

**Supporting children and young people to assume responsibility from their parents for the self-management of their long-term condition: An integrative review**

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# **Supporting children and young people to assume responsibility from their parents for the self-management of their long-term condition: an integrative review**

## **Abstract:**

**Background:** Children and young people with long-term conditions (LTCs) are usually dependent on, or share management with their families and are expected to develop self-management skills as they mature. However, during adolescence young people can find it challenging to follow prescribed treatment regimens resulting in poor clinical outcomes. Though reviews have looked at children's and parents' experiences of self-management, none have explicitly examined the parent-to-child transfer of self-management responsibility.

**Methods:** An integrative review was conducted with the aim of exploring the parent-to-child transfer of LTC self-management responsibility, through addressing two questions 1) How do children assume responsibility from their parents for self-management of their LTC? 2) What influences the parent-to-child transfer of this responsibility? Eight databases were searched for papers published from 1995-2017. Methodological quality was assessed; included papers were synthesised to identify themes.

**Results:** 29 papers were identified. Most papers used qualitative designs and focused on children with diabetes. Participants were predominantly children and/or parents; only two studies included health professionals. Assuming self-management responsibility was viewed as part of normal development but was rarely explored within the context of the child gaining independence in other areas of their life. Children and parents adopted strategies to help the transfer, but there was limited evidence around health professionals' roles, and ambivalence around what was helpful. There was a lack of clarity over whether children and parents were aiming for shared-, or self-management, and whether this was a realistic or desired goal for families. Multiple factors such as the child, family, social networks, health professional and LTC influenced how a child assumed responsibility.

**Conclusions:** Evidence suggests the parent-to-child transfer of self-management responsibility is a complex, individualized process. Further research across childhood LTCs is needed to explore children's, parents' and professionals' views on this process and what support families require as responsibilities change.

**Keywords:** child; chronic illness; long-term condition; parent; self-management; integrative review.

## **1. Introduction**

The number of children and young people age 0-18 years old (collectively referred to as children in this paper) with long-term conditions (LTCs) is significant and growing, with an increasing number now reaching adulthood (Campbell et al., 2016).

Childhood LTCs have been defined as: 1) occurring in children aged 0-18 years; 2) diagnosis based on scientific knowledge; 3) not (yet) curable; 4) present for longer than three months or will probably last longer than three months (Mokkink, van der Lee, Grootenhuys, Offringa, & Heymans, 2008). Children with LTCs need to manage and live with their condition throughout their life and require support to achieve their physical, psychological and social potential (While et al., 2004).

Due to the growing prevalence of LTCs, self-management is increasingly recognised as an important component of health care across all age groups. Self-management has been defined in different ways, but is usually viewed as “the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). This focus on the individual has been challenged however, and in recognition of the complexity of self-management and the role of the family in this, a Self-and Family Management Framework has been developed (Grey, Schulman-Green, Knafl, & Reynolds, 2015). This identifies facilitators and barriers that can influence the ability to perform self-management activities across the life course including resources, personal, environmental and health care system factors.

In addition to considering contextual factors, consideration of the unique needs of children is important in relation to self-management. The Shared Management Model suggests that children with LTCs are usually dependent on, or share management with their families and are expected to develop age-appropriate self-management skills as they mature; by drawing on developmental and leadership theories, it advocates that the child's and parents' participation in self-management tasks, roles and responsibilities change over time (Kieckhefer & Trahms, 2000). This means that self-management in childhood “is a process that involves shifting, shared responsibility between children/adolescents and their parents” (Schilling, Grey, & Knafl, 2002, p. 9).

Though developing self-management skills is part of growing up for many children with LTCs (Kieckhefer & Trahms, 2000), there is evidence that during adolescence young people can find it challenging to follow treatment regimens which can result in poor clinical outcomes (DoH, 2008). Self-management is often complex, requiring the individual to modify their typical habits and routines to accommodate self-management activities; this can be complicated by the developmental changes associated with adolescence (Gardener, Bourke-Taylor, & Ziviani, 2017). For children with LTCs, competent self-management is vital and healthcare professionals (HCPs) and parents need effective ways to help children learn self-management as they move towards adulthood (DoH, 2006). Therefore, evidence synthesis is needed to inform the development and evaluation of interventions to support the parent-to-child transfer of responsibility (Sawyer, Drew, Yeo, & Britto, 2007). To date, only one review has been conducted that explicitly focuses on the parent-to-child transfer of self-management responsibility (Leeman, Sandelowski, Havill, & Knafl, 2015). Due to its focus on children with cystic fibrosis and the uniqueness of different LTC treatment regimens, synthesis of research related to other LTCs is indicated (Hanna & Decker, 2010).

This paper reports on an integrative review of primary research that aimed to explore the parent-to-child transfer of LTC self-management responsibility, through addressing two questions 1) How do children assume responsibility from their parents for self-management of their own LTC?; 2) What influences the parent-to-child transfer of this responsibility? The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting systematic reviews

were followed in writing this paper to ensure quality and transparency (Moher, Liberati, Tetzlaff, Altman, & The, 2009).

## **2. Methods**

The integrative review method was used to allow for the combination of a range of methodologies that integrates conceptual findings rather than aggregates data (Russell, 2005). The methodological strategies proposed by Whitemore and Knafelz (2005) guided the review. A review protocol was developed and registered on PROSPERO, an international register of systematic reviews:

[http://www.crd.york.ac.uk/PROSPERO/display\\_record.php?ID=CRD42017080301](http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017080301)

### **2.1 Search strategy**

To identify relevant literature, key electronic health care databases were used: Ovid MEDLINE, Embase, PsycINFO, CINAHL, AMED, ASSIA, Web of Science and the Cochrane Library. In addition, complementary searching was completed, including: forward and backward citation tracking, reviewing reference lists of included papers, author searching and hand searching of two journals, the Journal of Pediatric Nursing and Diabetes Educator, which had published special issues on LTCs and health care transition.

Using the SPIDER framework (Sample, Phenomenon of Interest, Design, Evaluation, Research type) (Cooke, Smith, & Booth, 2012), search terms relating to children aged 0-18 years old, LTCs and self-management were identified and agreed by all authors (Appendix A). Table 1 outlines the inclusion and exclusion criteria. The search strategy was modified to fit each database. University librarians provided advice to ensure a systematic search strategy.

### **2.2 Study selection**

Using the inclusion/exclusion criteria a two-stage screening process was completed. During stage one, titles and abstracts of identified papers were screened; in stage two, full paper texts were assessed for eligibility. This process was completed by the first author (RN); however, consultation with the other authors took place when there was uncertainty whether a paper met the inclusion criteria.

### **2.3 Data extraction**

A standardised, pre-piloted form developed by RN was used to extract data from the included studies for assessment of study quality and evidence synthesis. Extracted information included: research aim; study design; setting; participants and main findings. Each study was assessed by RN and the content of data extraction forms was reviewed and discussed by all authors.

### **2.4 Quality assessment**

The quality of included studies was assessed by RN using a validated critical appraisal tool (Hawker, Payne, Kerr, Hardey, & Powell, 2002) which is widely used, especially in mixed studies reviews (Crowe & Sheppard, 2011). This tool has well-defined criteria and comprises nine items (e.g. sampling, data analysis) which enable an assessment of the methodological rigour of each study.

### **2.5 Data synthesis**

A synthesis approach based on the constant comparison method was adopted, which “converts extracted data into systematic categories, facilitating the distinction of patterns, themes, variations, and relationships” (Whittemore & Knafl, 2005, p. 550). This method allows for iterative comparisons across all data sources and involves: data reduction, data display, data comparison and conclusion drawing and verification. For example, RN started data reduction by extracting relevant data from each included study to address the review questions. Tabulation was used to display the data, initially at an individual study level and then combined to create one matrix that assembled the data from all the studies. Data were iteratively compared and diagrams developed to start identifying patterns and relationships across studies. Finally, any conclusions drawn were verified with the primary source data to check for accuracy and confirmability.

### **3. Results**

The search strategy produced 8848 references; 6917 were not relevant to the review’s questions. After assessment and deletion of duplicates, 29 papers reporting on 26 studies were included in the review (Figure 1). Table 2 provides a summary of each of the included papers, involving qualitative (n = 27), quantitative (n = 1) and mixed methods (n = 1) designs.

#### **3.1 Study characteristics, strengths and limitations**

Studies included children aged 7-21 years old and focused on a range of physical LTCs, the majority on children with diabetes (n = 19). Participants were predominantly children and/or parents; only two studies included HCPs (Husted, Esbensen, Hommel, Thorsteinsson, & Zoffmann, 2014; Lindholm Olinder, Ternulf Nyhlin, & Smide, 2011). Studies took place in North America (n = 17) and Europe (n = 12).

Nineteen studies were assessed as good and ten as fair (Hawker et al., 2002). Though all studies had weaknesses, their impact on the study findings were considered ‘non-critical’ rather than ‘fatal’ (Booth, Sutton, & Papaioannou, 2016). This meant no studies were excluded from the review based on their quality assessment though this was taken into account during synthesis.

Common strengths of the 19 studies assessed as good included: appropriate data collection methods to address the research aims; and results that relate directly to the study aims. Among the ten studies assessed as ‘fair’, common limitations included: unclear sampling strategies; poor consideration of ethical issues and bias, and limited transferability due to minimal description of the study context and setting. However, as some of the papers assessed as ‘fair’ were describing selected findings from larger studies (Babler & Strickland, 2015; Hanna & Guthrie, 2000a, 2000b; Mulvaney et al., 2008; Mulvaney et al., 2006) it is possible that the focus of reporting was on the findings, as methods had been described elsewhere. This highlights the issue that papers reporting on primary research rarely provide sufficient detail about study methods, resulting in quality assessment becoming an appraisal of the reporting quality (Hawker et al., 2002).

Through utilising the synthesis approach outlined by Whittemore and Knafl (2005), eight themes were inductively identified from synthesis of the included studies. Three themes related to the first review question: 1) process; 2) strategies; and 3)

outcomes, and five themes related to the second review question: 1) the child; 2) the family; 3) social networks; 4) the HCP; and 5) the LTC.

## **3.2 How children assume responsibility from their parents for self-management of their own LTC**

### **3.2.1 Process**

In some studies the process of children assuming self-management responsibility was viewed by children and parents as part of normal development but often described as a complex, uneven process (Chilton & Pires-Yfantouda, 2015; Karlsson, Arman, & Wikblad, 2008). Roles and responsibilities of children and their parents changed over time (Christian, D'Auria, & Fox, 1999; Lindholm Olinder et al., 2011) as children became less reliant on their parents and parents 'let go' (Babler & Strickland, 2015; Ersig, Tsalikian, Coffey, & Williams, 2016). Only one study viewed the parent-to-child transfer of self-management responsibility within the wider context of the child gaining independence in other areas of their life (Meah, Callery, Milnes, & Rogers, 2010).

Some aspects of self-management were taken on gradually by children, including managing medication, therapies and procedures (Buford, 2004; Meaux et al., 2014; Williams, Mukhopadhyay, Dowell, & Coyle, 2007) whereas skills such as decision-making and liaising with services needed to be acquired suddenly on transfer to adult services (Kirk, 2008). The parent-to-child transfer of self-management responsibility was modelled in various ways; some studies reported that the child, the parent or both, sequentially progressed through discrete stages (Babler & Strickland, 2015; Schilling, Knafel, & Grey, 2006) whereas others viewed the transfer as a fluid, bi-directional continuum where child and parental roles and responsibilities were regularly shifting (Chilton & Pires-Yfantouda, 2015; Williams et al., 2007). For example, in some families parents would resume management of the LTC when their child was tired, unwell or lacking motivation (Kirk, 2008; Schilling et al., 2006) or when complications arose (Meaux et al., 2014).

Though an individualised process, there were differing reports on whether the process of children assuming self-management responsibility was planned or occurred at a tacit level. In some studies, the child would self-initiate becoming involved in self-management, or parents would explicitly start transferring responsibility (Buford, 2004; Kirk, 2008; Meah et al., 2010) whereas for others, the process was not planned but happened in response to external events associated with a child's development such as starting secondary school (Newbould, Smith, & Francis, 2008). Some families found the transfer process stressful, experiencing conflict and difficulties interacting (Babler & Strickland, 2015; Karlsson et al., 2008; Schilling et al., 2006; Williams et al., 2007) whereas families who could perceive the benefits of transferring responsibility such as the child gaining freedom, and parents taking pride in their child's ability, had a more positive experience of the transfer process (Christian et al., 1999; Hanna & Guthrie, 2000a).

### **3.2.2 Strategies**

Strategies used by children to assume responsibility for their LTC management included: gaining factual and experiential knowledge (Christian et al., 1999; Karlsson et al., 2008), acquiring skills such as communicating with HCPs (Stinson et al., 2008)

and adopting practical strategies, for example using alarms and schedules (Babler & Strickland, 2015; Meaux et al., 2014). Parents used a range of strategies including: providing coaching, education and guidance (Kirk, 2008; Lindholm Olinder et al., 2011; Schilling et al., 2006) and offering rewards (Mulvaney et al., 2006). Parents and children sometimes differed in their views on whether support from parents was helpful or non-helpful (Hanna & Guthrie, 2001) and there was ambivalence about whether some strategies, such as learning through trial and error should be adopted (Akre & Suris, 2014; Ersig et al., 2016; Husted et al., 2014; Spencer, Cooper, & Milton, 2013). Though a few studies identified HCPs using strategies such as information provision, training, monitoring and advanced communication skills such as mirroring and active listening (Husted et al., 2014; Spencer et al., 2013; Williams et al., 2007), there was ambivalence amongst children and parents about the role of HCPs in supporting the parent-to-child transfer of self-management responsibility and a dearth of evidence about what strategies HCPs utilised and what families found helpful. The role of the HCP is explored further in section 3.3.4.

### **3.2.3 Outcome**

Though assuming responsibility and achieving independence in self-management is the implied ideal outcome for children with a LTC as they transfer to adult services (Babler & Strickland, 2015), there is limited empirical evidence that this is a realistic goal, in particular for children with complex treatment regimens. As children moved towards adulthood, some parents and children viewed continued parental supervision and/or involvement in some aspects of self-management, as important (Auslander, Sterzing, Zayas, & White, 2010; Meah et al., 2010). Studies referred to the challenge for families in achieving a 'balancing act' regarding the child's developmental need to move towards independence against the potential consequences of poor self-management (Hanna & Guthrie, 2000b), and also how parents could be supportive without taking control (Kayle, Tanabe, Shah, Baker-Ward, & Docherty, 2016; Meaux et al., 2014; Sullivan-Bolyai et al., 2014).

Though some families had aspired to the child assuming full responsibility for self-management, in reality the result was less clear as parents often remained involved in managing some aspects of their child's LTC (Buford, 2004; Christian et al., 1999; Kirk, 2008). In some studies, lack of clarity resulted in an unclear or unsatisfactory outcome; for example, different understandings of what it meant to be fully responsible (Hanna & Guthrie, 2000a; Hanna & Guthrie, 2001; Meah et al., 2010) and few children and parents explicitly discussing who held responsibility for self-management activities, meant some aspects of self-management were neglected (Lindholm Olinder et al., 2011).

## **3.3 Influences on the parent-to-child transfer of self-management responsibility**

### **3.3.1 The child**

In some studies, the transfer of self-management responsibility was related to the child's increasing age (Babler & Strickland, 2015; Buford, 2004; Karlsson et al., 2008; Meaux et al., 2014), whereas in other studies the transfer was influenced by the child's developmental stage (Kirk, 2008; Rhee, Belyea, Ciurzynski, & Brasch, 2009) or maturity (Hanna & Guthrie, 2000a; Williams et al., 2007). Gender appeared to influence the transfer process. For example, in one study, girls were more likely to



appreciate their parents' support with self-management (Jedeloo, van Staa, Latour, & van Exel, 2010); however, other studies suggested girls were more independent in self-management (Williams, 1999), and perceived less barriers to self-management than boys (Rhee et al., 2009). Only two studies explicitly explored the influence of ethnicity on children assuming self-management responsibility. Children from Black and Hispanic backgrounds reported more barriers to self-management compared to white children (Rhee et al., 2009) and African American adolescents with type 2 diabetes experienced more difficulties with assuming self-management responsibility due to co-morbid conditions (Auslander et al., 2010). The influence of the LTC and co-morbidities will be further discussed in section 3.3.5.

The child's motivation, cognitive and emotional readiness may influence the parent-to-child transfer of responsibility (Akre & Suris, 2014; Christian et al., 1999; Karlsson et al., 2008; Kirk, 2008). Studies suggest that it was predominantly parents who made the judgement that their child was ready, basing their assessment on prior experience with older siblings or the child showing an increased interest in aspects of self-management (Buford, 2004; Schilling et al., 2006).

### **3.3.2 The family**

The structure of the family was identified as a potential influence on the parent-to-child transfer of self-management responsibility. For example, whether the household included one or two parents due to differences in the way mothers and fathers dealt with how their child assumed responsibility and the presence of another family member with the same LTC as the child, could impact on the transfer process (Akre & Suris, 2014; Auslander et al., 2010). Studies suggested the approach, communication style and attitudes adopted by parents could influence how a child assumed self-management responsibility (Husted et al., 2014). Families found the transfer process less challenging when the child was able to communicate with their parents about their LTC (Kayle et al., 2016; Mulvaney et al., 2008) and when parents demonstrated encouragement, trust and a belief in their child's ability to self-manage (Karlsson et al., 2008; Meah et al., 2010; Stinson et al., 2008; Williams et al., 2007). The influence of the family's socioeconomic status (SES) on the transfer process was discussed in two studies. Rhee et al (Rhee et al., 2009) identified that children whose parents had a higher SES perceived fewer barriers to self-management whereas parents who worried about health insurance as their child became an adult, experienced more challenges with transferring responsibility to their child (Ersig et al., 2016). Some parents were highly motivated for their child to assume responsibility and were willing to 'let go' (Babler & Strickland, 2015; Dashiff, Riley, Abdullatif, & Moreland, 2011; Meah et al., 2010), whereas others struggled and had to 'force' themselves to relinquish responsibility due to fears of potential complications that could result from their child's self-management decisions (Akre & Suris, 2014; Lindholm Olinder et al., 2011; Meaux et al., 2014).

### **3.3.3 Social networks**

Some children found managing a LTC within a busy and structured school environment challenging, in particular dealing with competing demands such as school work, sports and spending time with friends (Chilton & Pires-Yfantouda, 2015; Christian et al., 1999; Meah et al., 2010). Peers were perceived by some children as a barrier to assuming self-management responsibility, in particular by adolescents, when 'fitting in' became key (Babler & Strickland, 2015; Dashiff et al., 2011; Rhee et

al., 2009). Some children worried about telling peers about their LTC due to a perception that others would respond negatively; this meant integrating self-management in a social context could be difficult due to concerns about the attention they may attract when carrying out self-management tasks (Chilton & Pires-Yfantouda, 2015; Hanna & Guthrie, 2000a; Mulvaney et al., 2008).

### **3.3.4 The healthcare professional**

There was limited evidence regarding the role of HCPs in supporting the parent-to-child transfer of self-management responsibility. Only two studies included HCP participants (Husted et al., 2014; Lindholm Olinder et al., 2011) so where HCPs were discussed this was mostly based on data from children and parents. When reported on, there was ambivalence around HCP input. Support from HCPs was viewed as helpful by some parents in facilitating the transfer of responsibility through information giving, training and emotional support (Kirk, 2008; Meaux et al., 2014; Williams et al., 2007). However, some families found HCP input less helpful due to poor communication with HCPs (Rhee et al., 2009; Spencer et al., 2013; Williams, 1999), provision of irrelevant advice due to unfamiliarity with the family's everyday activities and life situation (Karlsson et al., 2008) or a perceived lack of interest in supporting the transfer of responsibility (Newbould et al., 2008). In one study, some parents thought HCPs considered them 'bad parents' and were threatened with social services involvement if they were not physically involved in their child's diabetes management, due to HCP concerns around glycaemic control (Sullivan-Bolyai et al., 2014). Though parents tended to recognise a role for HCPs (Meah et al., 2010), some children thought HCPs should not be involved in supporting independence development, as they considered it a private family issue (Jedeloo et al., 2010; Sullivan-Bolyai et al., 2014).

Despite the limited evidence and ambivalence regarding HCP input, many studies recommended an increased role for HCPs in supporting children to assume responsibility (Buford, 2004; Dashiff et al., 2011). Recommendations included: helping parents to move from a paternalistic role to one that acknowledges the goals and independence of their child (Williams et al., 2007); adapting consultations so they focus on difficulties perceived as important by the child (Husted et al., 2014); viewing the child within a wider context rather than focusing solely on their LTC (Sullivan-Bolyai et al., 2014) and increasing opportunities for experiential learning (Mulvaney et al., 2006).

### **3.3.5 The long term condition**

The nature of the LTC was identified in some studies as influential on children assuming self-management responsibility. Factors included: 1) the diagnosis, for example children with a congenital condition, were less likely to want help from parents and HCPs in developing self-management skills, whereas those with a recently acquired condition were more likely to value parental and HCP support in learning how to self-manage (Jedeloo et al., 2010); 2) whether the LTC was progressive or stable as parents were more likely to resume responsibility during periods when the child was unwell (Lindholm Olinder et al., 2011; Meaux et al., 2014); 3) age of diagnosis and LTC duration, which could make incorporation of self-management activities into daily life easier (Meaux et al., 2014; Sullivan-Bolyai et al., 2014) and 4) co-morbidity, which could increase the complexity of self-management (Auslander et al., 2010; Mulvaney et al., 2008; Mulvaney et al., 2006). The

complexity of an individual treatment regimen such as medication frequency (Christian et al., 1999), the need to adjust treatments based on fluctuating symptoms (Karlsson et al., 2008) and level of risk of a particular procedure (Kirk, 2008; Lindholm Olinder et al., 2011) could mean children valued parental support and parents were reluctant to relinquish responsibility (Jedeloo et al., 2010);

## **4. Discussion**

### **4.1 Discussion**

This integrative review has systematically identified, critically appraised and synthesized the available evidence on how children assume responsibility from their parents for the self-management of their LTC and what appears to influence this process. Eight themes were identified that offer new understanding of this transfer process. Children assuming responsibility was found to be a complex, individualized process, with children and parents adopting various strategies that resulted in a range of planned and unplanned outcomes. Multiple factors such as the child, family, social networks, HCP and LTC appear to interact and influence how a child assumes responsibility. These factors seemed to have an impact on many aspects of the process, including: when the child started to assume responsibility; who initiated and was subsequently involved in supporting the transfer process; why the process was initiated; what aspects of self-management were transferred and the outcome.

Self-management has been conceptualised as involving three tasks: medical, role and emotional management (Lorig & Holman, 2003). As discussed in section 3.2.1, studies described how children assumed medical management and though it was suggested that children and parents needed to adjust to new roles during the transfer of responsibility (Chilton, 2015; Williams, 2007), how they accommodated changing roles was rarely discussed. Though it was recognised children needed to develop coping skills to contend with the emotional aspects of living with a LTC (Auslander et al., 2010), how children learnt to manage their emotions as they assumed self-management responsibility was not discussed in the literature and is important to explore.

Though health care guidance emphasises the importance of children being helped to manage their own LTC (NICE, 2016; DoH, 2006b) this review highlighted a limited evidence-base around the role of the HCP and ambivalence around whether HCPs should be supporting families with the parent-to-child transfer of self-management responsibility. Though strategies by children and parents were identified, there was ambivalence around what was helpful and a dearth of evidence concerning the HCP role and the strategies and/or interventions used by HCPs to support children to assume self-management responsibility.

Competency and/or task checklists outlining what children need to achieve at different stages of transition are recommended (DoH, 2008) yet there was no reference to these tools in any of the papers included in this review. Programmes, such as 'Ready Steady Go' (Nagra et al., 2015) have been developed and are used in some UK adolescent services; however, these tools are not yet evidence-based, tend to be centred on HCPs' expectations and assumptions without early and sustained input from children or parents in their development, and address the wider transition process, rather than focusing on self-management (Stinson et al., 2014).

A limited number of interventions have been developed and evaluated which support children with LTCs to manage their condition as part of wider transition programmes; however, not all are based on primary research and due to the scope of these interventions, choice of outcome measures (Husted et al., 2014b) and study designs (van Staa et al., 2015; Gorter et al., 2015) their effectiveness, is inconclusive. However these studies concluded that interventions focused on children only are insufficient in empowering self-management, suggesting interventions that focus on the family have potential to effectively support the parent-to-child transfer of responsibility. A UK-based research programme to design and evaluate a needs assessment tool for children with diabetes to guide educational interventions is currently underway (Cooper et al., 2014; Cooper et al., 2018). However, this tool is centred on the child's self-management needs; it does not explicitly focus on the parent-child transfer of self-management responsibility or take into account important contextual factors identified as influential in this review.

This review has identified gaps in the literature that indicate research is needed with children, parents' and HCPs to gain an understanding of how children and parents negotiate the transfer of self-management responsibility and how the transfer process fits within the wider context of children gaining independence. Future research should address these gaps by identifying what supports children and parents as their self-management responsibilities change, including the role HCPs could play in supporting the transfer of responsibility. Furthermore, research is needed to develop robust, well-developed interventions that take into account the unique social context of each individual child and their family.

#### **4.2 Strengths and limitations of this review**

A main strengths of this review was the use of the integrative review method; through using diverse data sources this review has captured the complexity of different perspectives and developed the most comprehensive understanding currently available of how children assume self-management responsibility from their parents (Hopia, Latvala, & Liimatainen, 2016). Due to the methodological diversity within and between qualitative, quantitative and mixed methods studies, it has been questioned whether mixed studies reviews are feasible or acceptable (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Sandelowski, Voils, & Barroso, 2006). By adopting a systematic and rigorous approach in this integrative review and in particular using established data analysis techniques from primary qualitative research in data synthesis, the aim has been to reduce bias and error (Whittemore & Knafl, 2005).

The studies included in the review were from the UK, North America or Europe, suggesting there could have been bias towards western cultures. Only two studies (Auslander et al., 2010; Rhee et al., 2009) explicitly explored how ethnicity could affect the transfer of self-management responsibility suggesting this is an area where further research is needed. Many of the studies examined specific LTCs which may limit the generalisability and transferability of the findings; however, through using the methodological strategies proposed by Whittemore and Knafl (2005) it was possible to explore the relationships between studies and identify common concepts across a range of childhood LTCs.

Another potential bias is that only one author (RN) conducted initial screening, data extraction and quality assessment, though other authors were involved in reviewing eligibility and data extraction forms, with any discrepancies being resolved through discussion. Though the search strategy was systematic, as this is not a well-indexed field of research, it is possible that some relevant studies were excluded. As the inclusion criteria comprised English language papers only, some relevant non-English studies may have been omitted.

#### **4.4. Conclusion**

Through synthesizing the evidence which examines how children assume responsibility from their parents for LTC self-management and the influences on this transfer, the findings from this review extends existing work in this area of health care. Gaps in the literature have been highlighted and areas for further research identified.

#### **Key messages:**

- How children assume responsibility from their parents for self-management of their own long-term condition is a complex process, with children and parents adopting various strategies that result in a range of planned and unplanned outcomes.
- Professionals should be aware of multiple factors such as the child, family, social networks, health professional and long-term condition that appear to interact and influence how a child assumes responsibility.
- The parent-to-child transfer of self-management responsibility is rarely viewed within the wider context of the child gaining independence in other areas of their life.
- There is limited evidence concerning the health professionals' role and the strategies and/or interventions used by health professionals to support children to assume self-management responsibility.
- Further research is needed to explore children's, parents' and health professionals' views on this process and what support families require as responsibilities change.

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**Table 1: Inclusion and exclusion criteria (based on SPIDER framework) (Cooke et al., 2012)**

Criteria	Inclusion	Exclusion
Sample: participants	<ul style="list-style-type: none"> <li>• Papers primarily focusing on children aged 0-18.</li> <li>• Papers involving or focusing on parents, or HCPs that relate to the LTCs described below and the age group above.</li> </ul>	<ul style="list-style-type: none"> <li>• Mean age of children/young people is reported as over 18 years of age.</li> <li>• If data are differentiated by participant's age, data from children/young people aged over 18.</li> </ul>
Sample: condition	<p>Children diagnosed with:</p> <ul style="list-style-type: none"> <li>• any physical LTCs AND/OR</li> <li>• five childhood-onset LTCs (asthma, CKD, cystic fibrosis, diabetes, epilepsy); these were selected as they differ from each other in the complexity of self-management and prognosis.</li> </ul>	<ul style="list-style-type: none"> <li>• Children with non-physical health conditions such as autism, mental health conditions and attention deficit hyperactivity disorder.</li> </ul>
Phenomenon of Interest	<ul style="list-style-type: none"> <li>• The process of children assuming responsibility from their parent for self-management of their LTC.</li> <li>• The individual child assuming responsibility, and/or parents transferring and/or letting go of responsibility and/or professionals supporting this process.</li> </ul>	<ul style="list-style-type: none"> <li>• The outcome of children assuming responsibility such as adherence or compliance.</li> <li>• The transition from child to adult health services.</li> </ul>
Design and Research type	<ul style="list-style-type: none"> <li>• Primary research including qualitative, mixed methods and quantitative studies of all designs.</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary research, theoretical papers, editorials, protocols, discursive/opinion papers, posters and/or conference proceedings and theses.</li> <li>• Unpublished and grey literature as the aim was for the review to be systematic, transparent and reproducible, and limited guidance is available on how to systematically search for grey literature (Mahood, Van Eerd, &amp; Irvin, 2014)</li> </ul>

Date range	<ul style="list-style-type: none"> <li>January 1995 and September 2017; this range was selected as interest in self-management of LTCs developed during the 1990s, leading to policy changes and research in this area (Lorig et al., 1999; Wagner et al., 1996; DoH, 1999).</li> </ul>	<ul style="list-style-type: none"> <li>Before 1995.</li> </ul>
Language	<ul style="list-style-type: none"> <li>Only studies published in English were included in the review.</li> </ul>	<ul style="list-style-type: none"> <li>Non-English.</li> </ul>

**Table 2: Summary of studies included in the review**

<b>Author</b>	<b>Research aim</b>	<b>Study design/ Methods</b>	<b>Setting/ Participants</b>	<b>Main findings</b>
Akre & Suris (2014)	To identify the needs of parents of adolescents with LTCs in dealing with their child's autonomy acquisition.	Qualitative. Focus groups.	Switzerland. 30 parents of children aged 14-19 with range of LTCs.	Varying degrees of autonomy in how children handled their treatment. Parents concerned re: potential future consequences as a result of child making self-management mistakes.
Auslander et al (2010)	To explore resources and barriers to self-management among African American youths with type 2 diabetes.	Phenomenology Individual interviews.	USA. 10 children aged 15-18 and their mothers.	Resources: mother's role as primary support person; stories about diabetic relatives used to motivate child. Barriers: comorbidity; fitting in with peers; financial concerns.
Babler & Strickland (2015)	To understand adolescents' experiences of living with diabetes and their management issues.	Grounded theory. Individual interviews.	USA. 11 children aged 11-15 with type 1 diabetes.	Taking over care from parents is a slow process, affected by parents' willingness to let go of care. Experience conflict with parents.
Buford (2004)	To explore the process for transfer of asthma management from parents to their children.	Grounded theory. Individual interviews.	USA. 14 children aged 8-13 with asthma, 14 adults.	Transfer of responsibility is complex process and involves identifiable stages. Families have unique characteristics e.g. health beliefs, parenting styles which affect transfer.
Chilton & Pires-Yfantouda (2015)	To understand how adolescents adapt to their self-management requirements.	Grounded theory. Individual interviews.	UK. 13 children aged 13-16 with type 1 diabetes.	Self-management can be understood as a continuum with success at one end, and difficulties at the other. Involves adapting to, and integrating regime into daily life.
Christian et al (1999)	To explore the experience of adolescents with diabetes as they take on responsibility for their own care.	Grounded theory. Individual interviews.	USA. 4 children aged 14-18 with diabetes.	Process of learning self-responsibility began at around 12 years old. Gradual transition from dependence to independence. Gaining freedom as gaining self-responsibility.

<b>Author</b>	<b>Research aim</b>	<b>Study design/ Methods</b>	<b>Setting/ Participants</b>	<b>Main findings</b>
Dashiff et al (2011)	To describe the experiences of parents of 16-18 year olds with diabetes in transitioning self-management to their child.	Qualitative. Individual and joint interview or joint interviews.	USA. 40 parent/family carers of child aged 16-18 with type 1 diabetes.	Support from school and HCPs, reminding child and noticing positive aspects of child's self-management helped. Parents' worried about when and how to let child take on responsibility.
Ersig et al (2016)	To identify stressors of adolescents with diabetes, and their parents, relevant to transition to adulthood.	Qualitative. Individual interviews.	USA. 15 children aged 12-18 with type 1 diabetes and 25 parents.	Over time teenagers relied less on parents. Some parents wanted to retain control of management, others viewed child's self-management as part of trial and error process.
Hanna and Guthrie (2000a)	What are adolescents' perceived benefits and barriers related to assuming diabetes management from their parents?	Qualitative. Individual interviews.	USA. 16 children aged 11-18.	Benefits: having knowledge of, or confidence in self-management abilities; having more freedom; having approval of others. Barriers: burden of responsibility.
Hanna and Guthrie (2000b)	What are parents' perceived benefits and barriers to transferring diabetes management during adolescence?	Qualitative Individual interviews.	USA. 17 parents of children (mean age = 14.5) with type 1 diabetes.	Benefits: relief from burden e.g. less worry, stress; knowledge, confidence and pride in child's abilities. Barriers: loss of control, authority and supervision; dealing with consequences.
Hanna and Guthrie (2001)	To identify positive and negative dimensions of support related to adolescents assumption of diabetes management responsibility	Qualitative. Individual interviews.	USA. 16 pairs of children aged 11-18, with type 1 diabetes and their parents.	Parents' views a) helpful: direct commands, reminding, discussion b) non-helpful: reminding too early; physical help when not wanted by child. Adolescents' views: a) helpful: negotiating, encouragement b) non-helpful: physically helping when it's not needed.
Husted et al (2014)	To explore what influenced developing life skills in adolescents with diabetes.	Qualitative realistic evaluation. Recorded sessions of adolescent-parent-HCP triads. Individual and joint interviews	Denmark. 13 children aged 13-18 with type 1 diabetes, 17 parents, 8 HCPs.	Beneficial to involve adolescents first, and parents second in decision-making and problem-solving; HCPs advanced communication skills useful to focus on difficulties perceived as important by adolescents.

<b>Author</b>	<b>Research aim</b>	<b>Study design/ Methods</b>	<b>Setting/ Participants</b>	<b>Main findings</b>
Jedeloo et al (2010)	To explore the attitudes of adolescents with LTCs towards health care delivery and self-management	Mixed methods. Q-methods.	Netherlands. 31 children aged 12-19 (mean age = 15.3), with variety of LTCs.	Identified 4 preference profiles 1) conscious and compliant 2) backseat patient 3) self-confident and autonomous 4) worried and insecure. Vary in how much they want parents and HCPs involved.
Karlsson et al (2008)	To elucidate experiences of teenagers with type 1 diabetes, and the transition towards autonomy in diabetes self-management	Phenomenology Individual interviews	Sweden. 32 children aged 13-17, with type 1 diabetes.	Some willing to take full responsibility for self-management, others too immature. Hovering between separating from parents and retaining parental support resulted in unclear responsibility.
Kayle et al (2016)	To describe the challenges faced by adolescents with sickle cell disease (SCD) and their parents, and adaptive work as management shifts from parent-to-child	Qualitative descriptive. Focus groups.	USA. 14 children aged 11-18 with SCD, 14 parents/ carers	Challenges: child mastering symptom management; parents balancing protection and risk with fostering independence. Adaptive work: child stepped up with time though on occasions defaults back to parent care; parents' co-manage with child.
Kirk (2008)	To investigate how young people with complex healthcare needs experience different transitions.	Grounded theory. Individual interviews.	UK. 19 children aged 8-19 with a range of LTCs, 9 parents	Learning to manage therapies: gradual process, moving from parental to shared responsibility to self-care, different activities transferred at different times. Individualised process, negotiated between child and parent.
Lindholm Olinder et al (2011)	To gain insight into the processes involved when insulin pump-treated adolescents take or miss taking their bolus doses.	Grounded theory. Individual interviews.	Sweden. 12 children aged 12-19 with diabetes, 4 parents, 1 diabetes nurse.	Responsibility for self-management discussed rarely. Optimal if responsibility moves gradually from parent to child. Need to clarify responsibility for self-management between child/ parent.
Meah et al (2010)	To explore how the distribution of responsibilities for asthma self-care is negotiated between children and their parents	Qualitative. Individual interviews.	UK. 18 children aged 7-12 with asthma and their parents.	Self-management is a negotiated, complex process. Changing role for parents. Children have different understandings of their bodies and asthma, so view being responsible differently to their parents.

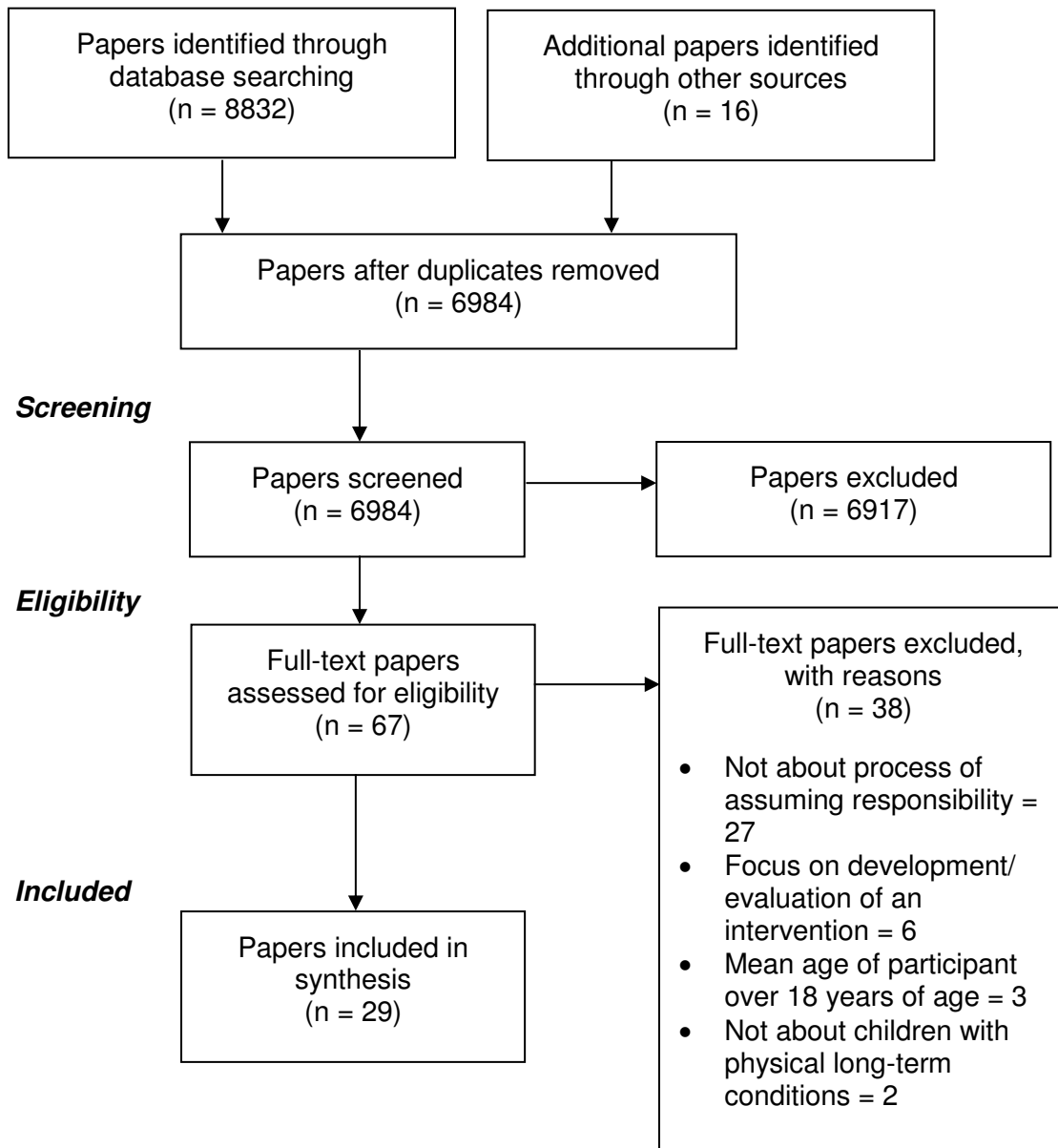
<b>Author</b>	<b>Research aim</b>	<b>Study design/ Methods</b>	<b>Setting/ Participants</b>	<b>Main findings</b>
Meaux et al (2014)	To explore how adolescents/ parents perceive self-management, and how adolescents navigate the transition to self-management	Qualitative descriptive. Computer mediated focus groups.	USA. 4 children aged 13-21, who had a heart transplant, 6 parents.	Parents' role modelling/ teaching. Child's responsibility increased with age. Time since transplant and development of complications also influential.
Mulvaney et al (2006)	To ask parents to describe barriers to, and facilitators of adolescent self-management of type 2 diabetes	Qualitative. Focus groups.	USA. 27 parents/ guardians. Mean age of child = 15.2.	Influences on self-management: role of others with diabetes; parenting skills; peers; environment typical adolescent development. Child's autonomy varied, some needed prompting, others independent.
Mulvaney et al (2008)	To explore barriers to and facilitators of self-management among adolescents with type 2 diabetes	Qualitative descriptive. Focus groups.	USA. 24 children aged 13-19 (mean age = 15.2).	Influences on self-management: adolescent psychosocial development; peer relationships; role of others with diabetes; environment; child's problem-solving and coping skills.
Newbould et al (2008)	To examine the partnerships between young people and their parents in the management of medication for LTCs	Qualitative. Individual interviews.	UK. 69 children aged 8-15 (43 with asthma, 26 with diabetes). 78 parents.	Transfer of responsibilities from parent to child often happened in response to specific occasions (e.g. starting secondary school, overnight trips). Only few parents spoke with HCPs about transfer as felt HCPs not interested in being involved.
Rhee et al (2009)	1) To assess the barriers perceived by adolescents with asthma 2) To examine associations between barriers and psychosocial factors.	Quantitative. Cross sectional study.	USA. 126 children aged 13-20 (mean age = 15.5) with asthma.	Perceived barriers: negativity towards providers; cognitive difficulty; peers. Males ( $p = \text{NS}$ ), non-whites ( $p < 0.05$ ) and those with disadvantaged SES ( $p < 0.05$ ) reported higher levels of barriers.
Schilling et al (2006)	To describe the transfer of management responsibility from parents to youth	Qualitative descriptive. Individual interviews.	USA. 22 children aged 8-19 (mean age = 14.5) with type 1 diabetes, 22 parents.	Parents took active steps to transfer responsibility to child e.g. educating. Importance of developmental readiness. Identified 3 patterns of self-management, primarily relating to age.

<b>Author</b>	<b>Research aim</b>	<b>Study design/ Methods</b>	<b>Setting/ Participants</b>	<b>Main findings</b>
Spencer et al (2013)	To explore the lived experiences of adolescents with type 1 diabetes and their parents.	Phenomenology Individual and joint interviews	UK. 20 children aged 13-16, 27 parents.	Adolescents felt education they received from HCPs didn't translate into real life. Parents negotiated finding a balance between letting child manage independently and helping with self-management tasks.
Stinson et al (2008)	To explore self-management needs of adolescents with juvenile idiopathic arthritis (JIA)	Qualitative descriptive. Individual and focus group interviews.	Canada. 36 children aged 12-19 (mean age = 15.1) with JIA.	Strategies used to learn self-management e.g. acquiring knowledge and skill to manage the disease (e.g. listening to, and challenging care providers, acquiring skills to communicate with the doctor).
Sullivan-Bolyai et al (2014)	To describe the perspectives of teens and their parents about self-management knowledge, behaviours and resources used to manage type 1 diabetes.	Qualitative. Focus groups.	USA. 10 children aged 13-17, 13 parents.	Age of diagnosis affected when got involved in management .Children thought HCPs shouldn't be involved in helping parents let go. Parents felt it was their job to make sure child self-sufficient in management but felt pressure from HCPs to physically do care.
Williams (1999)	To explore the ways gender impacts on the meanings and management of diabetes during adolescence	Grounded theory. Individual interviews.	UK. 20 children aged 15-18, 20 mothers	Girls tended to incorporate diabetes into their identities, boys tended to hide it - implications for management. Mothers of sons more likely to be involved in care, blamed by HCPs for being overprotective; girls actively encouraged by HCPs to take on responsibility for care.
Williams et al (2007)	1) What are the roles of family members in the implementation of home exercises? 2) How is the responsibility for physiotherapy exercises transferred from parent to child?	Qualitative. Individual interviews.	UK. 32 children aged 7-17, with cystic fibrosis, 31 parents.	Level and nature of involvement varied along a continuum of responsibility. Roles/responsibilities changed over time. Transfer seen as gradual, taken for granted process over time. Physiotherapists viewed as playing a key role in process.



**Figure 1: Selection process (Moher et al., 2009)**

**Identification**



## Appendix A: Search strategy

Example of the search strategy used in MEDLINE

#	Searches	#	Searches
1	child*.mp.	29	transition to adult care.mp.
2	teenager*.mp.	30	health care transition.mp.
3	adolescen*.mp.	31	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
4	young person.mp.	32	exp Chronic Disease/
5	young people.mp.	33	chronic disease*.mp.
6	youth.mp.	34	chronic condition*.mp.
7	juvenile.mp.	35	chronic illness*.mp.
8	p*ediatric.mp.	36	long term condition*.mp.
9	*Pediatrics/	37	long-term condition*.mp.
10	exp Adolescent/	38	diabet*.mp.
11	exp Child/	39	exp Diabetes Mellitus/
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11	40	exp Asthma/
13	exp Self Care/	41	asthma.mp.
14	self manag*.mp.	42	exp Cystic Fibrosis/
15	self-manag*.mp.	43	cystic fibrosis.mp.
16	self care.mp.	44	exp Epilepsy/
17	self-care.mp.	45	epilep*.mp.
18	self help.mp.	46	Renal Insufficiency, Chronic/
19	self-help.mp.	47	chronic kidney disease.mp.
20	collaborative care.mp.	48	chronic renal disease.mp.
21	collaborative manag*.mp.	49	Kidney Failure, Chronic/
22	shared manag*.mp.	50	chronic kidney condition.mp.
23	self medicat*.mp.	51	chronic renal condition.mp.
24	disease manag*.mp.	52	CKD.mp.
25	parent to child transfer.mp.	53	chronic kidney failure.mp.
26	parent to child transition.mp.	54	32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53
27	transition to adulthood.mp.	55	12 and 31 and 54
28	exp Transition to Adult Care/	56	limit 55 to (english language and humans and yr="1995 -Current")