cope with their own change in roles and responsibilities will likely impact on both their child's transition to independent self-care as well as their own psychological well-being. Understanding the challenges that parents face, from their perspective, will further indicate support needs.

#### 1.1 Aim & Objectives

This review aimed to collect and synthesise primary research relating to how parents understand and experience their role as their child with a LTC transitions to adulthood and adult healthcare services. The objectives were to: (a) understand how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services; (b) understand how parents experience their care-giving role in relation to their own well-being; (c) make recommendations regarding how healthcare providers can support parents during their child's transition.

## 2. Methods

The review adopted a systematic search methodology in accordance with PRISMA guidance [23] and followed the analytic procedure for 'thematic' synthesis [24].

### 2.1 Eligibility Criteria

To be included, papers had to report qualitative findings of primary research exploring parents' understanding and experiences of their role as their child with a LTC transitioned to adulthood and/or adult services. Parents included mothers, fathers and other primary care-givers (e.g. grandparents) of young people with long-term physical health conditions. In accordance with the WHO definition, an age range for young people of 10-24 years was stipulated. LTCs were defined as physical "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely" [25]. This meant conditions that require on-going clinical care and self-management, for which medications are critical, and require follow-up at clinic. Examples include diabetes mellitus and cystic fibrosis. As the review focused on physical health, mental health conditions such as anxiety and depression were excluded, as were learning difficulties such as autism. Papers reporting studies with mixed samples (e.g. perspectives of young people, parents and professionals), were included if data pertaining to parents were reported separately or could be separated by the reviewers. Studies with wholly young person or professional samples were excluded. No limits were placed on the year of publication; only studies reported in English were included.

### 2.2 Systematic Search

Five electronic databases (Medline; CINAHL; EMBASE; PsycINFO; HMIC) were systematically searched to identify potentially eligible articles from inception until June 2015. Google Scholar was used to search for grey literature. A comprehensive search strategy was developed to include a combination of free text and index terms. Key search terms included parents; transition; hospital; chronic illness. The Boolean operator 'OR' was used to combine synonymous keywords, with 'AND' used to combine key concepts (figure 1). Articles identified by the electronic searches were downloaded into a reference management database and duplicates removed. Remaining citations were screened by the first author by title and abstract. Articles that clearly did not meet the inclusion criteria were excluded and all other possible relevant citations retrieved as full-text copies. All authors independently assessed the eligibility of retrieved full-text papers against the inclusion criteria. They then met to discuss their assessments. Uncertainties were discussed until consensus agreed. References of all included studies were hand-searched for additional articles which were assessed for inclusion in the same way.

### 2.3 Critical Appraisal of the Included Studies

Included papers were quality assessed using the Critical Appraisal Skills Program [26]. Quality assessment was carried out by the first author and a subset of papers checked by a second author. Studies of all quality were included with the quality of studies taken into consideration during data synthesis [27].

#### 2.4 Data extraction

Studies were read before data were extracted and recorded. As well as basic study information, all text presented within the findings/results sections of each included article were extracted. This included data relating to key themes and concepts as expressed by the participants and by the authors, using a pre-prepared form. Data were then imported into NVivo version 10 to support coding and quotation retrieval. The corresponding author of included studies was contacted to obtain further information where necessary.

#### 2.5 Data synthesis

Data were synthesised thematically [24]. This method was selected as it provides a systematic and transparent approach which facilitates the production of rich and interpretive, yet data-driven themes, in order to broaden conceptual understandings of a particular phenomenon. Thematic synthesis has three stages: (1) coding of text; (2) development of 'descriptive themes'; and (3) generation of 'analytical themes'. While the development of descriptive themes remains 'close' to primary studies, analytical themes represent a stage of interpretation whereby the reviewers 'go beyond' primary studies, generating new interpretive constructs or explanations.

Inductive coding was carried out **across the data set**, independently by two authors **according to its meaning and content [24]**. Codes were then discussed with the third author and a coding frame agreed upon. This was subsequently applied to the findings of all included studies. Related codes were grouped together and labelled to form descriptive themes **and a summary of each theme written. The final step of analysis, moving 'beyond' a thematic summary of included studies, was achieved by grouping and developing the descriptive themes generated from our inductive analysis to address the review objectives. This involved interpretative work by all authors, using the coded data set to understand how parents experience their care-giving role in relation to a) supporting their child's transition and b) their own well-being and c) to make recommendations for healthcare providers. During this process, new, analytical themes were generated which inferred implications for service provision from parents' descriptions of their lived experience. Here we present the analytic themes that were generated from our descriptive themes (table 1).**

**Trustworthiness was maintained using a number of strategies including keeping a clear and transparent audit trail, maintaining a reflexive approach, and discussing emerging understandings within a research team. We were aware that our position as health and social psychologists with training and experience in qualitative health services research would inevitably influence our interpretations. We therefore strived to remain open to unexpected discoveries by consciously reflecting on our knowledge and experience, critically appraising our individual and group level interpretations and discussing alternative explanations. It was through this process that we managed to agree on categories in which our various interpretations fit and that would contribute to the existing knowledge base in parenting and transitional care.**

### 3. Results

#### 3.1 Systematic search

1966 articles were retrieved for assessment against the inclusion criteria with 32 papers included in the review (figure 2). Papers presented qualitative data on parents' views and experiences of their child's healthcare transition in a variety of LTCs (asthma, arthritis, cancer, cystic fibrosis, congenital heart disease, cerebral palsy, diabetes, epilepsy, Marfan syndrome, sickle cell disease and spina bifida). Studies were conducted across six countries (Switzerland, UK, Canada, USA, Australia and Netherlands) over a 17-year period (1997-2014) using a variety of qualitative data collection and analysis methods (table 2).

#### 3.2 Quality appraisal

All studies were assessed as having a clear statement of aims, with an appropriate research design and methodology for addressing those aims. Only one paper discussed issues of reflexivity. This is important for considering whether and how the researcher/s might have impacted on the research outcomes. The majority of papers presented an appropriate recruitment strategy with data analysis that was judged to be sufficiently rigorous, providing a clear statement of findings and a valuable contribution to the research area (table 3).

#### 3.3 Synthesis findings

Findings regarding parenting a child with a chronic illness as they transition into adulthood and adult services were generally similar across LTCs with some differences relating to the impact of the condition and treatment on the family's life and child's future. Findings that contributed to explaining parents' understanding and experience of their role during their child's healthcare transition were captured in eight themes, **grouped to address the first two review objectives**: views on transition; factors affecting child autonomy; preparation for healthcare transition; service provision; young person condition management; parents' experiences of their child's transition; parental transition; and impact of the LTC on the family (table 4). Each theme is briefly described with exemplar data extracts provided in table 5. Findings were then **used to address the third objective, making recommendations for service providers, which is presented within the practice implications.**

#### 3.4 Understanding how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services

##### 3.4.1 Views on transition

In most studies, independence-building, including transition toward self-management was regarded as "a positive social value" [28, p.997]; something parents viewed as important and were motivated to support their child to develop. Achieving healthcare independence was understood as an incremental and negotiated process of gradually transferring responsibility for self-care in accordance with other increases in responsibility unrelated to the child's health condition (e.g. staying away from home). Moving from childhood to adulthood was therefore characterised as having a number of different transitions (e.g. in healthcare systems, education). Healthcare transition was perceived as a process of mediated condition management; moving "forwards and

backwards along the continuum" [10, p.2146] of young person and parental management, with parents stepping in to provide respite during times of stress or episodes of illness. The transition process was activated consciously following triggers such as parents being at work or child leaving home, or unconsciously in accordance with other "developmental considerations" [28, p.997].

### 3.4.2 Factors affecting child autonomy

Several factors influenced the child's autonomy acquisition in relation to the management of their LTC. These included parents' perceptions of their child's "developmental readiness" [29, p.419], including beliefs about their child's "overall maturity and sense of responsibility" [30, p.9], their emotional stability and capacity to self-care. Reaching a point of readiness was considered individual to each child and depended on parental understanding of their child's competence and motivation to carry out self-management tasks such as medication administration, symptom monitoring and self-advocacy. This in turn was linked to parental trust in their child to be responsible for their condition, that is, how much they believed their child would adhere to their treatment regimen and not endanger themselves by engaging in risky behaviours. In addition, "stability of the young person's condition" [31, p.121] impacted on when transition to self-care was encouraged and how management tasks were shared. Generally, transition to self-care was seen to need to happen during a time of "perceived wellness" [10, p.2140].

### 3.4.3 Preparation for healthcare transition

Strategies used to prepare young people for assuming healthcare autonomy included parents encouraging and supporting their child to self-care, explaining and allowing their child to "experience the consequence of their actions" [30, p.10], modelling self-care behaviours, monitoring condition management and prompting treatment administration. Parents in several studies discussed actively teaching their children self-management skills including condition and treatment management, self-advocacy and "self-surveillance" of bodily symptoms [32, p.446]. They employed strategies for ensuring that their child was aware of and had access to their own medical history and practiced asking questions for consultations. Parents talked about offering "tangible assistance" [33, p.216] to their child in terms of filling prescriptions, making appointments and transporting the child to clinic. This was presented as the young person taking responsibility for self-management by instigating treatment adherence, but parents providing assistance where needed. Such a 'shared care' approach, where parents and young people worked in partnership to manage the health condition was described as a useful intermediary between parental and young person management.

### 3.4.4 Service provision

Concerns were raised about changes to service provision across paediatric- and adult-centred healthcare. In contrast to the adult sector, children's services were viewed as providing care that was tailored to the child's "unique and complex" needs [34, p.35] within a "warm, familiar, cosy and trusted" environment [35, p.826]. However, lack of preparation for transfer between services and a perceived lack of transitional care left parents experiencing a sense of "loss" [36, p.351] of support, resources and trusted relationships. This was regarded as a form of "abandonment and rejection" by paediatric professionals [37, p.362]. The absence of adequate transitional care further left parents to act as their child's transition co-ordinator, assuming responsibility for communicating between services, arranging orientation visits and clinic appointments at new hospital sites and organising the

transfer of clinical notes. Service changes impacted on parents in terms of them experiencing a discontinuity of information from lone consulting and a loss of “their own support systems” [38, p.484]. Suggestions for improvement included better collaboration between paediatric and adult sectors; joint visits; starting the process of transition earlier; increased information provision, transition preparation and support groups.

### 3.4.5 Young Person Condition Management

Parents described varying degrees of involvement in the management of their child’s condition, with mothers describing themselves as highly involved in managing their child’s LTC on a day-to-day basis, taking responsibility for ensuring treatment adherence and administration [10, p.2138]. In contrast, fathers were found to take a more laissez-fair approach, assuming responsibility for ensuring the health of all family members rather than concentrating solely on the child’s condition [39, p.767]. Many parents described conflicts arising from their protective parenting behaviours, for example, constant checking and questioning of their child’s treatment adherence, lifestyle choices or engagement in potentially risky behaviours [40, p.13].

## 3.5 Understanding how parents experience their care-giving role in relation to their own well-being

### 3.5.1 Parents’ experiences of their child’s healthcare transition

Parents’ experiences of their child’s healthcare transition were characterised by feelings of “stress” [34, p.36], “turmoil” [37, p.361] and “fear” [37, p.362]. Stress and turmoil related to the families’ detachment from paediatric services and “uncertainty” [41, p.345] regarding the move to adult care. A prominent source of anxiety was the tension between how much control parents should maintain over their child’s condition/treatment and “how much responsibility” [30, p.4] they should handover to the young person. Parental reluctance to relinquish control was linked to their fear of “long-term health complications” [42, p.224] resulting from their child’s engagement in risky behaviours including treatment non-adherence. “Letting go” [39, p.768] of control over their child’s condition and treatment was found to be a “difficult process” [28, p.999] for parents, while maintaining control helped to manage their anxiety. However, this “need to stay involved in the child’s health care” [43, p.330] delayed the onset of young person autonomy. Enlisting a network of “others outside the family” (e.g. friends, professionals at school/college) [42, p.226], who would help the young person adjust to their increasing independence and provide self-management support in the absence of parents also served to manage parental worry.

### 3.5.2 Parental transition

Included studies indicated that parents too were required to go through a process of transition, from parenting a child to parenting a young adult with a LTC. This transition presented “developmental challenges” [28, p.999] for parents themselves, demanding changes to their behaviour and adjustment to their role. An example was substituting “watching” [30, p.9] a young person administer treatment with “passive supervising” [10, p.2139]. In particular, parents described having to revise “their definition for successful [condition] management” [42, p.226] in line with what their child could achieve. In several studies parents expressed “ambiguity and uncertainty about what the new arrangements for care signified about their changed role” [28, p.997]; struggling to reconcile



relinquishing control with providing support and guidance. Frequently this meant that parental support was not withdrawn completely, but that their previously held “managerial role” gave way to a new “consultant role” [44, p.190]. Most challenging was the role of “passive initiator” where parents initiated but had “no direct involvement or knowledge” [10, p.2140] of the child’s condition management behaviours beyond reminding them.

### 3.5.3 Impact of LTC on family

Parents described how their child’s LTC impacted on their family, including the impact of the condition on siblings, on parents’ other roles, relationships and responsibilities and on the child’s capacity to live a ‘normal’ life. Parents felt it was their duty to maintain “a positive attitude and outlook” for their child [42, p.226], redirecting focus away from the young person’s limitations toward “possibilities of the future” [32, p.449]. Parents described their desire to maintain a sense of “normalcy” for their child [42, p.226]. This was achieved through treating the LTC as a “normal part of life” [45, p.12] and ensuring that the child lived as “normal” [44, p.190] a life as possible, despite their LTC. However, also expressed was a sense of “burden” [46, p.53] and burnout from parenting a child with a chronic illness, particularly those with life-limiting conditions.

## 4. Discussion and Conclusion

### 4.1 Discussion

This review thematically synthesised 32 papers from six countries reporting how parents understand and experience their role as their child with a LTC transitions into adulthood and adult healthcare services. Developing understanding of the parent perspective is essential for ensuring the provision of effective transitional healthcare. Although studies were diverse in terms of LTCs, they were comparable, enabling the development of overarching themes.

Findings revealed that parents generally view their child’s progression towards self-care as a positive and incremental process which they seek to facilitate through up-skilling them in self-management practices. Parent perceptions of their child’s readiness, wellness, competence and LTC **impacted on** child healthcare autonomy. A lack of transitional care, perceived differences between paediatric and adult services, and a loss of relationships, resources and support for parents and young people **served as barriers to effective healthcare transition**. Parents’ experiences of their child’s healthcare transition were characterised by ambiguity and uncertainty, leading to feelings of anxiety and distress. A strong source of anxiety related to fear of poor health outcomes from relinquishing control of the condition to the young person. In parallel with their adolescent child, parents were required to go through their own process of transition. This involved supporting the child’s growing independence and adapting to a new role. Parents required support **from healthcare providers** to prepare for and manage their child’s healthcare transition.

The core finding that parents have difficulties relinquishing control of their child’s LTC for fear of poor health outcomes supports previous research on healthcare transition from the perspectives of young people and professionals [8,15,48]. It also aligns with research on emerging adulthood in a non-clinical population [49]. **In this review**, parental reluctance to relinquish control was related to perceived risk of shifting allocation of treatment responsibility to young people, and to inadequate professional co-ordination of the child’s transfer across services [31]. While protective parenting

practices served to promote child safety, they could also lead to reduced autonomy in early adulthood [15,50] stemming from increased parental attachment behaviour [51] and leading to emerging adults being averse to assuming adult responsibilities [52]. Young people have also expressed frustration at the over-involvement of parents post healthcare transition [53,54]. Parents therefore appear to be more concerned than their children about the adolescent's ability to be autonomous [35,55]. It is essential that parents understand the importance of supporting young people to develop the skills and confidence they need to effectively manage their own LTC throughout and beyond transfer to adult care [56]. **Healthcare professionals are ideally placed to work with parents to facilitate their and their child's growth and change.**

Four domains of perceived parental support have been identified by young people and professionals throughout transfer to adult services. These include parents providing practical support, acting as 'trouble-shooters' in times of health-related crisis, working in partnership with young people to manage their condition and providing emotional protection [53]. Our findings support the need for parents to adjust their role to embrace that of 'partner'; sharing healthcare management with their child in a state of inter-dependence, as a bridge to full independence [57]. Shared care might include parents 'prompting' young people to administer treatment, fulfilling prescriptions and up-skilling them in self-care activities. This role is similar to that of a 'lay carer' as described by parents of adults with LTCs [58].

**While parents are responsible for adapting their role to support their child during transition, healthcare providers are responsible for providing transitional care that addresses the needs of both parents and young people. Working in partnership with parents, as well as young people, will likely lead to a smoother and more effective transition for all. However,** despite acknowledgement of the need for parent-targeted transition support [10,55,62] Allen et al [28] highlight that provision for parents is withdrawn at the time they need it most. Intervention studies remain limited. One paper reporting the development and evaluation of a peer support group for parents of young people with health conditions transitioning to adulthood [63] found that parents who attended the group gained new knowledge and became more future-oriented and active in their transition preparations. Further research is required to explore the effectiveness of interventions helping parents and young people define and respond appropriately to their shifting roles and responsibilities [8].

Lone consulting for young people remains controversial. Our findings suggest that exclusion from consultations is difficult for parents, particularly when they perceive their child is not coping well [12]. While professionals have shown empathy for parents' information needs, a belief that parents gradually lose their right to information about their young adult child's health is embedded in practice [53,59]. However, this issue is complex; while lone consulting is cited as a common goal in the transition process [9,60], research is clear on the protective nature of parental involvement in terms of disease control [8,11,61]. Thus tensions exist between guidance in the adolescent health literature emphasising the benefits of independent self-management and evidence that continued parental involvement leads to improved health outcomes. Recent best practice guidelines emphasise the need to regularly discuss with young people how they would like their parents to be involved throughout their transition [7]. Nevertheless, effectively balancing the young person's need for privacy/ confidentiality with their parents' need for sufficient information to provide self-management support requires further research [11].

Finally, our findings provide empirical support for the conceptualisation of healthcare transition as a multifaceted process involving **partnership** between numerous stakeholders (young people, parents, service providers) and systems (family, healthcare), as proposed within systemic and ecological theories [6,64-66] and in keeping with international policy studies suggesting the need for system-level transition strategies [67]. The finding that parental perceptions of the child's condition and abilities guide their willingness to transfer responsibility for condition management to young people further indicates utility of the Common Sense Self-Regulation model in which health behaviour is theorised to be guided by cognitive and emotional illness perceptions [68,69]. Parents have been shown to hold representations of their child's condition and treatment which influence their behaviour regarding healthcare professional advice [70]. Parental self-efficacy beliefs about their capacity to change and effect change in their child's self-care behaviours is likely to be central to the success of interventions, as suggested by Social Cognitive Theory [71]. Theories of learning such as Social Development Theory [72] could also be applied, particularly the idea that learning self-management skills occurs during the interaction between individuals and more knowledgeable others (e.g. parents or professionals), and that the range of skill that can be developed with adult guidance exceeds that which can be attained alone.

A strength of this review is that by consolidating qualitative findings from diverse LTCs, we were able to identify a range of common experiences and needs of parents in dealing with a child's increasing autonomy acquisition, which may not otherwise have been identified had a disease specific approach been taken. These findings indicate the need for transitional care interventions which **address the needs of** parents as well as young people. That only small differences between conditions were found, suggests that the issues parents experience during their child's healthcare transition are generic. This aligns with existing research and suggests the utility of non-disease specific interventions [12,15,39,48,73,74]. A limitation of this review is that even though our definition of young people was broad, searches still identified papers discussing healthcare transition from the perspective of parents of children who fell outside of our specified age range [e.g. 62,75] and papers in which the parental perspective could not be distinguished from that of young people or professionals [e.g. 76,77]. These papers were subsequently excluded. Moreover, by focusing the review on physical health, mental health conditions and learning disabilities were excluded. Further research is needed to establish **how transition may differ when young people have needs in these areas**. Finally, despite a lack of (reported) reflexivity within included studies, which could be argued to impact on the trustworthiness of our review, that insights were derived from across (rather than within) 32 individual studies, indicates confidence in our findings.

## 4.2 Conclusion

Parents **can** be key facilitators of their child's healthcare transition, supporting and encouraging them to become experts in their own condition and care. To do so, **parents require clarification on their role and support from service providers**. Healthcare practitioners need to work in partnership with parents, in order to help them to facilitate their child's transition, and to maintain their own psychological wellbeing during a stage of parenting that is characterised by ambiguity, uncertainty and risk.

## 4.3 Practice Implications

#### 4.3.1 Supporting parents to facilitate their child's transition

Findings suggest that parents can be key facilitators of their child's move toward healthcare independence. Rather than being excluded from the transition process, parents **can** be assets/resources for supporting the child's adaptation to self-care. Parents, as well as young people, therefore **should be supported by health professionals and their needs addressed** within transitional care interventions. Particular attention should be given to **incorporating parents' helpful insights about their child and their child's condition, as well as clarifying and supporting them in their changing role.** Healthcare providers **could work more effectively** with parents to facilitate young person autonomy, by introducing families to the concept of "inter-dependency" and supporting them to practice a partnership approach which incrementally engages the young person in developmentally appropriate self-care. Strategies for supporting parents to facilitate their child's transition might include encouraging parents to identify or create opportunities to witness their child's capacity to be responsible for their healthcare; working with families to establish helpful condition management routines, systems and structures, and teaching parents to guide and supervise adolescents in their efforts to self-care; explaining the rationale for developmentally appropriate care (including lone consulting) and negotiating ways of feeding back to parents; teaching parents how to help their child to advocate for themselves (e.g. practising asking questions, modelling communication skills).

#### 4.3.2 Supporting parents through their own transition

Findings further indicate that parents are required to go through their own transition process, from parenting a child to parenting a young adult with a LTC. Parental thoughts, feelings and behaviours regarding such change will inevitably impact on their acceptance of, and adaptation to a new role. Particularly anxious parents who overestimate the risks associated with young person autonomy for example, may be reluctant to relinquish control of their child's condition, leading to them practicing extreme levels of vigilance and protectiveness. **This can be** perceived as 'problematic' by professionals. However, these parents could be supported through their own transition by healthcare staff working with them to identify particularly anxiety provoking situations and teaching adaptive coping skills. Offering brief psychological interventions individually or in peer/parent support groups would convey sensitivity to the difficult and potentially distressing nature of transition for parents, as well as provide education and support. This would benefit parents who may be at risk of experiencing high levels of anxiety concerning "letting go" of established roles and responsibilities. For parents who are particularly distressed, referral to psychology services may be warranted.

#### 4.3.3 Providing effective transitional care

Findings demonstrate that transitional care arrangements should be in place for **parents and** young people endeavouring to concurrently assume greater responsibility for self-care with transferring to an unfamiliar healthcare setting, regardless of their condition. While childhood chronic illnesses vary in clinical characteristics and treatment regimens, it is clear that transition issues are not unique to particular disease processes, but are shared among young people with LTCs and their parents. There may be scope therefore for generic transition programmes that **address the needs of parent as well as young people** and can be tailored to specific conditions. The current state of inadequate transitional care increases the need for a level of parental involvement which undermines the

concept of healthcare transition. It further places significant burden on parents, increases perceived differences between paediatric and adult sectors and emphasises the impact of those changes on both parents (e.g. discontinuity of information) and young people (e.g. fewer resources).

**Acknowledgements:** AF and KS were funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) West Midlands. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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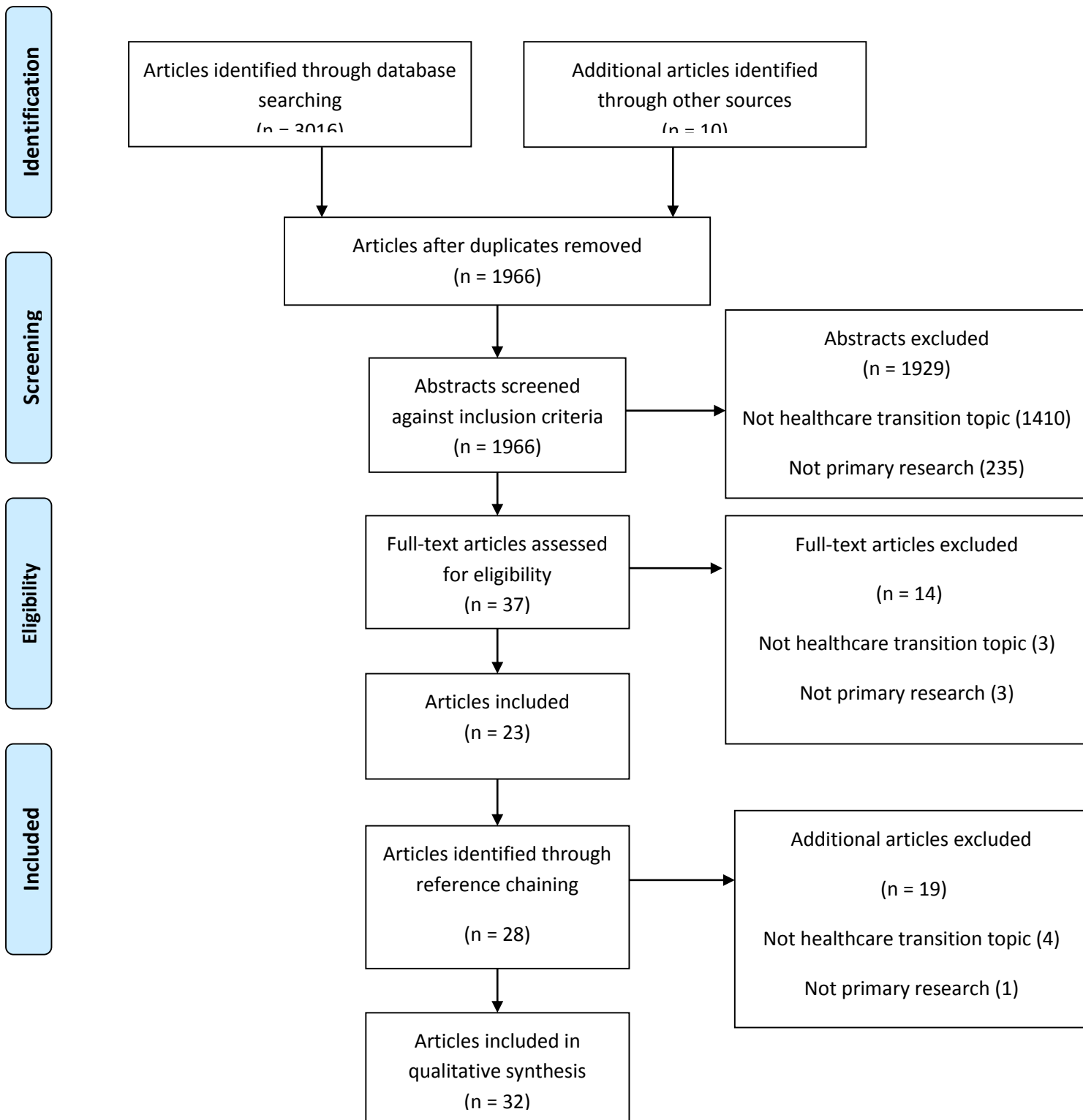
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**Figure 1 Example Search Strategy: Medline**

1. MEDLINE; (parent\* OR mother\* OR father\* OR famil\* OR caregiver\* OR care-giver\*).ti,ab; 1168823 results.
2. MEDLINE; exp PARENTS/; 74614 results.
3. MEDLINE; exp FAMILY/ OR exp FAMILY HEALTH/; 256004 results.
4. MEDLINE; 1 OR 2 OR 3; 1268813 results.
5. MEDLINE; (adolesc\* OR teen\* OR youth\* OR young\*).ti,ab; 659938 results.
6. MEDLINE; exp ADOLESCENT/ OR exp ADOLESCENT HEALTH SERVICES/ OR exp ADOLESCENT MEDICINE/; 1641143 results.
7. MEDLINE; 5 OR 6; 2039457 results.
8. MEDLINE; 4 OR 7; 3078685 results.
9. MEDLINE; (transition\* OR transfer\*).ti,ab; 708408 results.
10. MEDLINE; exp HEALTH TRANSITION/ OR exp TRANSITION TO ADULT CARE/; 1170 results.
11. MEDLINE; 9 OR 10; 708958 results.
12. MEDLINE; ("chronic condition\*" OR "chronic disease\*" OR "chronic health\* need\*" OR "chonic\* ill\*" OR "chronic health\* need\*" OR "life limiting illness" OR "long term condition\*" OR "long term disease\*" OR "long term illness\*").ti,ab; 50257 results.
13. MEDLINE; exp CHRONIC DISEASE/; 222155 results.
14. MEDLINE; 12 OR 13; 259845 results.
15. MEDLINE; 8 AND 11 AND 14; 1344 results.
16. MEDLINE; 15 [Limit to: (Languages English)]; 1166 results.

Figure 2 PRISMA Flow Diagram



**Table 1 Analysis: Moving from descriptive to analytic themes**

<b>Objective</b>	<b>Analytic theme</b>	<b>Descriptive theme</b>	<b>Codes</b>	<b>Description</b>
To understand how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services				
	Views on transition			
		Transitional care - general		
			Child independence = important goal	<i>Parents striving for child independent self-management – Independent SM = positive social value</i>
			Transition = an incremental process	<i>Healthcare transition a graded process, which is un/consciously instigated in parallel with normal child development</i>
			Adolescence = a time of many transitions	<i>Development from child to adulthood</i>
			Triggers for YP SM	<i>Factors / events triggering need for YP SM e.g. parent at work; child going to college</i>
			Transition = back and forth process	<i>Condition management goes back and forth between parent and young person</i>
	Factors affecting child autonomy			
		Perceived readiness for transition		
			Perceptions of child readiness	<i>Parental perceptions of their child's maturity, emotional readiness, motivation to self-manage / self-advocate</i>
			Perceptions of child wellness	<i>Parental perceptions of their child state of wellness – LTC seen as cyclical where children interchange between wellness and</i>

				<i>unwellness. Transition seen to need to happen during a time of wellness</i>
			Perceptions of child's competence	<i>Parental perceptions of their child's ability (competence) to self-manage / self-advocate – (linked to perceptions of risk)</i>
		Resisting child autonomy	Parents relinquishing control	<i>Letting go is hard - Controlling helps parents to manage their anxiety. Parents know they should be facilitating independence but find it hard to go against what it means to be a parent (i.e. to nurture, protect, hold close)</i>
			Parental trust	<i>How much parents trust their child to be responsible for their condition management – how much they believe their child will be adherent to treatment and not put themselves in danger</i>
	Preparing child for healthcare transition			
		Facilitating child autonomy		
			Parental behaviours	<i>Things parents do to prepare / facilitate young people becoming independent e.g.</i> <ul style="list-style-type: none"> <li>• <i>Encouraging independence</i></li> <li>• <i>Behavioural experiments</i></li> <li>• <i>Modelling</i></li> <li>• <i>Monitoring</i></li> <li>• <i>Teaching self-advocacy</i></li> <li>• <i>Teaching self-surveillance</i></li> <li>• <i>Teaching treatment management</i></li> <li>• <i>Transferring medical history</i></li> </ul>
			Shared Care	<i>Things parents do to mediate young person management – partnership e.g.</i> <ul style="list-style-type: none"> <li>• <i>Directive guidance</i></li> </ul>

				<ul style="list-style-type: none"> <li>• <i>Negotiating expectations</i></li> <li>• <i>Shared decision-making</i></li> <li>• <i>Technical assistance</i></li> </ul>
	Service provision			
		Service changes		
			Family-centred to adult-centred care	<i>Changes experienced in models of care – paediatrics = family-centred, adult services = adult-centred</i>
			Lack of transitional care	<i>Lack of transitional healthcare leads to parents needing to be involved to advocate and co-ordinate child's care</i>
			Service changes impact on parents	<i>e.g. lone consulting = discontinuity of information= problematic in context that parents continue to provide support for their child at home</i> <i>Incongruence between services changes and realities of family life</i> <i>Lack of preparation for transition = sense of abandonment</i> <i>Parents having to navigate new systems all over again</i>
			Service changes impact on young people	<i>Young people loose services and resources when they transition to adult care</i>
			Service provision - suggestions for improvement	<i>Things hospitals can do to improve healthcare transition e.g. better transition co-ordination</i>
	YP Condition Management			
		YP Condition Management		
			Child's LTC management behaviours	<i>Tasks and things young people do / have to do to manage their LTC</i>

			Parental involvement	<p><i>Things parents do to manage their child's LTC- approaches they take e.g.</i></p> <ul style="list-style-type: none"> <li>• <i>Fathers = Laissez-faire management</i></li> <li>• <i>Mothers = micro-manage child + LTC</i></li> <li>• <i>Parent helplessness to elicit change</i></li> <li>• <i>Parents experts in their child</i></li> </ul>
To understand how parents experience their care-giving role in relation to their own well-being				
	Parents' experiences of their child's healthcare transition			
		Impact of transition on family		
			Parental distress	<p><i>From worry about child's transition fear of harm for child</i></p>
			Sources of parental anxiety	<p><i>Things that contribute to parental anxiety e.g.</i></p> <ul style="list-style-type: none"> <li>• <i>Attachment to paediatric services</i></li> <li>• <i>Controlling vs. letting go</i></li> <li>• <i>Fear of poor child outcomes</i></li> <li>• <i>Future who takes on parent role</i></li> <li>• <i>Loss - role of parent</i></li> <li>• <i>Non-adherence</i></li> <li>• <i>Uncertainty - service provision</i></li> <li>• <i>Parent-child conflict</i></li> </ul>
			Coping	<p><i>How parents cope with their anxiety e.g.</i></p> <ul style="list-style-type: none"> <li>• <i>Developing new relationships</i></li> </ul>



				• <i>Informing others</i>
	Parental transition			
		Changes to parent role and behaviour		
			Changes in parent behaviour	<i>Parents required changing their behaviour during transitional phase</i>
			Changes in parental role	<i>Parent's support not necessarily withdrawn completely, but their role changes to one of care consultant rather than care provider</i>
	Impact of LTC on family			
		Impact of LTC		
			Impact of LTC on child's future	<i>How LTC affects YP. e.g. impact of LTC on child's opportunities for a 'normal' and fulfilled life</i>
			Impact of LTC on family	<i>How LTC affects family life and what this means for their support needs</i>
			Impact of LTC on parent	<i>How LTC affects parents and what this means for their support needs</i>
To make recommendations regarding how healthcare providers can support parents during their child's transition				
	Supporting parents to facilitate their child's transition			
		Views on transition		
		Factors affecting child autonomy		
		Preparing child for healthcare transition		
		YP Condition		

## Manuscript: Patient Education and Counseling

		Management		
	Supporting parents through their own transition			
		Parent experiences of their child's healthcare transition		
		Parental transition		
		Impact of LTC on family		
	Providing effective transitional care			
		Service provision		

Table 2 Characteristics of included studies

Paper	Long term condition	Country and setting	Participants	Data collection method	Theoretical framework	Data analysis method	Aim
Akre, 2014	Various long term conditions	Switzerland: recruited through 5 specialist hospital paediatric clinics (gastroenterology; endocrinology; neuro-rehabilitation; pulmonology; rheumatology)	30 parents (18 mothers; 12 fathers) of young people age range 14-19 years	Focus groups		Thematic analysis	To identify the needs and preoccupations of parents of adolescents with CI in coping with their children's autonomy acquisition and to determine whether mothers and fathers coped differently.
Allen, 2011	Diabetes	UK: recruited through five diabetes services across UK	39 mothers of young people age range 13-22 years	Longitudinal semi-structured interviews (x 3 per participant)	Strauss and co-workers' concept of an illness trajectory	Thematic analysis	To explore the experiences of young people and their carers during the transition from child to adult diabetes services.
Anthony, 2009	Heart transplant	Canada: recruited through the Heart Transplant Programme at The Hospital for Sick Children (SickKids)	17 parents (13 mothers; 4 fathers) of young people age range 12-18 years	Semi-structured interviews	Phenomenology	vanManen's Phenomenological approach	To explore the perceptions and experiences of paediatric HTx recipients and their parents surrounding their future transfer of care to an adult care facility.
Buford, 2004	Asthma	US: recruited from a children's hospital	14 care-givers (11 mothers; 2 fathers; 1 grandmother) of young people age range 8-13 years	In-depth interviews		Grounded theory	To explore the process for transfer of asthma management from parents to their school-age children.
Casillas, 2010	Cancer	US: recruited through a Community-based organisation serving cancer patients	21 parents of young people age range 15-30 years	Focus groups	Community-based participatory research	Huberman & Miles' Content analysis	To determine Latino adolescent and young adult cancer survivors' perceived barriers or facilitators to transition from paediatric to adult-centred survivorship care and to assess the parents' perspective of care.
Davies, 2011	Neurological disorders	Canada: recruited through a hospital-based paediatric neurology clinic	17 care-givers (10 mothers; 5 fathers; 1 grandmother; 1 foster	In-depth, semi-structured interviews		Burnard's constant comparison	To explore parents' perceptions of the transition of healthcare from paediatric to adult services for the young adult with a

## Manuscript: Patient Education and Counseling

			mother) of young people age range 18-21 years			method	complex chronic neurological condition. To explore what facilitated and/or hindered parents' and young adults' transition from paediatric to adult health care.
Dupuis, 2011	Cystic Fibrosis	Canada: recruited through paediatric clinics at an adult health care facility	11 parents (7 mothers, 4 fathers) of young people age range 15-18 years	Semi-structured interviews	Systemic theory	Huberman & Miles' Content analysis	To explore the experience of parents and adolescents living with cystic fibrosis prior to the transfer of the adolescent's care from a paediatric to an adult health care facility.
Giarelli, 2008a	Marfan Syndrome (Chronic genetic disorder)	US: recruited through a genetics clinic and the National Marfan Foundation	39 parents of young people age 14-34	In-depth interviews (telephone)	Self-surveillance (Giarelli, 2006); symbolic interactionism	Grounded theory	To explain the socially complex process by which parents transfer, and children take on, the responsibility for managing a chronic genetic disorder.
Giarelli, 2008b	Marfan Syndrome (Chronic genetic disorder)	US: recruited through a genetics clinic and the National Marfan Foundation	39 parents of young people age 14-34	In-depth interviews (telephone)	Model developed from findings in above study; Lerner's developmental contextualism	Secondary analysis of data generated for the above study using Thematic content analysis	To examine systemic factors that influence transition to self-management (TSM).
Gray, 2011	Various chronic conditions	UK: recruited by primary care and hospital clinicians	18 parents/care-givers of young people age range 10-17 years	Semi-structured interviews		Constant comparison techniques	To explore issues that affect adherence to medications, from the perspectives of young people and their parents, and to describe their partnerships in medication taking.
Hanna & Guthrie, 2001	Type 1 Diabetes	US: recruited through diabetes specialist clinic in one Midwestern and one western state	16 parents/care-givers of young people age range 11-18 years	Interviews	Social support	Deductive content analysis	To identify positive and negative dimensions of support related to adolescents' assumption of diabetes management responsibility from the perspectives of parents and adolescents.
Hartman, 2000	Various chronic conditions	US: recruited as part of a participatory action needs assessment to improve services for adolescents with special healthcare needs	3 parents of young people age range 15-25 years	Life history interviews		Thematic and taxonomic analysis	To deepen our understanding of the lives and transition experiences of adolescents with special health care needs through their parents' perspectives.
Hauser &	Sickle Cell	US: recruited via four	22 parents/care-givers	Focus groups		Content analysis	To identify and understand the concerns,

## Manuscript: Patient Education and Counseling

Dorn, 1999	Disease	paediatric sickle cell centres in a large Midwestern city	of young people age range 13-21				expectations and preparation needs the adolescent/young adult and his/her parents have about the move from child centred care to adult centred care
Ivey, 2009	Type 1 Diabetes	US: recruited through an endocrinology clinic in a children's hospital	28 parents of young people age range 11-15 years	Interactions between parents and teens		Secondary analysis based on template generated from the literature	To describe the ways that parents and teens communicate and the recurrent themes and patterns of behaviour that were revealed by participants during brief interactions about diabetes management.
Kirk, 2014	Various life-limiting conditions	UK: recruited through a children's hospice	16 parents of young people age range 16-31 years	Semi-structured interviews		Grounded theory	To examine how young people with life-limiting conditions and their parents experience transition.
Magill-Evans, 2005	Cerebral Palsy	Canada: recruited from a cohort of youths who took part in a previous study	6 parents of young people age range 20-23 years	In-depth interviews	Phenomenology	Generic qualitative analysis	To explore the perceived dynamics of relationships between parents and youths with disabilities during the child's transition to adulthood.
Mellin, 2002	Type 1 Diabetes	US: recruited through a paediatric endocrine and diabetes clinic in a metropolitan area	30 parents of adolescent girls aged between 13-20 years	Semi-structured interviews		Huberman & Miles' Content analysis	To provide greater understanding of how parents experience their role when they are parenting an adolescent with DM.
Moola, 2011	Cystic Fibrosis & Congenital Heart Disease	Canada: recruited through a children's hospital	28 parents of young people age range 11-17 years	Semi-structured interviews	New social studies of childhood	Thematic analysis	To explore how young people with CF and CHD – and their parents – understand their health in the future and the perspectives they bring towards the concept of time.
Newbould et al, 2008	Asthma and diabetes	UK: recruited through GP surgeries	43 parents of young people age range 8-15 years	Semi-structured interviews		Generic qualitative analysis	To explore how the responsibilities for different aspects of medicine management are shared between young people and their parents in the home.
Osterlund, 2005	Spina Bifida	US: recruited through a regional referral centre	6 parents (4 mothers; 2 fathers) of young people age range 18-21 years	Focus groups and structured interviews		Grounded theory	To assess how young adults with spina bifida and their parents interact with their medical records.
Porter, 2014	Sickle Cell Disease	US: recruited from a paediatric hospital with a SCD programme	12 parents of young people age range 12-18 years	Focus groups	Bronfenbrenner's bio-ecological theory	Generic qualitative analysis	To describe the perspectives of adolescents with SCD, siblings closest in age to the adolescent, and their

## Manuscript: Patient Education and Counseling

							caregivers regarding the transition from paediatric to adult SCD care and to identify recommendations for improving the transition process.
Rehm, 2010	Various chronic conditions	US: primary care	57 parents of young people age range 14-26 years	Interviews	Symbolic interactionism	Generic qualitative analysis	To examine the decision-making processes of parents and HCPs around when and how to transition youth from paediatric to adult primary care.
Sasse, 2013	Various chronic conditions	Australia: recruited through Children's Hospital	17 parents (15 mothers; 2 fathers) of young people age range 13-18 years	In-depth semi-structured interviews		Content and thematic analyses	To investigate the beliefs of Australian parents of adolescents regarding confidential consultations for young people.
Shaw, 2004	Juvenile idiopathic arthritis	UK: recruited through hospitals	23 parents of young people age range 12-18; young adults age range 19-30 years	Focus groups	Phenomenology	IPA	(i) To gain insight into and understanding of the transitional health-needs of adolescents who have JIA and their parents, and (ii) to explore how these needs could be met within a structured programme of transitional care.
Schilling, 2006	Type 1 Diabetes	US: recruited through clinics	22 parents of young people aged 8-19 years	Semi-structured interviews		Content analysis	To explicate activities in the self-management of type I diabetes in youth by: (1) describing the division of labour in illness management between parents and youth, including the nature of the conflict between them, and (2) describing the state of the transfer of management responsibility from parents to youth.
Schultz, 2013	Epilepsy and cognitive impairments	US: recruited through a parent-led transition group	7 parents of young people aged 20-33		Symbolic interactionism	Grounded theory	To explicate processes that parents of adolescents with epilepsy and cognitive impairments undergo as they help their adolescent transition from paediatric to adult health care.
Sparacino, 1997	Congenital Heart Disease	US: recruited through University medical centre	8 parents (7 mothers; 1 father) of young people age range 13-25 years	Semi-structured interviews		Grounded theory	To provide a better understanding of parents' experiences as their children with congenital heart disease mature through adolescence and young

## Manuscript: Patient Education and Counseling

							adulthood.
van Staa, 2011	Various chronic conditions	Netherlands: recruited through specialist children's hospital	24 parents of young people age range 15-22 years	Semi-structured interviews		Thematic analysis	(1) to map experiences with the recent transfer to adult care of young adults (YA) with chronic conditions receiving care in one university hospital in the Netherlands; and (2) to identify recommendations to improve the transition process from the perspectives of YA, their parents and healthcare providers (HCP).
Williams, 2000	Asthma and diabetes	UK: recruited through 5 hospitals, 7 GP practices and a diabetes magazine	40 parents of young people age range 15-18 years	Unstructured interviews		Generic qualitative analysis	To explore how young people with a chronic illness and their main carer negotiated responsibility for self-care.
Williams, 2007 (a)	Cystic Fibrosis	UK: recruited through hospital-based CF clinics in two Scottish regions	31 parents of young people age range 7-17 years	In-depth interviews	Kleinman's concept of explanatory models; Leventhal's illness representations; Becker's Health Belief Model	Framework analysis	To explore the nature and variation in roles of family members, how responsibility was transferred from the parent/family to the child, and what factors aided or hindered this process.
Williams, 2007 (b)	Cystic Fibrosis	UK: recruited through specialist CF nurses, physiotherapists and consultants	34 parents of young people age range 7-17 years	In-depth interviews		Framework analysis	To explore the impact of beliefs on emotional coping and motivation to implement treatment regimes among parents of children with cystic fibrosis in Scotland
Young, 2009	Various chronic conditions	Canada: recruited through a children's treatment centre	30 parents of 30 young people age range 14-19	Semi-structured interviews		Constant comparison method	To examine the issue of clinical transition from the perspectives of individual patients with mild, moderate, and severe CP, SB, and ABIC and their parents, to better understand the scope of this issue and to assist with the development of evidence-based health care transition programs.

**Table 3 Quality summary of included studies**

<b>Question – CASP quality criterion</b>	<b>Yes</b>	<b>No</b>	<b>Can't tell</b>
Was there a clear statement of the aims of the research?	32 (100%)		
Is a qualitative methodology appropriate?	32 (100%)		
Was the research design appropriate to address the aims of the research?	32 (100%)		
Was the recruitment strategy appropriate to the aims of the research?	28 (87.50%)	1 (3.13%)	3 (9.38%)
Were the data collected in a way that addressed the research issue?	31 (96.88%)		1 (3.13%)
Has the relationship between researcher and participants been adequately considered?	1 (3.13%)	28 (87.50%)	3 (9.38%)
Have ethical issues been taken into consideration?	23 (71.88%)	3 (9.38%)	6 (18.75%)
Was the data analysis sufficiently rigorous?	29 (90.63%)	1 (3.13%)	2 (6.25%)
Is there a clear statement of findings?	30 (93.75%)	2 (6.25%)	
How valuable is the research?	31 (96.88%)		1 (3.13%)



Table 4 Themes generated from included studies

	Views on transition	Factors affecting child autonomy	Preparation for healthcare transition	Service provision	Young person condition management	Parents' experiences of their child's transition	Parental transition	Impact of LTC on family
Akre, 2014		•	•		•	•		•
Allen, 2011	•	•		•	•	•	•	
Anthony, 2009				•		•	•	
Buford, 2004	•	•	•		•	•	•	•
Casillas, 2010				•		•		•
Davies, 2011		•	•	•		•		•
Dupuis, 2011								•
Giarelli, 2008a	•	•	•		•	•	•	•
Giarelli, 2008b	•		•	•	•	•	•	
Gray, 2011				•	•			
Hanna & Guthrie, 2001		•	•		•			
Hartman, 2000	•		•			•		•
Hauser & Dorn, 1999	•	•	•	•	•	•	•	•
Ivey, 2009		•	•		•	•		•
Kirk, 2014				•		•		•
Magill-Evans, 2005		•	•		•	•	•	•
Mellin, 2002	•	•	•		•	•	•	•
Moola, 2011								•
Newbould, 2008	•	•	•	•	•	•	•	•
Osterlund, 2005			•	•				
Porter, 2014		•	•	•		•		
Rehm, 2010				•				
Sasse, 2013	•	•		•	•	•	•	
Shaw, 2004	•	•	•	•			•	
Schilling, 2006	•	•	•		•	•	•	
Schultz, 2013	•			•		•		
Sparacino, 1997	•		•	•		•	•	•
van Staa, 2011	•	•		•		•	•	
Williams, 2000	•	•	•	•	•	•	•	
Williams, 2007 (a)	•	•	•		•	•	•	
Williams, 2007 (b)		•	•	•		•		
Young, 2009			•	•	•	•		

Table 5 Example data extracts

Theme	Example data extracts
Views on transition	<p><i>“The whole role for me of being a parent is to get them to that independent stage where they can think for themselves and do for themselves and be able to start to relate to other people in all aspects of their life.”</i> (Sasse, 2013)</p> <p>All of the informants placed significant emphasis on the critical importance of “independence-building” opportunities to the future independence and confidence of their adolescents. (Hartman, 2000)</p> <p>A range of contingent clinical and social factors including perceived wellness, episodes of illness, performance uncertainty, and family routines caused temporary shifts forwards and backwards along the continuum (Williams, 2007a)</p> <p>Often, the parents and young people were unable to remember the age of the young person when the changes had occurred. Rather, they related such changes to social or life events, such as moving to senior school (Newbould, 2008)</p> <p>Many of the mothers discussed specific separation experiences that helped them see a need for their children to assume more responsibility. These included changes in the mother’s work or child-care arrangements, children starting school, or children going to camp. (Buford, 2004)</p>
Factors affecting child autonomy	<p>Several mothers indicated that the children’s overall maturity and sense of responsibility were key factors in their readiness to assume responsibility. A mother said, <i>“You have to know your child very well. You have to know her inside and out.”</i> She stated that she felt her younger son would have been ready earlier than her daughter was because he was always more independent. (Buford, 2004)</p> <p><i>“We’ve really, to a large extent, waited until [the child is] ready. We gave hints; we gave opportunities. But it was more as [the child] was ready, then it was an easier transition.”</i> (Schilling, 2006)</p> <p>Parental perceptions of wellness and periods of illness had an important impact on how directive and interventionist parental involvement was. When the child was perceived to be well mothers had more confidence in relinquishing interventionist roles. (Williams, 2007a)</p> <p>Although many parents believed their adolescent children were capable of performing the regime some parents did not trust the child to do it as recommended. (Williams, 2007b)</p>
Preparation for healthcare	<p><i>“While I am here to supervise them, I can let them get worse than I would want them to, ever allow them to really, so that they know what the body is going to do if they don’t take their medicines as opposed to going out of the</i></p>

transition	<p><i>house and not under my care in that position.” (Buford, 2004)</i></p> <p><i>“We have input, but it’s ultimately her decision and then the consequences are hers... You just have to sit back and smile.” (Mellin, 2002)</i></p> <p>Parents... reminded their children to check blood glucose levels and to bolus, and then checked to make sure they did... They instructed their children on counting carbohydrates and calculating boluses, what to do in different situations, what to do when not feeling well, healthy eating, and adjusting basal rates on the pump. (Schilling, 2006)</p> <p><i>“I think they need practice in that [self-advocacy]. I think it’s good if they did have some time before we moved on when they worked at it, you know, be on their own and have to get the questions ready and organize themselves and it isn’t easy.” (Shaw, 2004)</i></p> <p>Parents told their teenagers how to ‘listen to their bodies’ and encouraged self-surveillance (Giarelli, 2008b)</p> <p><i>“It’s teamwork really, we do it together, I do some things, she does others – we are always talking about how she is feeling, how wheezy she is sounding and making decisions together about things really.” (Newbould, 2008)</i></p>
Service provision	<p>Parents also perceived that their young adults were unique and complex, and while care had previously been adapted to meet these needs, they were not convinced that this would be a priority in the adult health care setting (Davies, 2011)</p> <p><i>“You get such a lot of support with children’s services, but as soon as you move to adult services it’s just terrible. It’s non-existent. ... we had a paediatrician one day and then we had nobody the next.” (Kirk, 2014)</i></p> <p><i>“All we got on her 16th birthday was, three days later, a letter which says ‘You are now over 16. You’re discharged’. (Shaw, 2004)</i></p> <p>Parents and YA described paediatric surroundings and relationships with the staff as warm, familiar, cosy and trusted (‘feels like a second home’, ‘they are family’). They were mostly negative about the look-and-feel of the adult-oriented surroundings (‘treated like a number’, ‘sterile environment’). (Van Staa, 2011)</p> <p><i>“I just would wish it would start early and get parents involved, to the point that we kind of know where we’re going. I think the hardest part is we’re scared, we’re nervous.” (Young, 2009)</i></p> <p>Parents felt pressure from health providers to transfer responsibility, and some were not comfortable with exclusion from discussions during routine visits. (Gray, 2011)</p> <p><i>“I was very nervous and upset at the (paediatric) team for not preparing me.</i></p>

	<p><i>It was scary. It was lonely. It was like, where do I start?"</i> (Davies, 2011)</p> <p>Additional issues were the parents losing their own support system (Hause, 1999)</p>
<p>Young person condition management</p>	<p><i>"If we ask her "did you take your medication?" or "Do you have enough until the next medical visit?" it can quickly become electric [she will answer]: "I know, I'm taking care of it". But sometimes, suddenly she'll say "I don't have anymore!!" So we quickly have to run to the hospital pharmacy to pick up what we need."</i> (Akre, 2014)</p> <p>Situations occurred when the mothers did not agree with their children's decisions or perceived that their children were not acting responsibly. (Buford, 2004)</p> <p>As their daughter got older, tension related to control increased. While many parents recognized the need for their adolescent to assume more responsibility, some (30%) described frustrations over not knowing how much help to provide. (Mellin, 2002)</p>
<p>Parents' experiences of their child's transition</p>	<p><i>Parents consistently used language such as 'Scared for him', 'Worried', 'Overwhelmed', 'Panicked' to describe their feelings about the prospect of transition.</i> (Anthony, 2009)</p> <p>The majority of parents perceived the process of transition as an extremely stressful time in their lives... They experienced a sense of loss, fear and uncertainty, as they navigated the transition of their young adult. (Davies, 2011)</p> <p>Whilst most parents valued independence and believed that letting go was the right thing to do, many described this as a difficult process, particularly if they perceived that their child was not managing their condition as well as they had been when it was under greater parental control. (Allen, 2011)</p> <p>Mothers described being anxious and uncertain about how much responsibility to give their children... They experienced a sense of risk in letting the child act independently. (Buford, 2004)</p> <p>Fear was defined as the participant's expression of their dread of an unpleasant, undesired, or regrettable outcome... <i>"I don't ever want to look back, either one of us, and say, well, if I had done this it would've made a difference."</i> (Ivey, 2009)</p> <p><i>"There are a lot of unknowns... there's too many of them—just to leave them hanging."</i> (Schultz, 2013)</p> <p><i>"Letting go... [...] I mean, we have to accept the idea that that's how things are and deal with them as well as possible. Accept losing... not having control. That we never have control ... [...] yes, it's a pretty hard transition I think..."</i> (Akre, 2014)</p>

	<p><i>“Raising kids implies that you have to let them go and accept that they make their own choices. I didn’t like it that he had to go, but I saw the necessity. And now I see it’s good.” (Van Staa, 2011)</i></p>
Parental transition	<p><i>“I don’t get hung up on one [blood sugar] number anymore... I pick the most important battles and let the rest go.” (Mellin, 2002)</i></p> <p><i>“I don’t know what’s expected of me anymore and I don’t know what to expect from them...he’s an adult and they keep saying that...but for me he’s still my son and he’s still got diabetes and he still needs help and guidance..” (Allen, 2011)</i></p> <p><i>“I used to stand over there and watch them do it and mark them down on a chart...and I don’t do that anymore. Usually they’re in the same room, but I’m not watching to see how much they take.” (Buford, 2004)</i></p> <p>Most challenging for parents and YA is the role shift with respect to self-management and responsibility. (Van Staa, 2011)</p>
Impact of LTC on family	<p>Al-though some participants’ statements often reflected the under- standing that normalizing was the goal, fear, frustration around issues of trust, and discounting communications were barriers to achieving that goal. (Ivey, 2009)</p> <p><i>“He's just a normal child. So, we always try to be normal with him; [or] You have to let yourself forget about the heart problem in order to go on through life; land] Live normally. Let your family continue on as normal as possible, because the rest of the world is not going to give one hoot that this kid's got this defect, so don't let him use it as an excuse. Think positive, hold the vision of good results” (Sparacino, 1997)</i></p> <p><i>“We want to live for the moment while we can do these things. We have another girl in our town who is a few years older than our daughter who has been in the hospital multiple times. If my daughter wants to take singing lessons now, I do not care how much it costs-she is going to take them” (Moola, 2011)</i></p> <p><i>“We tried to treat her as normally as possible, but she's not really a normal child... We have to be more concerned about things that other people wouldn't have to be, and maybe you have to remind yourself sometimes that you need to look a little below the surface as to what's going on with her, because of her physical health and perhaps emotional issues. Think that comes up more often now as she's a teenager.” (Sparacino, 1997)</i></p>