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REVIEW

# Parents' experiences of transition from hospital to home of a child with complex health needs: A systematic literature review

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## Abstract

**Aims and objectives:** To critically appraise primary research on the views and experiences of parents of children with complex health needs during the transition from hospital to home.

**Background:** Children with complex health needs frequently transition across and within healthcare systems, due to their age, care needs and ongoing health conditions. Repeated and unplanned admissions are significantly higher for children with complex health needs. Yet parents, as the primary providers of care, report being unsupported and unprepared during the transition from hospital back to home due to poor communication, inadequate discharge planning and education, resulting in stress and anxiety within the home environment.

**Design:** Systematic review following PRISMA guidelines.

**Methods:** A systematic search was completed of the databases CINAHL, MEDLINE, PsycINFO, EMBASE and the Cochrane Library Review between January 2009 and September 2019. Data were extracted, categorised and analysed using a thematic analysis approach. An adapted CASP qualitative assessment tool was utilised for quality assessment. All included articles were marked for validity and relevance to current research with an overall score from 0–20.

**Results:** A total of 13 studies of mixed quality were identified. CASP quality scores ranged from 13–18. Four themes emerged highlighting parents' experiences of the emotional processes, communication, coordination and support and resources when transitioning from hospital to home.

**Conclusions:** Hospital discharge and transition from hospital to home is a complicated and at times frustrating process for parents of children with complex health needs. Parents report being exhausted and stressed during this often-challenging period of adjustment which was perceived as a difficult and emotional process. There is a clear lack of support available for parents both from hospital and community services.

## KEYWORDS

child, community, complex health needs, discharge, home, transition

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## 1 | INTRODUCTION

The increasing survival rates and quality of life for children with rare medical conditions and complex health needs have been consistently reported in the literature (Carter, Bray, Dickinson, Edwards, & Ford, 2014; Department of Health, 2008). In the UK, Fraser et al. (2012) identified 32 per 10,000 children surviving with rare medical conditions and complex health needs, a rise from 25 per 10,000 children in the previous 10 years. In the USA, 19.8% of all children under the age of eighteen are deemed to have “special health-care needs” (Maternal & Child Health Bureau, 2014). However, the precise number of children worldwide with complex health needs is unclear due to the lack of consensus on an agreed definition and the limited data available (Pinney, 2017).

There is a range of terminology used throughout the literature to describe the population of children with complex health needs. Examples include “medical complexity,” “life-limiting conditions” and “life-threatening conditions.” Many of these terms were utilised during the literature search to ensure a comprehensive search was completed. However, for clarity and consistency, the term “complex health needs” will be used throughout this review. Rankin and Regan (2004) describe a complex need as comprising of both breadth (referring to amount of needs) and depth (the severity of the need). They suggest that the term “need” shifts the focus of support to the response requirement of others. Terms such as “medical complexity” could be argued as conveying those societal requirements as more of a personal characteristic of the individual. The use of the term “complex health needs” can therefore represent a more social model of disability and illness.

Whereas McConkey, Barr, and Baxter (2007) recommended using the definition of “complex physical healthcare needs” to differentiate physical needs from mental health disorders or emotional concerns, Carter, Cummings, and Cooper (2007) highlight that children with complex health needs do not just require physical support but rather, require a holistic approach including their psychological, social and educational care needs. The use of McConkey et al.'s definition may overlook these support requirements. Therefore, the use of the term complex health need was chosen for the purpose of this review.

*Complex Health Needs* can be defined as those that require a range of additional support services beyond the type and amount required by children generally, usually related to children with impairments and/or long-term illnesses (Department of Health, 2004).

Home is the primary place of care for the majority of these children (Carter et al., 2014), with parents providing a nurturing environment (Elias & Murphy, 2012). Traditionally, the majority of these children received care within a hospital environment, which often had a detrimental effect on the child's social, emotional and cognitive development (Noyes, 2000). Thus, care of children with complex health needs is being provided primarily by families in the home, with many parents now delivering clinical care that was historically provided by healthcare professionals (McCann, Bull, & Winzenber, 2012).

### What does this paper contribute to the wider global community?

- The number of children with complex health needs living into adulthood at home is increasing. Understanding the complexities of the transition process enables children to live at home by enhancing the services that are provided to these families.
- These children typically require care and support from a range of multidisciplinary team professionals. Therefore, understanding the family's care needs is necessary to ensure care and support is effective and thoroughly meets the individual and family needs.

Reliance on parents as care providers during this transition from hospital to home is a critical period requiring multidisciplinary co-ordination, education and support for families (Weiss et al., 2008), yet there is a clear lack of support available to parents during the transition from hospital to home (Brenner et al., 2015). Children with complex health needs are associated with a significant amount of repeated and unplanned admissions (Kun, Edwards, Davidson Ward, & Keens, 2012) due to poor discharge planning and limited education and preparation of parents to deliver clinical interventions. Parents report experiencing significant levels of stress, feeling unsupported and unprepared during the transition home (Nicholl & Begley, 2012). Therefore, for healthcare professionals to better understand the transition process from hospital to home, the views and experiences of families are essential (Solan et al., 2015).

### 1.1 | Aims

The aim of this systematic review was to critically appraise primary research on the views and experiences of parents of children with complex health needs and the transition from hospital to home. The questions guiding this review were as follows: (a) “What are the views and experiences of families of children with complex health needs during the transition from hospital to home,” (b) “What are the priorities of families to improve this transition process,” and (c) “What interventions are available that aim to meet the needs of families during this transition from hospital to home?”.

## 2 | METHODS

### 2.1 | Sampling

A systematic search strategy was developed with the assistance of an expert subject librarian to improve rigour. Author S.R. conducted an electronic search of five major databases for the period 2009–2019. The databases searched were as follows: Cochrane

Library–Cochrane Reviews, Other Reviews and Trials (2009 - 20th September 2019), CINAHL (2009 - 20th September 2019), MEDLINE (2009 - 20th September 2019), PsycINFO (2009 - 20th September 2019) and EMBASE (2009 - 20th September 2019). The search terms used were 'child', 'child, medically fragile', 'child, disabled', 'complex needs', 'complex health needs', 'life-limiting', 'life-threatening', 'ventilator dependent', 'chronic disease', 'transition', 'discharge', 'patient discharge', 'community' and 'home'. The terms were linked with AND and OR, with a hand search carried out to identify other relevant articles. A template of the search strategy is included in Table 1.

Titles and abstracts of all retrieved articles were screened by author S.R. for relevance to the aims and questions of the review. If identified as potentially relevant, the text was retrieved and

reviewed in full. The reference lists of all full-text papers were reviewed to identify further relevant articles. The full text of these papers was read in their entirety by author S.R. and screened against the review inclusion and exclusion criteria. A PRISMA flow chart in Figure 1 demonstrates the research process. See supplementary file one for a completed PRISMA checklist for systematic reviews and meta-analyses (Moher, Liberati, Tetzlaff, & Altman, 2009).

### 2.2 | Inclusion and exclusion criteria

Inclusion criteria included publication between January 2009 and September 2019 and articles that were written in the English

TABLE 1 Combination of search terms

Criterion A	AND	Criterion B	AND	Criterion C	AND	Criterion D
Child		Complex needs		Transition		Home
OR		OR		OR		OR
Disabled child		Complex health needs		Patient discharge		Community
OR		OR		OR		
Child, disabled		Chronic disease		Discharge		
OR		OR				
Child, medically fragile		Ventilator dependent				
		OR				
		Technology dependent				
		OR				
		Life limiting				
		OR				
		Life threatening				
		OR				
		Medical complexity				

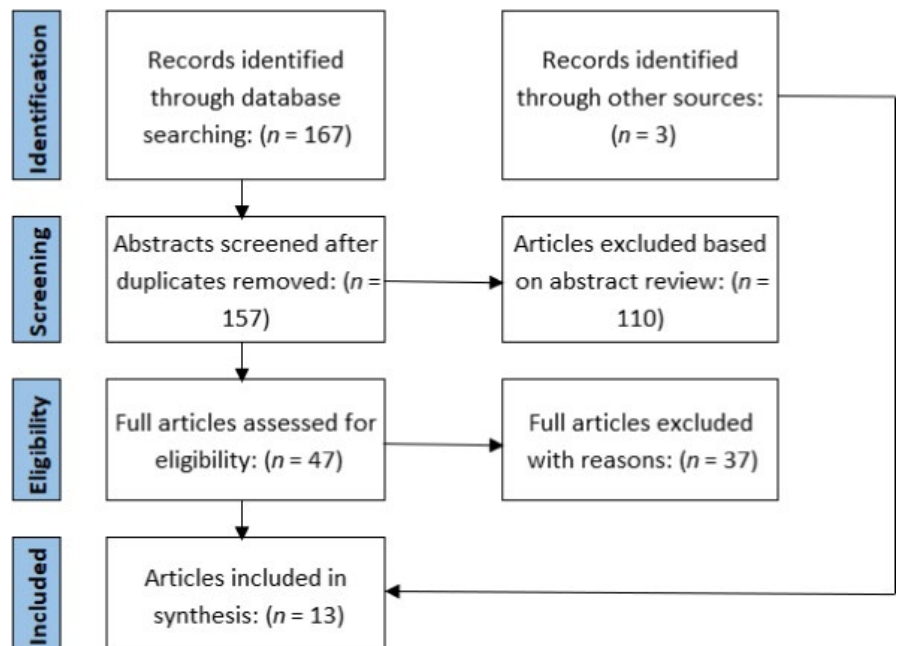


FIGURE 1 PRISMA search strategy flow chart

language only. Articles had to focus on the experiences of parents or guardians of children under the age of eighteen who are diagnosed with long-term complex health needs during the transition from hospital to home. Articles that also examined other viewpoints during the transition process were included if they presented the views and experiences of parents of children with complex health needs separately. This information was then extracted for the purpose of this review.

### 2.3 | Data screening

Articles were screened against the inclusion and exclusion criteria by the author S.R. Preliminary data on the article's relevance to the research questions were presented in meetings with authors M.B. and L.M., and confirmation on article relevance/inclusion was agreed.

### 2.4 | Data extraction and analysis

Data were extracted and analysed using a thematic analysis format by author S.R. Rigour was maintained by following Nowell's, Norris, White, and Moules (2017) steps in thematic analysis to improve trustworthiness. The articles were read and re-read several times before being coded and mapped onto tables listing the author, year, country, sample sizes, methods, findings and recommendations. Authors M.B. and L.M. reviewed these tables for relevance to the research questions and aims. The collected data were then further categorised and developed into themes.

### 2.5 | Quality assessment

The Critical Appraisal Skills Programme (CASP) qualitative tool was used to appraise the included studies (CASP, 2018). As the majority of the included articles were qualitative articles, or interventional studies with a significant qualitative component that did not fit the eligibility for other quantitative assessment tools, adapting a qualitative tool allowed for evaluation and comparison. The tool was adapted by changing the question inquiring whether a qualitative methodology was appropriate for the research, to whether the chosen methodology was appropriate. This allowed evaluation of studies of various methodologies by the same assessment tool for a clearer comparison. A scoring system was created to provide a more visual representation of the included papers' quality for further comparison and evaluation. This approach enabled the appraisal of the papers and was adapted from approaches used by Rushbrooke, Murray, and Townsend (2014), McCann and Brown (2017) and McCann, Lee, and Brown (2016). All papers were assessed using the CASP tool. Questions were scored zero, one or two with each paper awarded an overall score out of twenty. Quality scores ranged between 13–18. The article not answering the question adequately was given a score of zero, a score of one

indicated that the question was moderately answered and if answered fully, a score of two.

## 3 | RESULTS

A total of 13 studies of mixed quality were included in the review of which eight were from the USA (Callans, Bleiler, Flanagan, & Carroll, 2016; Canary & Wilkins, 2017; Desai, Durkin, Jacob-Files, & Mangione-Smith, 2016; Lakshmanan et al., 2019; Leyenaar, O'Brien, Leslie, Lindenauer, & Mangione-Smith, 2017; Thrasher et al., 2017; Van Orne, Branson, & Cazzell, 2018; Wells et al., 2017) and one each from Brazil (Esteves, Silva, Conceicao, & Paiva, 2015), Canada (Manhas & Mitchell, 2012), Italy (Zanello et al., 2015), Ireland (Brenner et al., 2015) and the UK (Price, McCloskey, & Brazil, 2017). Three studies adopted a mixed-method design (Thrasher et al., 2017; Van Orne et al., 2018; Wells et al., 2017) while the ten remaining papers were qualitative (Brenner et al., 2015; Callans et al., 2016; Canary & Wilkins, 2017; Desai et al., 2016; Esteves et al., 2015; Lakshmanan et al., 2019; Leyenaar et al., 2017; Manhas & Mitchell, 2012; Price et al., 2017; Zanello et al., 2015). A table of the included studies is presented in Tables 2 and 3.

### 3.1 | Experiences of the transition from hospital to home

#### 3.1.1 | Emotional experiences

The transition of the child from hospital to home led to some parents experiencing a range of emotions, mirroring the feelings experienced when their child was first diagnosed. For some, the emotions associated with the discharge home resulted in a further sense of loss due to the severing of supportive relationships developed with health professionals. The sense of loss was also associated with leaving the hospital environment that was perceived as being safe and familiar, compounded by the stress of assuming full responsibility for providing care for their child at home (Zanello et al., 2015). Parents reported becoming accustomed to the perceived "safety" of the hospital environment, with the transition home resulting in new upheaval requiring further adaptation and adjustment (Callans et al., 2016; Esteves et al., 2015). Emotions were further exacerbated for some parents due to the uncertainty regarding their child's future and their ability to adapt and cope with the additional roles and responsibilities of caregiving (Canary & Wilkins, 2017; Manhas & Mitchell, 2012).

Fear was another recurrent factor as parents felt afraid to leave an environment where experienced nurses and other hospital practitioners were constantly available to provide help, advice and support (Price et al., 2017; Zanello et al., 2015).

Parents were concerned that their child would deteriorate and require readmission to hospital while at home. Once home, parents described being overwhelmed with the gap in services that became

apparent within the community. They found minimal assistance was available in contrast to the resources and trained practitioners within the hospital setting. Canary and Wilkins (2017) referred to this phenomenon (2017) as a “care chasm.” Mothers in particular cited their lack of interaction outside their home coupled with their anxiety over their child's well-being as negatively impacting their mental health (Lakshmanan et al., 2019). It was suggested that nurses and other healthcare practitioners needed to appreciate and understand the difficult emotions that parents' experience during this transition, with respect and sensitivity being valued (Callans et al., 2016; Esteves et al., 2015).

### 3.1.2 | Communication

A significant breakdown in communication between hospital and community services resulted in a lack of coordination. This impeded and delayed transition from hospital to home (Brenner et al., 2015). During the transition process, it was noted in some studies that a planned handover did not occur between hospital practitioners and the primary care providers and community services who would assume responsibility for delivering care in the home (Canary & Wilkins, 2017; Desai et al., 2016). This impacted parents' confidence in accessing their primary care provider as some parents' believed the healthcare professionals were inadequately informed about the child's needs and could therefore not provide appropriate support and advice (Brenner et al., 2015; Leyenaar et al., 2017). In this regard, parents experienced a form of consultation fatigue from having to repeatedly update others on the child's condition and care needs (Canary & Wilkins, 2017). A parent interviewed in Zanello et al. (2015) study expressed their frustration over the disconnect between services:

The problem is that everyone has his/her own way to do things. And now the community nurse has another method. (Zanello et al., 2015, p. 5)

Poor communication between parents and healthcare practitioners was identified as a concern by parents in one study undertaken in the USA, who felt excluded from discharge planning and information sharing (Leyenaar et al., 2017). This contrasted with the experiences of parents in a study undertaken in Italy (Zanello et al., 2015). Rather, these parents reported feeling more prepared and confident for the transition from hospital to home as they were included in the multidisciplinary planning process which provided them with control in decision-making about their child (Zanello et al., 2015). Therefore, it is necessary for healthcare professionals to ensure that parents feel supported and understood (Callans et al., 2016) and utilise a coordinated team approach, promoting inclusion and continuity of care (Leyenaar et al., 2017), which is essential in increasing positive experiences for the child and family (Brenner et al., 2015). Without parental involvement in the planning period, the transition process can become

confusing, increasing the possibility of mistakes and avoidable complications in care provision within the home (Desai et al., 2016). Poor information-sharing and communication breakdown was also highlighted (Manhas & Mitchell, 2012).

Thus, the need for further contact for parents with familiar hospital-based practitioners immediately postdischarge is essential (Canary & Wilkins, 2017; Esteves et al., 2015). One recommendation from parents was to receive a follow-up phone call from trusted professionals to allow parents time to ask pertinent questions (Canary & Wilkins, 2017).

## 3.2 | Parents' priorities for the transition from hospital to home

### 3.2.1 | Coordination

As many parents reported feeling anxious and unprepared for the transition from hospital to home, a concept of “discharge readiness” emerged (Canary & Wilkins, 2017; Leyenaar et al., 2017). These parents related their “readiness” for discharge to whether they felt their child was clinically fit to leave the hospital environment. It was also significantly linked to parents' in-hospital training and their confidence in their ability to deliver the relevant clinical interventions and care. Parents emphasised the importance of identifying and respecting their discharge readiness in coordinating safer discharges. They wanted to begin education and preparation for discharge as early as possible (Esteves et al., 2015; Lakshmanan et al., 2019). When early preparation was implemented, it was noted to increase family empowerment (Zanello et al., 2015). A discharge readiness tool was suggested to assist healthcare providers in assessing this “readiness” more holistically (Canary & Wilkins, 2017). Discharge checklists which would include a list of items and procedures to be achieved before discharge were also suggested to assist nurses and other hospital practitioners with strategically planning a comprehensive and efficient transition home (Canary & Wilkins, 2017).

Practical measures such as ensuring a home discharge occurred early in the day were emphasised as being important (Leyenaar et al., 2017). It was highlighted that the evenings and overnight were the most difficult time of the families' day where the least support is available. Discharges occurring at these times made it difficult for parents to settle into a care routine at home (Leyenaar et al., 2017), and introducing better links between hospital and community teams to facilitate the ordering of equipment and supplies in advance of discharge was recommended. It was also suggested that vital medication and clinical equipment be available in the home in advance of the child and family leaving hospital (Callans et al., 2016; Canary & Wilkins, 2017; Leyenaar et al., 2017). Support with transition home for parents was also highlighted in other studies (Callans et al., 2016; Leyenaar et al., 2017; Manhas & Mitchell, 2012).

**TABLE 2** Summary of included articles examining parents' experiences and preferences

Study citation	Country	Aims	Sample (parental sample only)	Data collection method	Complex need(s) studied
Manhas and Mitchell (2012)	Canada	To examine the transition from hospital to home for two young, ventilator-dependent children and contextualise this experience by examining the perceptions of 26 adults involved in this transition	3	Interviews	Tracheostomy and/or ventilator dependence
Brenner et al. (2015)	Ireland	To explore parents' perspectives of the transition of a child with complex respiratory health care needs from hospital to home	15	Interviews	Tracheostomy and/or ventilator dependence
Esteves et al. (2015)	Brazil	To examine the concerns of parents of children with complex health needs regarding their technology dependence	6 caregivers	Semi-structured interviews	Tracheostomy/colostomy/gastrostomy/venous catheters
Zanello et al. (2015)	Italy	To explore parents' experiences and perceptions on informational, management and relational continuity of care for children with special health care needs from hospitalisation to the first months after discharge	16	Interviews and focus groups	Birth weight <1 kg/technology dependence/acute neurological deficit/severe endocrinopathy/complex congenital conditions/palliative oncological or complex oncological conditions
Callans et al. (2016)	USA	To examine family experiences of caring for their child with a tracheostomy during the transition from hospital to home. To identify the types of support that families request to be successful caregivers.	18	Focus groups	Tracheostomy
Canary and Wilkins (2017)	USA	To explore how parents and physicians describe their paediatric hospital discharge experiences. To examine the role of communication in the discharge and postdischarge experience of both groups	8	Interviews and focus groups	Complex chronic health conditions requiring frequent hospitalisation (not otherwise specified)
Desai et al. (2016)	USA	To explore caregiver needs and preferences for achievement of high-quality paediatric hospital to home transitions. To describe similarities and differences in caregiver needs and preferences according to medical complexity	18	Interviews	Complex chronic conditions such as technology dependencies and epilepsy with chronic respiratory insufficiency (not otherwise supplied)
Leyenaar et al. (2017)	USA	To examine the scope of preferences, priorities and goals of parents regarding hospital to home transitions To ascertain healthcare providers' perceptions of families' transitional care needs	23	Interviews	Multisystem diseases/oncological conditions/technological dependences—causing severe functional limitations and involvement of multiple healthcare services



Key findings	Recommendations	CASP score out of 20
The transition causes a continuous shift in responsibility for the child's care with little support for parents. Parents experience loss and uncertainty during this time. Mothers are expected to coordinate all care and services while undertaking a full care role for the child	More support is needed especially for Mothers. Staff need to understand signs of grief or uncertainty around the transition period and offer appropriate support. More homecare staff are needed. This role should be promoted. Trust between parents and the medical team needs to be improved. Enhanced communication could assist this	16
Parents experienced adequate training and preparation for the discharge home while in the acute setting. Transitional care units in the hospital helped build competence and confidence. Lack of coordinated thinking and working between services delayed discharge. This also impeded equipment set up and delivery. Lack of trained community nurses was a source of frustration	Shared policies and protocols are needed between community and hospital services to improve coordination and communication. Clearer assessments for the needs of the child and family are needed pre-discharge to organise care. More specialised community nurses and care coordinators are needed	18
On initially hearing that the child will become technology-dependent, parents were predominantly focused on the underlying condition. They gradually began to consider the medical technology although this created tension and anxiety. Confidence eventually grew in the use of the equipment within the hospital setting. However, the use of equipment at home created uncertainty and worry. Parents request more information about their child's condition and equipment and turn to the internet at times to access this	Preparation for discharge should begin at admission and continue throughout the hospital stay and throughout the transition home. Families require nurses to be clear, respect the families' wishes and encourage autonomy. Nurses need to be involved in the whole discharge process including follow-up at home	15
Parents need clear, accessible information on clinical care. Parents want discharge information laid out in one clear document. Once home, parents had to coordinate all care. Parents form attachments to hospital staff and going home is stressful and frightening for them. They feel unsupported at this time	Continuous, coordinated care throughout the hospital to the community. Plans for discharge should be implemented early in admission. Parents need a clear, shared care plan. A follow-up by hospital staff should be provided to staff post-discharge. Including parents in team meetings and care plan decisions and commencing training for discharge home as early as possible is key for their empowerment	16
Difficult emotions emerge from the discharge process. Parents tried to keep their normal lives and strive for routine. They experience a lack of coordinated care. Nurses who push them to learn and listen to them are desired. Families with experience want to help others who are newly coping with a tracheostomy and the transition home	Nurses need to act confident in their care while listening to families, encouraging them to learn clinical skills. Experienced parents should act as peer mentors for other families. Parents recommended videos to aid clinical learning. Connection to clinic or specialised nurses in the community would help with daily homecare	18
Teamwork was highlighted as necessary for successful discharge. The ideal discharge was described including: early preparation, support and checklists. Parents highlighted a "care chasm" in the gap in services once home. A "discharge paradox" was described where the parents were reassured that in their child would get better once home when the child often did not. Parents describe lack of support once home causing distress	Communication noted as a large factor in improving discharge process: between parents, primary care providers and healthcare professionals. This needs to be improved. More preparation is needed for discharges. Staff should evaluate parents' discharge readiness and coordinate care through checklists	16
Transition needs highlighted for all levels of medical complexity. More needs were stressed for children with complex health needs. Caregivers of children with complex health needs had difficulty coping and needing support to enhance self-efficacy. Parents needed more training in learning clinical skills	Tiered system of transition based on level of medical complexity suggested due to increasing needs/priorities in discharge process. Written discharge and contingency plans needed by healthcare professionals for parents	17
Family engagement within discharge process and timely/efficient discharge is vital. Care coordination before discharge is strived for by parents. Pain and symptom control during discharge and a focus on normalisation/routine is also stressed by parents. Support is needed to improve parent's self-efficacy. Respect for families' discharge readiness was a concept that emerged	More evaluations needed of the families' needs and readiness regarding discharge. Parents need support creating routines for their child's needs. Care coordination needed around transition process. Aspects of discharge such as time of day should be considered as per the families' wishes	17

(Continues)



TABLE 2 (Continued)

Study citation	Country	Aims	Sample (parental sample only)	Data collection method	Complex need(s) studied
Lakshmanan et al. (2019)	USA	To examine the ideas that families of infants with medical complexity have to support parents in the transition from the neonatal intensive care unit to home	21 caregivers	Semi-structured telephone interviews	Complex medication regimes/ oxygen requirement/ enterostomy/tracheostomy/ ventilator dependence/ involvement of multiple medical specialities

TABLE 3 Summary of included intervention articles

Study citation	Country	Aims	Sample (parental sample only)	Complex need(s) studied
Price et al. (2017)	UK	To report parent and professional perspectives of step-down care in assisting the transition from hospital to home within one children's hospice in the UK	5	Tracheostomy and/or ventilator dependence
Thrasher et al. (2017)	USA	To incorporate high-fidelity simulation training into a multimodel discharge preparedness training curriculum for family caregivers of children with long-term mechanical ventilation To determine what curricular elements were most useful to participating caregivers	87	Tracheostomy and/or ventilator dependence
Wells et al. (2017)	USA	To assess the utility of postdischarge home visits to identify and address health problems for recently hospitalised children with medical complexity	36	Chronic conditions such as nervous systems disorders, respiratory and/or digestive conditions with technology dependences such as tracheostomy/enterostomy/ oxygen requirements
Van Orne et al. (2018)	USA	To evaluate the effectiveness of a boot-camp style training programme for parents of children with complex health needs and technology dependence	34 caregivers	Tracheostomy

### 3.2.2 | Support and resources

There was conflicting evidence regarding the training that was provided to parents in hospital predischarge and postdischarge. Some parents reported that they received adequate and comprehensive training that met their needs (Callans et al., 2016; Zanello et al., 2015). Others, however, highlighted that the training received left them feeling unprepared and lacking confidence in using the clinical equipment for their child (Desai et al., 2016). In terms of resources and supports, care plans were recommended by parents

in an effort to improve the transition process as they could include clear contingency plans with important emergency contacts (Desai et al., 2016; Leyenaar et al., 2017). Additionally, discharge summaries outlining details of the child's hospital stay were also recommended to facilitate information transfer and further reduce the communication breakdown. Parents suggested that these resources be made available to community and primary care service providers (Desai et al., 2016).

Further, the provision of peer support to assist and advise caregivers in similar situations was identified as a positive strategy in

Key findings	Recommendations	CASP score out of 20
Parents often compared their baby to those without medical complexity. This was compounded by feelings of grief, denial and anxiety around diagnosis. Mothers cited their loneliness and worry about their child's health and development as negatively impacting their mental health. Parents of children with complex health needs require more information about services and technology than those of children without complex health needs	Parents of children with complex health needs would like their information needs met pre-discharge. They suggest that contact be made with multidisciplinary services pre-discharge and services such as homecare to be in place before transitioning home. Parents recommended the use of mobile technology to increase information sharing. Tiered discharge interventions were suggested based on medical complexity and family needs	15

Data collection method	Key findings	Recommendations	CASP score out of 20
Interviews and focus groups	Parents felt that the hospice allowed for a more peaceful and beneficial transition home. Parents could learn skills in a supportive, 1:1 environment while their child had their social, emotional and educational needs fulfilled which wouldn't have been met in a hospital setting. Allowed phased transition home which alleviated stress. This intervention empowered the whole family	More studies needed on the benefits of hospices as a step-down service with bigger sample sizes. Step-down care services are a promising option for families transitioning home from hospital. Policy and Commissioning plans needed for same	18
Mixed Methods: Quantitative survey questionnaire with 3 open-ended qualitative questions	Use of simulation equipment increased parents' confidence in clinical skills and caring for the child at home. Parents expressed that they found the training to be very helpful and they were more prepared for emergencies and less stressed about the transition home	Further research is needed to see if skills remain/develop over time and decrease readmissions. Simulation training should be incorporated into discharge training programmes for parents	15
Mixed Methods: Total amount of time needed for visit documented and percentage of visits that resulted in an identification of a problem recorded. Interviews with parents and nurse who undertook visits	The home visits identified 3 or more issues on most visits that the nurse was able to promptly resolve or refer onwards. All visits identified at least one concern. Rate of readmissions reduced. Families expressed satisfaction and reassurance with this intervention	More rigorous studies needed to more definitively prove effectiveness. Home visits appear to have a positive effect on parents who have just transitioned home. Hospital and community-based nurses should work together to support transitions home	15
Quasi-experimental study including Demographic Data, Parenting Stress Index and a Likert Scale Survey with a qualitative comment section	A structured boot-camp style training programme resulted in a decrease in length of stay of children in a transitional care unit. Over 90% of parents were very satisfied with the programme and specified that it has alleviated their fear in going home. Parental stress levels before and after the programme were reduced	A structured training programme with multiple training elements such as the one evaluated in this study was recommended. Beginning training before the child is ready for discharge lowers stress levels, length of stay and readmissions	13

supporting transitions (Callans et al., 2016). Parents reported often accessing information on their child's condition and support from peers online (Esteves et al., 2015; Lakshmanan et al., 2019). Mobile health technology was suggested to provide readily available information for parents such as apps on particular conditions, videos and articles while also providing forums for parents to discuss concerns and provide emotional support (Lakshmanan et al., 2019).

A shortage of healthcare practitioners in the community exacerbated by the lack of education and training in complex care was reported by Desai et al. (2016) and Manhas and Mitchell (2012).

Parents reported that they often had to train registered nurses and healthcare support workers in clinical interventions and care (Brenner et al., 2015; Callans et al., 2016) which was an additional source of strain and frustration, particularly for mothers who often undertook the major share of their child's care needs. A parent interviewed in one article described community nurses as "...afraid of her... they were afraid of her equipment, we had to be there all the time" (Brenner et al., 2015, p. 6).

Nurses as a potential source of support for parents emerged strongly in the review. Within the hospital, pre-discharge, nurses

were seen as empowering educators, resulting in satisfied and confident families (Callans et al., 2016). Additional registered nurses trained in meeting the needs of children with complex care were promoted, particularly within the community thereby improving the transition experiences (Callans et al., 2016; Manhas & Mitchell, 2012). Desai et al. (2016) and Lakshmanan et al. (2019) evaluated the discharge needs of families of children with and without complex health needs. Both studies recommended tiered discharge support systems based on the child's medical complexity. While all families required similar support during discharges, as the complexity of the child's needs and condition rose, so did the parents' ongoing community support, information and educational requirements. A structured tiered approach to support systems offered to families during the discharge process may enhance the quality of the transitions home while also potentially improving resource allocation and utilisation.

### 3.3 | Interventions to improve the discharge and transitional experience

Thrasher et al. (2017) and Van Orne et al. (2018) evaluated the use of structured predischarge training programmes for parents of children with a technology dependence. These programmes included a range of training methods such as visual material, emergency simulation training and practice "homecare" sessions where parents completed all medical care for the child independently over a 24- or 48-hr period while supervised by registered nurses. These studies demonstrated a decrease in parental stress, an increase in knowledge and clinical skills, and parents reported satisfaction with the training they received, suggesting increased clinical training for parents is required predischarge. A parent summarising the training programme relating back to the theme of fear described it as having "...taken away my fear of not knowing how to care for my daughter" (Van Orne et al., 2018, p. 389).

A study by Wells et al. (2017) in which nurses visited the child's home following a recent discharge alleviated parents' anxiety and their experiences of feeling overwhelmed. The nurse would, following an assessment protocol, assess the home environment, review the child's medication, equipment and supplies and reinforce clinical and care education. This service was evaluated through the quantity of concerns that the nurse noted in each visit and whether they were effectively resolved. Most home visits identified three or more concerns with all identifying at least one issue. The nurse was able to use their knowledge and link with both hospital and community teams to resolve the concerns. The involvement of the nurse in these visits also reduced readmission rates and rates of clinical error for these children (Wells et al., 2017). The level of support provided from home nursing visits significantly relates to parents' desires for future transitions home (Callans et al., 2016; Leyenaar et al., 2017; Manhas & Mitchell, 2012).

Another effective support noted was from Price et al's study (2017) in which parents who had undergone a step-down

transitional care programme through a children's hospice for children with technology dependence reported great satisfaction with this type of training. As parents, they felt supported and valued the emotional support and comprehensive training provided. One parent described the hospice service as not just providing transitional and educational support but one that offers a new outlook on the child's condition:

One of the other families... said that up until their child came here [hospice], they were waiting for him to die in the hospital... here, they learned to... you know, to enjoy him living again. (Price et al., 2017, p. 402)

This service offered a stage between the hospital and community in which one-to-one training was carried out over time with parents and a phased transition occurred later from the hospice to home. The coordination and communication between services that the hospice facilitated have been highlighted by parents as vital for positive experiences (Canary & Wilkins, 2017; Desai et al., 2016). However, this could be resource intensive requiring highly skilled and competent staff to be available.

## 4 | DISCUSSION

While research is available examining the discharge process for children with complex health needs, there appeared to be limited focus on the qualitative experiences of parents and families of children with complex health needs and the transition from hospital to home. The findings establish that the transition process is a difficult time for parents, full of mixed emotions and uncertainty. In less parental-focused reviews on this discharge and transition process, similar concerns around care coordination, accountability, communication between hospital and community and the lack of skilled community staff were identified by Noyes, Brenner, Fox, and Guerin (2014) and Breneol, Belliveau, Cassidy, and Curran (2017). This suggests a need to re-examine the discharge process in light of parents' experiences and perceptions.

### 4.1 | Implications for policy

Noting the disparity between parents' wishes for the transition home and their experiences, it is evident that there are few policies and procedures in place to guide the transition process for children and their families. Internationally, policy reports acknowledge the complexity of the transition process and discharge home for families and outline standards for professionals (American Academy of Pediatrics, 2002; Department of Health, 2004). In more recent years, the UK has developed policies to improve the discharge process for children such as The Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs (DHSSPS, 2009) and the implementation of the Scottish Intercollegiate Guidelines Network Discharge Document (SIGN, 2012).

However, minimal reviews and audits of the implementation of these services make their use and effectiveness in practice unclear. Noyes et al. (2014) highlighted the disparity between policy's conceptions of the discharge process and what was occurring in practice in their review on discharges of children with complex health needs.

These reports are also often written from the perspective of the acute setting, lacking a wider community and family focus (Department of Health, 2003). This is despite the collaborative service provision required for children with complex health needs (Carter et al., 2014). A clear and effective bridge between hospital and community services is necessary to ensure that the needs of children and their families are addressed (Brenner et al., 2015). Healthcare providers have also emphasised the clearly defined boundaries and separate policies/arrangements that divide services, particularly tertiary and primary services (Law, McCann, & O'May, 2011). Policy therefore needs to reflect the needs of the child and the family across hospital and community settings, thereby seeking to provide a seamless family-centred approach to improve their overall experiences.

## 4.2 | Implications for practice and education

Parents predominantly related their experience of support from nursing staff as either negatively or positively influencing their transition home. Despite this, there is little research on nursing involvement in the discharge process (Breneol, Hatty, Bishop, & Curran, 2018). Nurse-led discharge programmes have displayed effectiveness when used with children with less complex conditions such as asthma (Ekim & Ocakci, 2016). However, the increased clinical care needs of children with complex health needs may require more input from a wide range of professionals. A clinical nurse specialist role within paediatric complex health needs could promote nursing involvement in these transitions, providing leadership, clinical expertise, education and a communication link between hospital, community and other services. The potential for nurses to act in a key worker role for children with complex health needs is also advocated to improve communication and coordination between services and organisations (Murray & Mahoney, 2012).

It is clear from this review that parents experience difficult emotions during the discharge process. The importance of nurses in providing support and education is also highlighted. While the development of specialist roles is a potential area for improvement, focus on their experiences and priorities is particularly important for all nurses currently encountering these families. Parents identified the value of nurses who can provide emotional support, guidance and understanding of when to refer families for additional support (March, 2017). Nicholl and Begley (2012) emphasise that all nurses whether hospital or community-based should be able to provide parents with information on changing care needs and accessing services.

However, nurses require training and support to enable them to provide these skills effectively. Yet the lack of training being provided

to staff is highlighted by parents, particularly in relation to community nurses. Community nurses explicitly reflect this within their perceptions of their role, describing themselves as poorly educated and trained in complex paediatric care (Law et al., 2011). Therefore, postgraduate training programmes in complex community care are required as a matter of urgency to train existing staff working in this field given the increasing numbers of children with complex health needs being supported by parents in the home. Undergraduate nursing programmes also need to provide theoretical and practical training within community care of complex health needs to prepare future nurses.

The education and support of parents in preparation for discharge were another highlighted need for improvement. This could be enhanced through shared care plans and discharge tools such as discharge checklists completed by nursing staff in conjunction with the family. Families have endorsed engagement in the child's care and discharge process alongside pre-discharge support and coordination as important factors in the discharge of children with complex health needs (Leyenaar et al., 2018). The use of a step-down service within a hospice model reviewed by Price et al. (2017) was also recommended by the Regulation and Quality Improvement Authority (2013) to provide increased education and support for families through its phased discharge home. The use of the hospice framework to facilitate discharges would ensure support for parents while also meeting the social, educational and emotional needs of the child with complex health needs.

## 4.3 | Implications for future research

There is limited research within the area of children with complex health needs and the discharge/transition home. Despite positive results from the four intervention studies, it should be noted that they each displayed wavering methodological adequacy. Quantitative research of methodologically higher quality is required before these interventions could be implemented. Qualitatively, there is a significant focus in the available literature on children with tracheostomies and/or ventilation requirements. More research in children with a range of technology dependencies and other complex health needs is needed to gain a wider view of the discharge experience. The views of the child are also important to ensure a more child-centred approach to care, and this too requires a future research focus. The lack of consensus on an appropriate definition of complex health needs created difficulty in searching the literature. For ease of future literature reviews and in practical terms for allocating services and resources, a clear universally agreed and recognised definition is required.

## 4.4 | Strengths and limitations

The number of children with complex health needs surviving and undergoing recurrent hospital admissions and discharges is rising.

This review has identified important aspects of these processes to guide policy, further education and clinical practice. The low levels of available research were the most significant limitation to this review. No limits were set on the quality of included evidence due to the lack of available papers. This evidently lowers the quality of this reviews' findings. All papers that met the inclusion criteria were included; however, within the reviewed articles, selection and publication bias were not effectively addressed or reported. The multiple definitions of complex health needs also created a limitation. Rigorous efforts were taken to alleviate this by attempting to be as inclusive as possible of terminology used in the literature searching process. However, it is possible that relevant articles were inadvertently overlooked and is an area that requires attention in future research.

## 5 | CONCLUSION

Hospital discharge and the subsequent transition from hospital to home is a complicated and at times frustrating process for parents of children with complex health needs who often report being overwhelmed and stressed during this period. Aspects that could significantly and positively improve the transition home include enhancing communication, coordination and training for parents, nurses and other care staff. This could have a long-term positive effect for the move home and more generally for the daily lives of these families. Considering the growing number of children with complex health needs living longer and being discharged from the hospital environment, there is now a growing opportunity to develop transition plans with the child and parents. Understanding parents' experiences and needs during transition from hospital to home is critical in promoting positive care outcomes for the child and the family. Further research of policy and service development is also required that reflect the support needs of the child, parents and healthcare professionals during transition at a local and service-wide level.

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## CONFLICT OF INTEREST

All authors can declare that there are no conflicts of interest related to this research paper and this paper has not been published or being considered for publication elsewhere.

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#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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