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Reconceptualising children's complex discharge with health systems theory: Novel integrative review with embedded expert consultation and theory development

ABSTRACT

Aim: To report a novel review to develop a health systems model of successful transition of children with complex healthcare needs from hospital to home.

Background: Children with complex healthcare needs commonly experience an expensive, ineffectual and prolonged nurse-led discharge process. Children gain no benefit from prolonged hospitalisation and are exposed to significant harms. Research to enable intervention development and process evaluation across the entire health system is lacking.

Design: Novel mixed-method integrative review informed by health systems theory.

Data Sources: CINAHL, PsychInfo, EMBASE, PubMed, citation searching, personal contact.

Review Methods: Informed by consultation with experts. English language studies, opinion/discussion papers reporting research, best practice, and experiences of children, parents, and healthcare professionals, and purposively selected policies/guidelines from 2002 to December 2012 were abstracted using Framework synthesis, followed by iterative theory development.

Results: Seven critical factors derived from thirty-four sources across 5 health system levels explained successful discharge (new programme theory). All seven factors are required within an integrated care pathway, with a dynamic communication loop to facilitate effective discharge (new programme logic). Current health system responses were frequently static and critical success factors were commonly absent thereby explaining ineffectual discharge.

Conclusion: The novel evidence-based model which reconceptualises 'discharge' as a highly complex longitudinal health system intervention makes a significant contribution to global knowledge to drive practice development. Research is required to develop process and outcome measures at different time points in the discharge process, and future trials are needed to determine the effectiveness of integrated health system discharge models.

250 words

SUMMARY STATEMENTS

Why is this review needed?

- There are increasing numbers of children with complex healthcare needs, many of whom spend too long in hospital waiting for discharge home.
- Hospital to home nursing discharge guidelines have had minimal impact and problems associated with ineffective discharge processes have consistently been articulated at the hospital/home interface.
- There has been no review of the 'transition process' across the entire health system using health systems theory to determine the critical success factors to successful discharge home.

What are the key findings?

- Seven interrelated critical success factors need to be incorporated within a single integrated transition pathway across a 5 level dynamic health system, with an effective communication loop (new programme theory and logic).
- Although treatment advances have been dynamic and enabled these children to survive, the health system response to discharging children home has been less dynamic and in many cases static.
- Critical success factors, an open communication loop, and audit and feedback are frequently absent from the health system, thereby explaining why current discharge processes are ineffective.

How should the findings be used to influence policy/practice/research/education?

- The nurse-led transition process should be reconceptualised as a complex intervention on the highly complex end of the spectrum.
- The theoretical model and new programme theory/logic can be used to underpin intervention and practice development and evaluation.
- Research is required to develop process and outcome measures that accurately capture desired outcomes at different time points in the discharge process, and future trials are needed to determine the effectiveness of different discharge models.

Keywords: integrative review, systematic review, health systems theory, technology-dependent, ventilator-dependent, children, community nursing, complex home care, complex discharge planning, nurse-led care

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INTRODUCTION

Whatever the health system, many children with complex healthcare needs reside in hospital long after they have a medical or nursing need to be there (Elias & Murphy 2012). These children receive little benefit from expensive and unnecessary hospitalisation and suffer harms such as hospital acquired infections, and distress caused by prolonged separation from their families (XXXXXX 2007). Although international definitions vary, irrespective of the child's medical diagnosis, healthcare is generally characterized as 'complex' if including one or more of the following dimensions: management of long-term ventilation, dialysis, parenteral/enteral feeding, a complex drug regime, or a range of other life-sustaining adjunctive technologies (Elias & Murphy 2012). Problems in organising an efficient, child-centred and timely discharge process from hospital to home have been known for over two decades (Goodwin *et al.* 2011).

Compounding inadequacies in discharge processes is the steadily increasing numbers of children with complex needs in high-income countries (defined by World Bank 2013) (Kirk 2008). Recent United Kingdom (UK) population prevalence estimates suggest that 32 per 10,000 children under 19 years have a life-limiting condition and ongoing complex needs (Fraser *et al.* 2012). Children living with long-term ventilator-dependency have increased nearly 10 fold in the UK since 1999, with some geographical areas seeing a 30 fold increase in prevalence since 1994 from 0.2 to 6.7 per 100,000 (Wallis *et al.* 2011). International child health policy has responded to parent and child wishes by shifting focus to community and home-based care (eg TSANZ 2008). Follow-up studies show that children with tracheostomies and positive pressure ventilation have a 5 year survival rate of 89% once home with 25% being decannulated (Com *et al.* 2013), thereby reinforcing the need to discharge these children home to get on with their lives.

Why is a review needed?

To date, barriers to discharge have been consistently articulated at the hospital/home interface from various stakeholder perspectives (see for example, Murray and Mahoney 2012). There has

been no review of the 'transition process' across the entire health system to establish the critical success factors to successful discharge. The purpose of the review is to address this gap.

Philosophical and theoretical frameworks

Family-Centred Care

This universally adopted philosophy recognises the uniqueness of each family, and requires healthcare staff, in partnership with parents, to establish a dynamic, safe and effective care plan (Casey 1988).

Health Systems Theory

We also selected health systems theory to provide a broader context to locate the entire transition process. Health systems theory has been widely used to better understand complex health processes and generally incorporates two sets of concepts: emergence and hierarchy, and control and communication (Ackoff 1971, Putt 1978, Keating 2000, Sturmberg 2004, Anaf *et al.* 2007, Chuang & Inder 2009). A model of the specific health system in its broadest sense is constructed and expressed as a hierarchy of levels. Safety, quality and governance processes are made explicit and viewed as emergent regulatory/control properties of the whole health system (Chuang & Inder 2009). A dynamic health system has interrelated subsystems with open communication loops of information, and governance processes (communication and control). Development of effective practice and governance processes is mediated by safety and quality constraints related to behaviour across the health system components or subsystems. Chuang & Inder (2009, p195) suggest that 'Since control implies the need for communication, reverse communication within the system hierarchy from controlled to controller is required to stimulate system behaviour towards the accepted standard of safety and quality'.

We identified 5 levels of the health system (socio-political, legal and governance, hospital, community, and family) that aligned with the philosophy of family-centred care and interacted with what we conceptualised as a highly complex transition process (Figure 1).

THE REVIEW

Aim

To identify critical components in the 5 level health system, and the barriers and facilitators, and critical success factors, to transition from hospital to home of children with complex healthcare needs. The objectives were to:

1. Set the review parameters by understanding how Irish and international expert professionals conceptualised effective transitioning;
2. Examine selected key policy documents and guidelines to identify key concepts and best practice across 5 levels of the health system;
3. Integrate expert knowledge (objective 1), key concepts and best practice (objective 2) with philosophy of family-centred care and 5 level health system to develop an *a priori* analytical framework;
4. Map evidence from the literature against the *a priori* analytical framework to identify the barriers and facilitators across the health system to successful transition home from a family-centred care and health systems theoretical perspective, and
5. To further refine a health systems model of effective transition from hospital to home.

Design

Scoping the literature indicated a diverse evidence-base written by a small number of clinical experts who have pioneered policy and practice development in this emerging niche area. A mixed-method integrative review design with an embedded international expert consultation (see Figure 2) was selected to enable inclusion of diverse literature that was most relevant to address review objectives (Cooper 1998, Whitemore & Knafelz 2005, de Souza *et al.* 2010).

Where appropriate, we enhanced the rigor of the basic integrative review stages (problem formulation, literature review, data evaluation, analysis and data presentation) by where possible incorporating the same level of systematic data processing as a theory-informed systematic review (multi-disciplinary review team, consulting experts, theory-informed design, involving health information scientist, double independent data processing, quality appraisal, theory-informed data abstraction and synthesis, prolonged engagement to interpret evidence, and theory development).

Problem formulation stage

We consulted with Irish and international experts to help with conceptual clarity, question development and setting review parameters, and developing an *a priori* analytical framework.

Thirteen Irish experts met for a half day with the authors (3 clinical/academic nurse experts and 1 undergraduate nurse student), or were consulted individually in person or by phone, including 1 nurse decision-maker, 1 discharge manager, 1 clinical manager of a Transitional Care Unit, 2 clinical nurses and 8 clinical/nurse academics. Consultation with international experts was conducted individually by video conference or telephone and involved 2 doctors and 1 nurse academic from international centres of excellence in Australia, Northern Ireland and the United States. We justified inclusion of medical doctors as multi-disciplinary team members.

We explored the following broad questions as part of the conversation and made notes of responses:

1. How do experts conceptualise the problem of transitioning children with complex healthcare needs from hospital to home?
2. What constitutes international best practice in transitioning children with complex healthcare needs from hospital to home?

There was general consensus that successfully transitioning children with complex needs from hospital to home was a global problem in high-income countries.

Search methods

We used the SPICE Framework (Figure 3) to refine objectives, inclusion criteria and search strategy (Figure 4) (Booth 2004). CINAHL, PsychInfo, EMBASE, and PubMed were searched for the last 10 years to ensure a reasonably contemporary lens. Reference lists were unpicked and potentially relevant articles screened. As academic nurses working in this field, we drew on our expert knowledge and practice, supplemented by internet searching to identify and purposively select relevant policies/guidelines with support from experts.

Search outcome

See Figure 5 for the flow of literature through the review. See Table 1 for included studies, and supplementary information file 1 for excluded studies.

Quality appraisal

Findings drawn from well-conducted studies were regarded as more dependable (Lincoln & Guba 1985). We therefore appraised how well empirical studies were conducted (data evaluation) using appropriate versions of the Critical Appraisal Skills Programme (CASP) quality-assessment tools (CASP 2010). We sought to corroborate opinion and best practice with empirical evidence as an indicator of reliability and validity. Guidelines were appraised using AGREE criteria (AGREE 2013). See supplementary Information file 2 for the outcome of the quality appraisal process.

Data abstraction and synthesis

Integrative review methodology is generally unclear about methods for data abstraction and synthesis. We took a pragmatic decision to process the evidence by methodology/type and interpret by perspective (parent, child, healthcare professional – Figure 5). We used the “Framework” synthesis approach (Ritchie & Spencer 1994) as it has been used successfully for analysis of mixed-method health systems policy oriented primary research (Rashidian *et al.* 2008, Jafari *et al.* 2011) and in qualitative systematic reviews (XXX 2007).

Developing an a priori analytical framework

A preliminary *a priori* framework (Figure 1) was developed in stages and discussed in a series of team meetings. It was not feasible or desirable to search for all relevant global policy and guidelines from high income countries. We made a pragmatic decision to use our expert knowledge to purposively select three key UK, and one Australian/New Zealand policies/guidelines and extracted an initial composite set of seven critical success factors and associated components to successful transition home across the 5 level health system (XXX 2005, TSANZ 2008, DHSS 2009, DH 2010). There were common evidence links between documents - see Table 2. The composite critical success factors were as follows:

- Effective health and multi-agency agreements and funding arrangements within and across the health system
- Robust clinical governance, quality and safety policies
- Effective discharge planning procedures

- Appropriate and effective home care package
- Key worker: individually-tailored family support and education
- Accessible accommodation equipment and transport
- On-going hospital/community interface

See Figure 1 for the subcomponents of the composite critical success factor.

To ensure international relevance, we then mapped UK and international clinical, experiential, and empirical expert knowledge derived from the consultation exercise onto the initial seven composite critical success factors. There was high level consensus and no additional critical success factors were identified. We then mapped the seven composite critical success factors (themes) and associated sub-components (sub-themes) of a successful transition from hospital to home, against 5 levels of health systems theory (socio-political, legal and governance, hospital, community, family) to develop an *a priori* analytical framework to map barriers and facilitators of a successful transition home in selected literature (Figure 1).

The initial *a priori* analytical framework (Figure 1) was checked against the primary studies, policy, opinion and best practice documents through a process of reading and rereading (familiarisation) (Table 1). All included studies and documents were read until no new sub-themes emerged. Agreements were reached on the definition and boundaries of each theme identified across the health system.

The text of each document was then indexed by 2 people, using codes relating to themes and sub-themes of the thematic framework (Figure 1). Consensus was sought amongst reviewers. Sections of text were indexed with one or more codes (cross-indexing) wherever appropriate. Evidence aligned with themes and sub-themes was transferred to analysis tables ('charts'), so that columns and rows reflected the studies/documents and the sub-themes (Miles & Huberman 1994).

FINDINGS

Evidence contributing to each critical success factor across the health system is shown in Table 2. By synthesising and mapping evidence against the *a priori* framework it was then possible to

move beyond single studies and synthesised themes to develop theory that incorporated expert observation/interpretation to create what Britten *et al* (2002) call third order constructs – that is new synthesised observations, hypotheses and explanations derived from a theory-informed process that were not inherent in single studies. The analytical model underpinning this process is shown in supplemental file 3. As children’s discharge is almost entirely conceptualised as a movement from hospital to home in single studies, findings are mainly presented as third order constructs.

Mapping the entire dataset against the a priori framework in Table 2 enabled development of a new programme theory and logic (how an intervention is intended to work and its component parts). Seven interrelated critical success factors need to be incorporated within a single integrated transition pathway across the 5 level health system, with an effective communication loop, for transition home to be optimised and effective (see theoretical model in Figure 6 and component elements in Figure 1).

Table 2 shows that no studies took account of all critical success factors across the health system and only two studies addressed 6/7 factors. Importantly, guidelines (eg. xxx 2005) indicate that the transition process cannot complete unless joint financial agreements are in place across the health system to fund resources for home care. Key working (a designated coordinator) is also essential for overseeing the entire transition process and ensuring a communication loop across the health system. The communication loop is however frequently incomplete with policy makers (controllers) at one end of the hierarchical health system not in contact with outcomes or feedback of children/parents (the controlled) at the other, so little quality improvement is achieved. When a continuous governance/control and communication loop across the 5 level health system components is not present or ineffective, as commonly seems to be the case, parents (the controlled) frequently turned outside the health system to the media, political representatives, or judicial review in a court of law as levers for action as they can see no other way of getting the health system to respond (xxx2002).

Despite socio/political policy intentions for development of emergent properties within the health system to achieve a seamless and safe process (eg. XXX 2005), the hospital to home transition is more often conceptualised as discharge from a to b with defined boundaries and separate organisational regulation and control arrangements (xxxx 2002, Kirk and Glendinning

2002, 2004, Tommet 2003; Margolan et al 2005; Law et al 2011; Manhas and Mitchell 2012; Nicholl & Begley 2012). Only two studies included the views of children, which confirmed children's desires to be at home and their frustration that the process took too long (XXXX 2002,2006) .

Safety concerns and the need to control and regulate (ie prevent the child going home) primarily arose from not having agreed financial arrangements in place for continued safe care at home. Many children are not discharged home because it was not considered by professionals (or sometimes parents) safe to do so. Safety concerns relate to the absence of, or incomplete, governance and discharge processes and/or attributes required (training/equipment/sufficient carers etc) to safely care for the child at home (Kirk and Glendinning 2002; Tommet 2003; Kirk et al 2005; Margolan et al 2005; Manhas and Mitchell 2012; Nicholl & Begley 2012). Control and regulation over whether the child would be safe or not at home is not however consistently linked with resolving the inefficiencies in the transition process and the 'default option' is the status quo with the child remaining in a place of safety ie. hospital.

In the following sections empirical evidence and hypotheses are mapped against the seven critical success factors and health system levels and explored in more detail.

Effective health and multi-agency agreements and funding arrangements within and across the health system

This factor has already been flagged as the key to the overall transition process and unless agreed policies and funding arrangements were in place across the health system it was not possible to discharge a child within a reasonable time. Within a family-centred care context, prolonged hospitalisation meant that parents were often prohibited from responding adequately to their child and wider family as they could not be in two places at once. Moreover, they were often faced with changes in employment status that created additional stress. (Hewitt-Taylor 2005; Kirk and Glendinning 2004 Law et al 2011; Margolan et al 2005; Noyes 2002; Tommet 2003).

Robust clinical governance, quality and safety policies

Explicit mention of accountability is largely missing in studies with the exception of Kirk et al 2005, Manhas & Mitchell 2012 and xxx 2002. Quality assurance/control processes were observed to be missing across all levels of the health system – some were the responsibility of nursing and some were political, corporate or financial. Appropriate shared legal, risk management and quality assurance processes were frequently inadequate or inappropriate to guide and protect the process of transition, and to ensure protection of parental rights and clinical governance of carers. From a nursing perspective, this emergent property was incomplete and lack of clarity and consultation still persisted regarding the roles, scope of practice, responsibilities, competences, supervision and monitoring of nurses, trained carers and parents. This lack of clarity between controller(s) and controlled (parents, children, carers) had a negative impact on parents (eg. frustration, anger, confusion) who reported they received inconsistent/inappropriate care package assessments, information, training and supervision, and had to navigate the different cultures and inconsistent clinical governance arrangements and practices between hospital and home.

Effective discharge planning procedures

Organising the process of discharge and follow-up care as a continuous unified process and communication loop across the health system had a direct and positive effect on the ability of families to care for their child at home (eg. confidence, shared skills, coordinated support). The need for a cohesive and joint approach across health system levels reflects the interdependency between all levels. The development of clear and shared policies and assessment/discharge protocols, in consultation with key stakeholders and parents, was consistently identified as essential to enable seamless and anticipatory care of the child and family across different levels of the health system (eg XXX 2005). Many parents however identified specific barriers to effective discharge including lack of joined up thinking, poor management, lack of a co-ordinated approach to undertaking assessments and addressing complex social and psychological issues, lack of inter-agency planning, and lack of discharge guidelines and streamlined processes (Law et al 2011, Margolan et al 2004, Nicholl & Begley 2012, Toly et al 2012 ab). The lack of co-ordinated and anticipatory care in part stems from hospital and community based nurses (and in some contexts where doctors lead care such as the United States) not being adequately involved in discharge planning, and not having appropriate clinical skills to provide safe and competent care (Hewitt-Taylor & Farasat 2006, Farasat and Hewitt-Taylor 2007). An effective communication

loop from the child's hospital bedside back to the socio-political level is not yet in place to address these issues.

Many parents said they felt inadequately prepared during their first months at home (Margolan et al 2004, Nicholl & Begley 2012) thereby highlighting further weaknesses in the system hierarchy and emergence of appropriate support and governance procedures, and control and communication across the health system. Parents were unclear what to expect at home, they received insufficient support and information on how to access key services, were often unclear about their expected level of participation in care and could be unclear about how to address any changing condition of their child (Margolan et al 2004, Nicholl & Begley 2012). When parents were inadequately prepared, they were less able to cope with fluctuations in their child's condition, which could mean that the child was readmitted to hospital and a second discharge process was required.

Appropriate and effective home care package

Agreeing on an appropriate care-package is highly challenging and often highly contentious if parents (controlled) cannot agree with assessors and budget holders (controllers). Organising an appropriate and effective care package was dependent on many people, their competence and behavioural responses and completion of activities in various levels of the health system. For example, even if joint finances and a care package had been agreed, recruiting, training and retaining appropriate community-based carers remained problematic and frequently outside the control of the child's hospital care team (Kirk & Glendinning 2004; Margolan et al 2004; Noyes 2002).

Clinical training in complex care should be addressed by professional development of trained carers and undergraduate and postgraduate children's community nurses, but as yet this does not consistently happen (Law et al 2011; Farasat & Hewitt-Taylor 2007). To resolve these human resource issues, there needs to be support at the socio-political level, the interdependency between community, hospital and socio-political levels of the health system needs to be better understood, and an effective feedback loop established.

Although community-based services have increased for children with complex care needs, in particular with the introduction of trained carers, regional variation remains (Hewitt-Taylor & Farasat 2006). Parents frequently provide substantial amounts of care and they require individual training programmes to do this, which according to parents, varied in quality. Once experienced and highly competent in their child's care, mothers were however eager to stress that they knew their child best and this influenced their trust in 'handing-over' to any carer/nurse perceived to be not as capable as themselves (Kirk & Glendinning 2004; Law et al 2011; Margolan et al 2004; Nicholl & Begley 2012; Noyes 2002). Parent carers were often seen on the margins of this particular care-delivery controller/controlled communication loop or sometimes outside it, with the loop being interpreted by professionals as hierarchical and concerned with clinical governance and monitoring parents rather than including them.

Key worker: individually-tailored family support and education

A single key worker/discharge coordinator/case manager is conceived as the person to facilitate a co-ordinated approach across all health system levels, and the point of advocacy for families (eg xxx 2005). It is the key worker's role to create a communication loop across all health system interfaces. If funding is agreed a single key worker is then able to create, quality assure and coordinate discharge processes more effectively. In reality, families commonly did not have access to a key worker and individual organisations and services across the health system had their own lead practitioner systems with many practitioners inexperienced in complex discharge management, (Kirk and Glendinning 2002,2004, Kirk et al 2005, law et al 2011; Manhas & Mitchell 2012; Noyes 2002), which meant that everyone was controlling their own bit of the process with little account of the bigger hierarchical system or what others were doing (ie competing controllers). Transition frequently became a competing and adversarial process between professionals and organisations within the health system.

A significant and inadequately addressed aspect of supporting families through the transition process across all levels of the health system was recognising the potential emotional and social impact on the child, siblings and parents (Toly et al 2012 ab). Physical or mental ill health in family members can induce partial or total disengagement from the process or being able to care for their child. Linked to mental health and wellbeing, a common stressor expressed by parents

was a deficit in the quality and consistency of training to care for their child (ie. another insufficiently developed emergent property) and the negative impact on their ability to cope (eg Kirk & Glendinning 2002)

Accessible accommodation, equipment and transport

There is an inter-dependency that is frequently not acknowledged or addressed between the socio-political and hospital community interface from initial identification of equipment requirements to final instalment, follow-up, and trouble-shooting. Procurement of the most cost-effective equipment and service contracts and especially adaptation to housing is noted but frequently located outside the more narrowly defined health systems described in the literature. Nonetheless, children are dependent on organisations responsible for these aspects of their transition to be part of the health system and included in the communication loop. When this is not the case, parents report problems with long waiting times for equipment such as ventilators, inappropriate housing such as lack of accessibility, damp interiors and lack of adaptations such as hoists and fittings (Kirk & Glendinning 2002,2004; Margolan et al 2004; Noyes 2002). Inadequate housing means delayed discharge, with delays sometimes instigated by parents who refuse to take their children home until their perceived housing needs have been addressed, whilst other parents are forced to wait due to slow contractors and additional bureaucratic processes both inside and outside of the health system. Those parents that go home quickly are inevitably those who already have an accessible house or are willing to go home with minimal adaptations and are sufficiently flexible and able to reorganise existing accommodation until further adaptations can be completed over time.

On-going hospital/community interface

There is often a disregarded or insufficiently understood emergent property concerning nursing communication at the interface between hospital, socio-political, legal and governance, and community levels of the health system. Hospital practice is frequently different, or not applicable, to home-based practice and parents disliked the lack of continuity, inconsistent governance, confusion and distrust this caused. A dynamic and trusting relationship and communication loop between home, community and hospital is critical, but often individuals and organisations were set up to be competing and distrustful and did not see themselves as being part of the bigger health system that the child depends upon for successful transition home.

Children's and parents experiences of coordination and communication across the health system were often poor and sometime dire (Margolan et al 2004 Nichol & Begley 2012). Examples of facilitating positive interdependent communication in a continuous loop included shared protocols, and accurate and clear documentation, but frequently this did not happen.

DISCUSSION

The robustness of the synthesis was confirmed by key members of the expert consultation group. A two way continuous audit and feedback loop from controller to controlled was missing from the literature so we added this as a sub-theme to Figure 1, and recommend its implementation in practice. Findings are significant in that for the first time a programme theory containing critical success factors for successful transition home are reconceptualised in the context of a 5 level dynamic health system as opposed to the usual hospital/home discharge interface. The interplay and interdependence between levels, success factors and components, and the importance of effective emergent properties and a two way dynamic communication loop for continuous service improvement are made explicit. Findings show what an effective and dynamic health system in the context of children's complex transition from hospital to home looks like (Figures 1 and 6). Plausible hypotheses and explanations are given as to why discharge is prolonged and what needs to be done to resolve these static issues. Additional validation of findings is provided by studies of ongoing care at home, which identify persistent unresolved care-coordination problems (Carter 2005, Carter *et al.* 2007, Heaton *et al.* 2005, Hewitt-Taylor 2008ab, Miller *et al.* 2009, Hobson & xxx 2011, Kuo *et al.* 2011, Woodgate *et al.* 2012).

The new model of a successful transition provides a practical understanding of how transition as a complex, interrelated and longitudinal health system process ideally works. The health system model (Figures 1 and 6) in combination with review findings provides greater conceptual understanding of the key components, active ingredients, and behavioural mechanisms for use in future research and practice development, against which tangible processes and outcomes can be measured (programme logic). At a time of increased fiscal restraint a leaner and more co-ordinated approach encompassing the 5 levels of the health system is needed to make the entire process more dynamic and effective.

Of particular significance, the primarily nurse-led transition process for this group of children has not yet been described adequately in the nursing literature as a highly complex and potentially

high risk intervention as conceptualised by the Medical Research Council Framework for designing and evaluating complex interventions (Medical Research Council 2000, XXXX 2007b, Craig *et al.* 2008). In reality, this nursing intervention is one of the most complicated, educational, behavioural, longitudinal, and multifaceted interventions to be implemented across a series of complex organisations in which people and teams are interdependent as well as independent and success is reliant on many people in different contexts and their behavioural responses. In the following sections, we discuss the findings in relation to the complex intervention and complexity literature.

Due to the relatively small number of children, discharge management to date in this context can generally be viewed as a product of self-organisation by a few key nurses taking the lead with adaptation and evolution over time of as yet insufficient emergent properties such as high quality parent training programmes and robust clinical governance processes (De Savigny & Adam 2009). Nurses primarily manage the transition process, which is particularly complex as it has a high degree of non-linearity in that components cannot be neatly arranged in sequential line, which makes development of a detailed care pathway challenging (De Savigny & Adam 2009, Hawe *et al.* 2009). Most importantly, the desired end point of the transition process – being discharged to safely at live at home - has high symbolic value for parents and children over and above the individual component parts of the process. Children and families require an individually-tailored process and dynamic discharge plan that is responsive to their needs. Facilitation of the transition process requires high level skills to enable a high degree of flexibility and tailoring for individual families, but there is a nursing skills deficit across the health system that can prevent this from happening (Craig *et al.* 2008, Hawe *et al.* 2009).

There are obvious positive and negative synergies and connectivities between health system levels, involving different cadres of staff, different organisations, parents and children, which as yet are not well understood (Campbell *et al.* 2000). We found that there are multiple mediators and moderators of a successful transition process, such as the capabilities and willingness of parents, and suitability of the home environment of the child and family (Emsley *et al.* 2010). In addition, interaction outside the health system is very important as additional capabilities can be created from this interaction (such as parents using litigation, their political representative or media to get the resources to safely discharge their child).

It is evident that the entire transition process is very susceptible to the positive and negative impact of different contexts (change of staffing, professional relationships, quality of leadership, introduction of new policy, new funding arrangements, wider economic stability, mental health and wellbeing of parents, geographical distance etc). Nonetheless, over time we are gaining a better understanding of the emergent properties and multiple outcomes from the transition process as a longitudinal complex intervention, including discharge home to parents, foster carers, adoptive parents or long term residential care, failure to discharge, and less commonly death before discharge due to the underlying medical condition or hospital acquired infection etc.

Largely absent from the entire transition process are feedback loops where changes in behaviour create the conditions for further behaviour change, such as development of best practice in one health system resulting in spread of best practice to neighbouring health systems, which means more nurses become experienced in managing the process, which means that timely discharge becomes the norm thereby encouraging more nurses to become skilled in now routine complex discharge processes (Galea *et al.* 2010, XXXXX *et al.* 2013). Change in any complex and large health system that involves a number of different organisations, interfaces with external bodies and communication between different stakeholders is however known to be challenging. Taking the UK and Irish health systems as typical examples, they have a range of different stakeholders, complex ownership and finance and resourcing arrangements, and professional autonomy of many cadres of staff (Pollitt 1993, Dawson 1999). Recent work in this area provides additional evidence about how best to implement policy interventions in contexts where the population is small and geographically dispersed and the nursing skill base is low and concentrated in a few centres of excellence (XX *et al.* 2013; Brooks et al 2013).

A dynamic health system is one that continuously influences and changes its environment and is being influenced and changed by its environment (Chuang & Inder 2009). Although children's acute and intensive care components of the health system have been generally dynamic in advancing the medical interventions and nursing care that enabled these children to survive, the service delivery and organisational response to enable these children to live at home has been far less dynamic and in many cases static (Hawe *et al.* 2009).

Finally, any review of this type has some features that need to be made transparent. We found no trials of discharge interventions or models, thereby confirming the appropriateness of an integrative design. We aimed to be comprehensive but not exhaustive in searching for relevant literature. There may be a negative publication bias in that studies are less likely to be conducted if transition is working well. Evidence was limited to studies and documents published in English, which inevitably introduces a language and context bias. The quality of included empirical evidence was variable with notable examples of higher quality studies (see Supplemental file 2). Findings were consistent across studies and contexts and therefore a high degree of certainty can be placed in the plausibility of findings. Opinion evidence was consistently corroborated by empirical evidence.

CONCLUSION

Evidence-based practice should underpin how hospitals and community organisations tasked with implementing hospital to home transition processes within a wider health system continually evolve as dynamic and not static organisations. This review contributes significant and new evidence by defining the components of a transition process for children with complex needs as a highly complex intervention across a dynamic health system, and developing new theory to underpin further intervention development, implementation and evaluation. The highly complex intervention to achieve children's transition from hospital to home needs to be understood from a health systems perspective and has potential for greater standardisation to focus on correcting the deficits in current processes highlighted in this review. Research is required to identify clinical indicators and outcome measures that accurately capture desired outcomes at different time points in the discharge process. Well designed randomised controlled trials and cohort studies are needed to test different transition interventions and implementation strategies to improve outcomes for children with complex healthcare needs and their families.

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Table 1. Included studies, evaluations, opinion papers and policy documents/guidelines best practice documents.

	Author & Context/Country	Focus	Evidence type/Methodology
Policies and guidelines used to develop a priori framework			
1	XXXX & Lewis (2005) Government supported discharge guidance, UK	Guidance on discharge management and community support. Care pathway and ongoing care management of a child requiring long-term ventilation.	Policy document and clinical guideline.
2	XXXXX (2007a) Discharge guidance, UK	Discharge management for children with complex needs. Best practice and evidence-based principles and procedures.	Journal article based on XXXXX 2005
3	XXXX (2007) Care package development, UK	Compiling costing and funding complex packages. Child with complex needs transitioning to community care.	Journal article based on XXXXX 2005
4	Thoracic Society of Australia & New Zealand (2008) Policy document	Principles of care for children requiring long term ventilation	Policy - recommendations on level of service provision
5	Department of Health Social Services and Public Safety (2009) Northern Ireland	Organisation of services to children and young people.	Description of integrated pathway and assessment tool for identifying and addressing needs of children and young people with complex healthcare needs.
6	Department of Health (2010) Government interagency policy, and policy impact evaluation UK	Framework for children's and young people's continuing care. Organisation of continuing care services.	Description of framework for assessing, deciding and agreeing packages of continuing care for those under the age of 18 who have continuing care needs. Includes pilot evaluation – subsequently published as a journal article outside the review period XXXXX et al 2013
Empirical studies, service and education evaluations			
7	Cady <i>et al.</i> (2009) Home care, USA	Tele health nursing intervention - impact on rehospitalisation of children with complex needs.	Service evaluation. Retrospective record review of 43 children with multiple, complex conditions.
8	Gordon <i>et al.</i> (2007) Service evaluation and model development, USA	Model for medically complex and fragile children. Impact of care coordination.	Service evaluation. Measured re hospitalisation pre and post the establishment of care coordination of 230 medically complex and fragile children and youth.
9	Haney <i>et al.</i> (2012) Post discharge communication/ USA	Impact of a nurse-established and nurse-managed electronic communication on the well-being of parent's caring for medically fragile (technology-dependent) children.	Quasi-experimental pre- and post-test design. 19 parents/caregivers
10	Hewitt-Taylor (2005) Homecare, UK	Education needs of staff caring for children with complex needs	Pilot study – education evaluation
11	Hewitt-Taylor & Farasat (2006) Professional education UK	Developing education opportunities for undergraduate students	Pilot study – education evaluation
12	Farasat & Hewitt-Taylor (2007) Education UK	Developing education opportunities for undergraduate students	Pilot study- education evaluation.
13	Kirk & Glendinning (2002)	Experience of parents and professionals caring for technology-	Interviews with 33 parents of 24 children and 44 professionals

	Professional support UK	dependent children	
14	Kirk <i>et al.</i> (2005) Homecare, UK	Parents experiences of caring for a child who is technology-dependent.	Grounded theory – experience of parents of 24 children.
15	Kirk & Glenndinning (2004) Homecare, UK	Developing services to support parents. Exploring experiences and needs of parents and examine how they are currently being met.	Parents of 24 children, 44 interviews with health, social care and other professionals.
16	Klitzner <i>et al.</i> (2010) Care co-ordination model, USA	Medical home project in resident teaching clinic. The integration of comprehensive care coordination for children with complex care needs.	Service evaluation – Retrospective analysis 30/43 family encounters with services pre and post an enhanced integrated care service.
17	Law <i>et al.</i> (2011) Community care, UK	Managing care of children with complex needs. Perceptions of nurses and allied health professionals.	Telephone interviews and focus groups with 6 nurses and 12 allied health professionals.
18	Manhas & Mitchell (2012) Ethical perspective, Canada	Challenges of the experience of transition to pediatric home care. Roles and accountability of individuals at time of transition.	Interviews with 26 members of hospital team, home team and family members.
19	Margolan <i>et al.</i> (2004) Homecare, UK	Parental experiences of services when child requires long term ventilation. Families experiences of services, description of care packages, identification of problems and good practice.	Cross-sectional survey and interviews with 15 families.
20	Nicholl & Begley (2012) Homecare, Ireland.	Mothers' experiences of caring for a child with complex care needs.	Interviews with 17 mothers.
21	XXXX(2002) Hospital Discharge, UK	Barriers delaying ventilator-dependent children from being discharged. Experience of children and young people dependent on ventilators, and their parents.	35 interviews with 18 children and young people age 6-18 years , 25 interviews with parents of 15 young people.
22	Xxxx <i>et al.</i> (2006) Economics of hospital and home care, UK.	Resource use and service costs for ventilator-dependent children. Cost of supporting the care of ventilator-dependent children and young people in hospital and at home.	35 index cases age 1-18 years and cost-consequences study. Interviews with index children over 6 years and parents.
23	Toly <i>et al.</i> (2012a) Home care USA	Families with children who are technology dependent. Relationship between a child's severity of illness, mother's depressive symptoms, and normalisation efforts in families.	Descriptive, correlational, cross-sectional study. 103 mothers caring for a technology-dependent child.
24	Toly <i>et al.</i> (2012b) Homecare, USA	Longitudinal study of families caring for technology-dependent children at home.	Quantitative observational study of family functioning and normalisation in 82 mothers.
25	Tommet (2003) Home care, USA	Experiences of families with children who are medically fragile.	Interviews with five families.
Case studies, practice development, discussion, expert opinion papers			
26	Brombley (2008) Discharge planning, UK	Children with acquired brain injury	Case study/opinion.

27	Elias & Murphy (2012) Discharge practice, USA	Discharge of children and youth from hospital to home. Home care of children and youth with complex health care needs.	Discussion of best practice.
28	Hewitt-Taylor 2012 Professional education, UK	Education for community nurses on transition of child from hospital to home	Evidence-based education – best practice.
29	Kertoy (2004) Professional development, Canada	Preparing professionals for the challenge of caring for children who are technology dependent. Improving emotional and social supports for parents and families.	Discussion paper on best practice. No overlapping cited papers.
30	Murphy (2008), Discharge practice, UK	Challenges of discharging children from PICU	Discussion paper
31	XXXXX (2011) Ventilator-dependent children, Global overview	Increasing numbers of ventilator-dependent children. Challenges for practice.	Editorial – opinion.
32	Samwell (2012), Discharge practice, Scotland	Journey of a child with complex care needs.	Discussion of case study
33	Stephens (2005) Discharge practice, UK	Complex care packages. Discharge of child with complex needs.	Development of framework for discharge.
34	Wright (2006) Discharge management, USA	Personal experience of discharge management.	Case study of one family.

Table 2. Evidence from policies/guidelines, studies, evaluations, practice development and opinion papers (showing participant perspectives), supporting each critical success factor.

Effective Health & Multi-Agency Agreements & Funding Arrangements	Robust Clinical Governance, Quality & Safety Policies	Effective Discharge Planning Procedures	Appropriate & Effective Home Care Package	Key worker: Individually tailored Family Support & Education	Accessible Accommodation, Equipment, and Transport	On-going Hospital & Community Interface	Comments
Policy/Guidelines used to develop a priori framework							
XXXX2005	XXXXX2005	XXXX 2005	XXXX 2005	XXXX 2005	XXXX 2005	XXXX 2005	National UK discharge guidance and care pathway for children with long-term ventilation
XXXX 2007		XXXX 2007	XXXX 2007	XXXX 2007			Journal article derived from XX 2005
XXXX 2007	XXXX 2007	XXX 2007		XXXX 2007	XXXX 2007	XXXX 2007	Journal article derived from XX 2005
Thoracic Society of Australia & New Zealand 2008	Thoracic Society of Australia & New Zealand 2008			Thoracic Society of Australia & New Zealand 2008	Thoracic Society of Australia & New Zealand 2008		National Australia and New Zealand consensus guidance and care pathway for children with long-term ventilation Draws on XXX 2005
Dept of Health, Social Services & Public Safety, 2009	Dept of Health, Social Services & Public Safety, 2009	Dept of Health, Social Services & Public Safety, 2009	Dept of Health, Social Services & Public Safety, 2009	Dept of Health, Social Services & Public Safety, 2009	Dept of Health, Social Services & Public Safety, 2009	Dept of Health, Social Services & Public Safety, 2009	National Ireland and Northern Ireland policy and care pathway – based on Department of Health 2010
Dept of Health 2010	Dept of Health 2010	Dept of Health 2010	Dept of Health 2010	Dept of Health 2010	Dept of Health 2010		Children’s Continuing Care Framework, England – developed by overlapping author/advisory team as in XXX 2005
Empirical studies, service and education evaluations							
KEY * service/education evaluation; + parent perspectives; ~ children’s perspectives; # healthcare professional perspectives							
							Cady <i>et al.</i> 2009*
							Gordon <i>et al.</i> 2007*
							Haney & Tufts 2012+
Hewitt-Taylor 2005*#			Hewitt-Taylor 2005*#				

		Hewitt-Taylor & Farasat 2006 *# Farasat & Hewitt-Taylor 2007*#	Hewitt-Taylor & Farasat 2006*# Farasat & Hewitt-Taylor 2007*#				
Kirk & Glendinning 2004+			Kirk & Glendinning 2004 +	Kirk & Glendinning 2002 +# Kirk & Glendinning 2004+	Kirk & Glendinning 2002 +# Kirk & Glendinning 2004+		
	Kirk <i>et al.</i> 2005 +			Kirk <i>et al.</i> 2005+			
		Klitzner <i>et al.</i> 2010*				Klitzner <i>et al.</i> 2010*	
Law <i>et al.</i> 2011# +		Law <i>et al.</i> 2011# +	Law <i>et al.</i> 2011#+	Law <i>et al.</i> 2011#+		Law <i>et al.</i> 2011#+	
	Manhas & Mitchell 2012#			Manhas & Mitchell 2012#			
Margolan <i>et al.</i> 2004+		Margolan <i>et al.</i> 2004+	Margolan <i>et al.</i> 2004+	Margolan <i>et al.</i> 2004+	Margolan <i>et al.</i> 2004+	Margolan <i>et al.</i> 2004+	
		Nicholl & Begley 2012+	Nicholl & Begley 2012+	Nicholl & Begley 2012+		Nicholl & Begley 2012+	
Noyes 2002~+	Noyes 2002 ~+	Noyes 2002~+	Noyes 2002~+	Noyes 2002~+	Noyes 2002~+		
			Noyes <i>et al.</i> 2006~+				
		Toly <i>et al.</i> 2012 a & b+		Toly <i>et al.</i> 2012 a & b+		Toly <i>et al.</i> 2012 a & b+	
Tommet 2003				Tommet 2003 +			
Case studies, practice development, discussion, expert opinion papers KEY ◊ Case study, ^ practice development, ®discussion, ∞ expert opinion							
Brombley 2008^∞		Brombley 2008∞	Brombley 2008∞				
		Elias & Murphy 2012^∞	Elias & Murphy 2012^∞	Elias & Murphy 2012^∞	Elias & Murphy 2012^∞	Elias & Murphy 2012^∞	
		Hewitt-Taylor 2012^∞	Hewitt-Taylor 2012^∞			Hewitt-Taylor 2012^∞	
			Kertoy 2004^				
Murphy 2008®		Murphy 2008®	Murphy 2008®				
		Noyes 2011 ∞	Noyes 2011 ∞				
Samwell 2012∞		Samwell 2012 ◊∞	Samwell 2012∞	Samwell 2012∞	Samwell 2012∞	Samwell 2012∞	
Stephens 2005^		Stephens 2005^	Stephens 2005^	Stephens 2005^	Stephens 2005^	Stephens 2005^	
		Wright 2006∞					

Figure 1. 7 Critical success factors mapped against 5 level Health System to account for successful discharge home.

5 Health System Levels	7 Critical success factors for a successful transition from hospital to home (themes)						
	Effective health and multi-agency agreements and funding arrangements	Robust clinical governance, quality and safety policies	Effective discharge planning procedures	Appropriate and effective home care package	Key worker: individually-tailored family support and education	Accessible accommodation equipment and transport	On-going hospital/community interface
	Essential (critical*) subcomponents (subthemes)						
Socio-political Government, policy, culture, leadership, and economics etc that may affect transitioning to home of child and family	Agreed multi-agency continuing care /discharge policy across all organisations*	Legal framework	Skilled nurse-led discharge - Community-lead	Adequately resourced, effective, outcomes based on child and family needs and preferences	Parent/family capacity – alternative to parental care if appropriate	Housing – accessible and appropriate	Effective Public Health/children’s community nurse/GP interface
			Doctors with appropriate skills to facilitate and maintain successful discharge	Culturally sensitive		Equipment	
Legal and governance Legal and governance framework applied to children and families, care organisation and delivery	Agreed budget policy and guidance for access / multi-disciplinary funding decision forum across entire health system*	Risk management policy	Documented detailed assessment procedures, protocols and single integrated discharge care pathway	Personal budget and guidance (option – dependent on health system)	Competency-based education parents and family members	Supplies	Co-ordinated medical follow-up and review
		Quality assurance policy	Person /Family centred philosophy	Available and appropriately trained workforce in the community		Parent and sibling support, emotional, financial, extended family	Transport
Hospital Care centre from which the child and family is discharged to home	Working agreements across multi-agencies*	Complaints policy	Single Key worker*/discharge coordinator/multi-agency liaison	Key worker			Ongoing updating of care protocols
Community Primary care environment in to which the child is discharged and subsequently lives, including housing, schools and leisure			Multi-agency needs-based assessment	Competency-based education and preparation for carers			
	Family Parents / guardian, siblings and extended family	Effective communication within and across boundaries across the entire health system *	Whole system audit and feedback – two way (*added post review)	Assessment toolkit	Protocol-based care – nurse led	Short-break flexibility	
Clear pathway/process to obtain funding				Care package delivered as anticipated			
			Timelines - Fast tracking (if appropriate)	Regular review/flexible			
			Transparency	Appropriate readmission procedure			

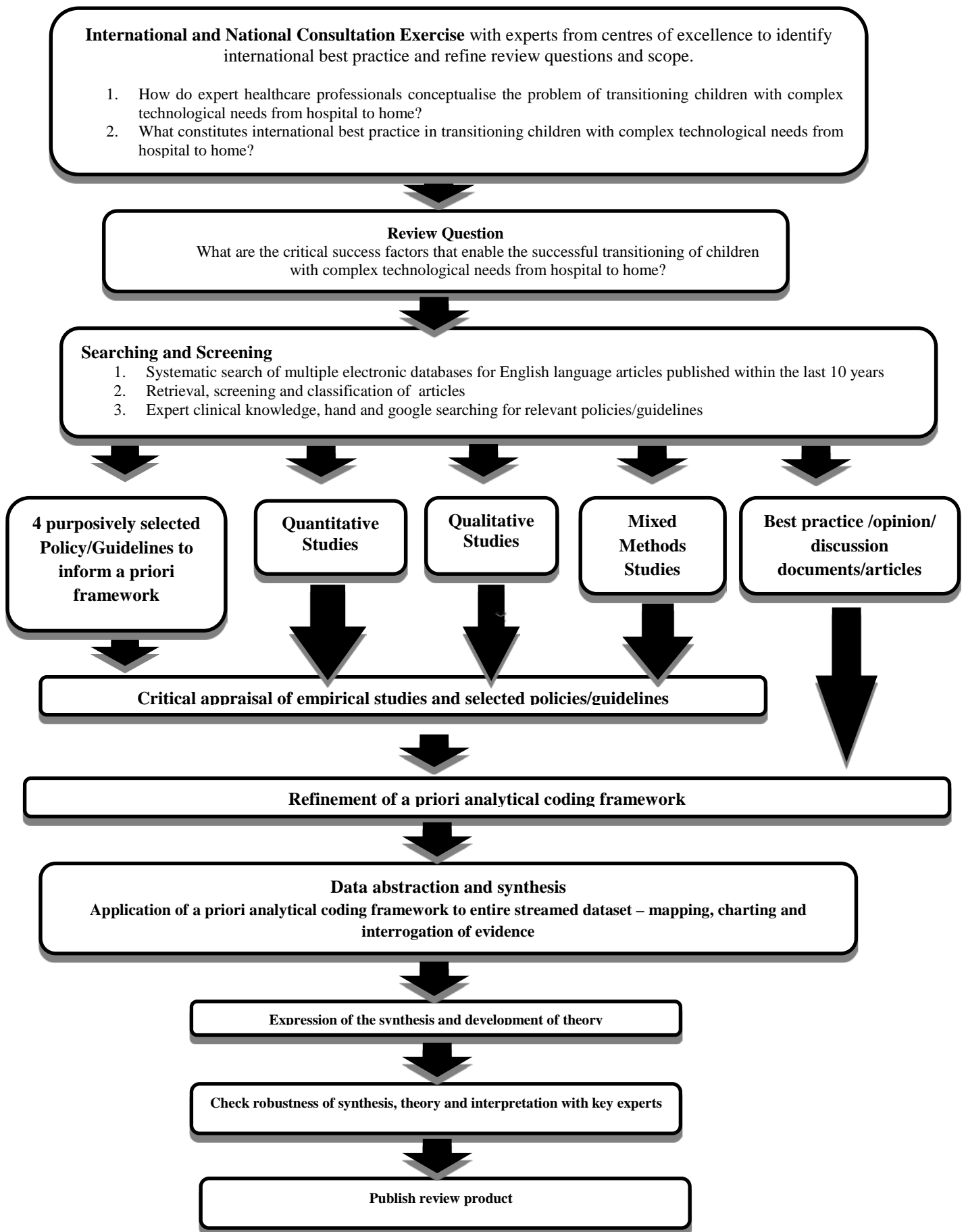


Figure 2. Mixed-method integrative review design with embedded expert consultation and theory development.

Figure 3. SPICE Framework and inclusion criteria

Setting: Care of children with complex healthcare needs in high income countries under eighteen years of age. Hospital (any type) and home settings in high income countries. Excluding neonates.

Perspective: Children, parents, healthcare professionals, who were receiving/providing discharge care or retrospectively provided accounts of discharge care and processes; health service organisations, Government and policy.

Intervention/Phenomenon of interest: Transition process from hospital to home and effective initial support at home.

Comparison: Any hospital to home transition process for this group of children - excluding neonatal discharge.

Evaluation: Framework analysis of peer-reviewed studies (any methodology except reviews which will be unpicked for relevant studies.), opinion, discussion/best practice papers, service/education evaluations, and selected policy documents and reports commissioned by health service organisations.
English language only, published between 2002- Dec 2012.

Figure 4. Search terms

Artificial respirat*, assisted ventilat*, attitudes, child, community care, complex care, continuing care, coping, discharg*, discharg* plan*, family coping, healthcare, long-term ventilat*, medically fragile, nurs*, technology-dependent

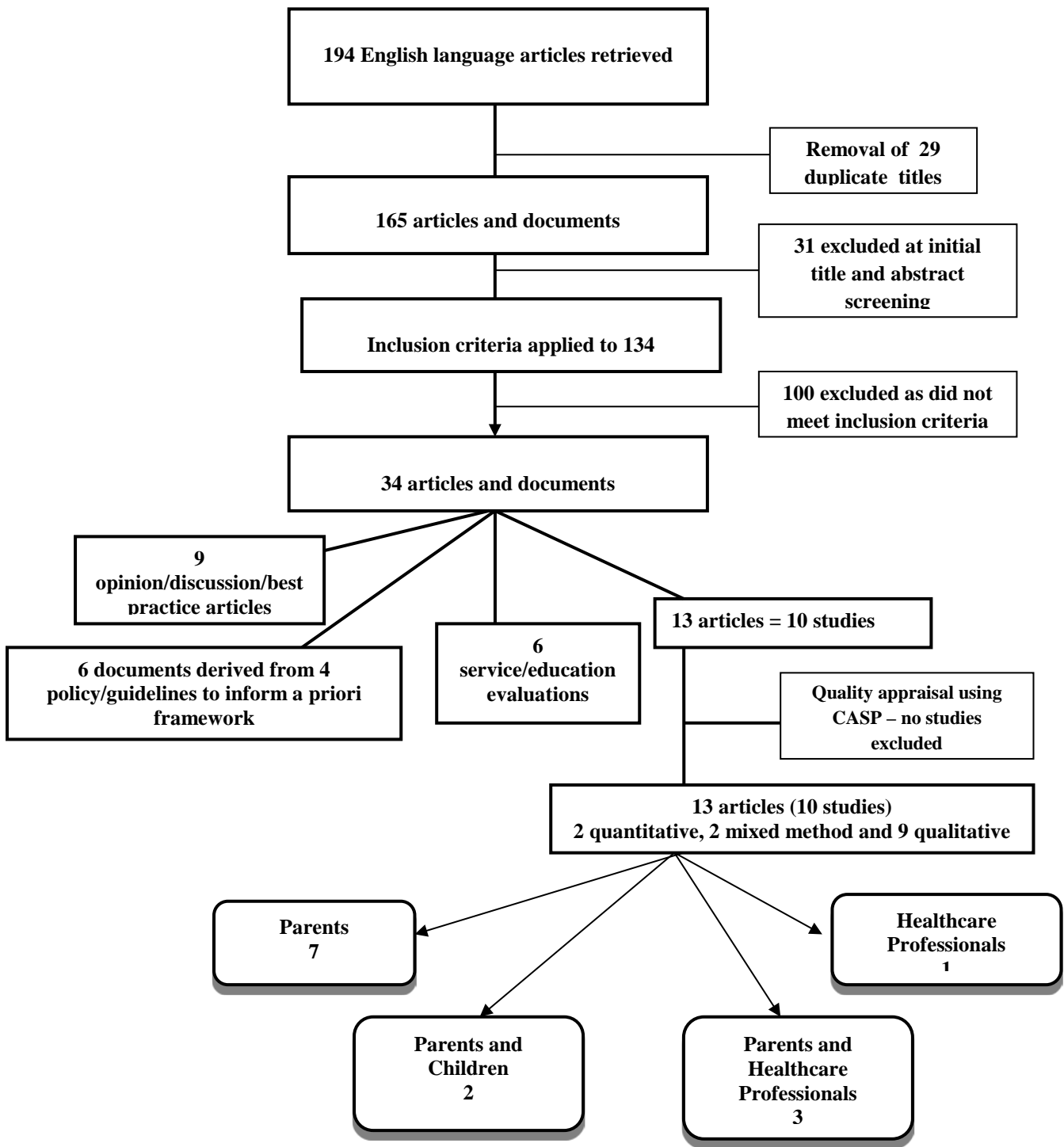


Figure 5. Flow of literature through the review.

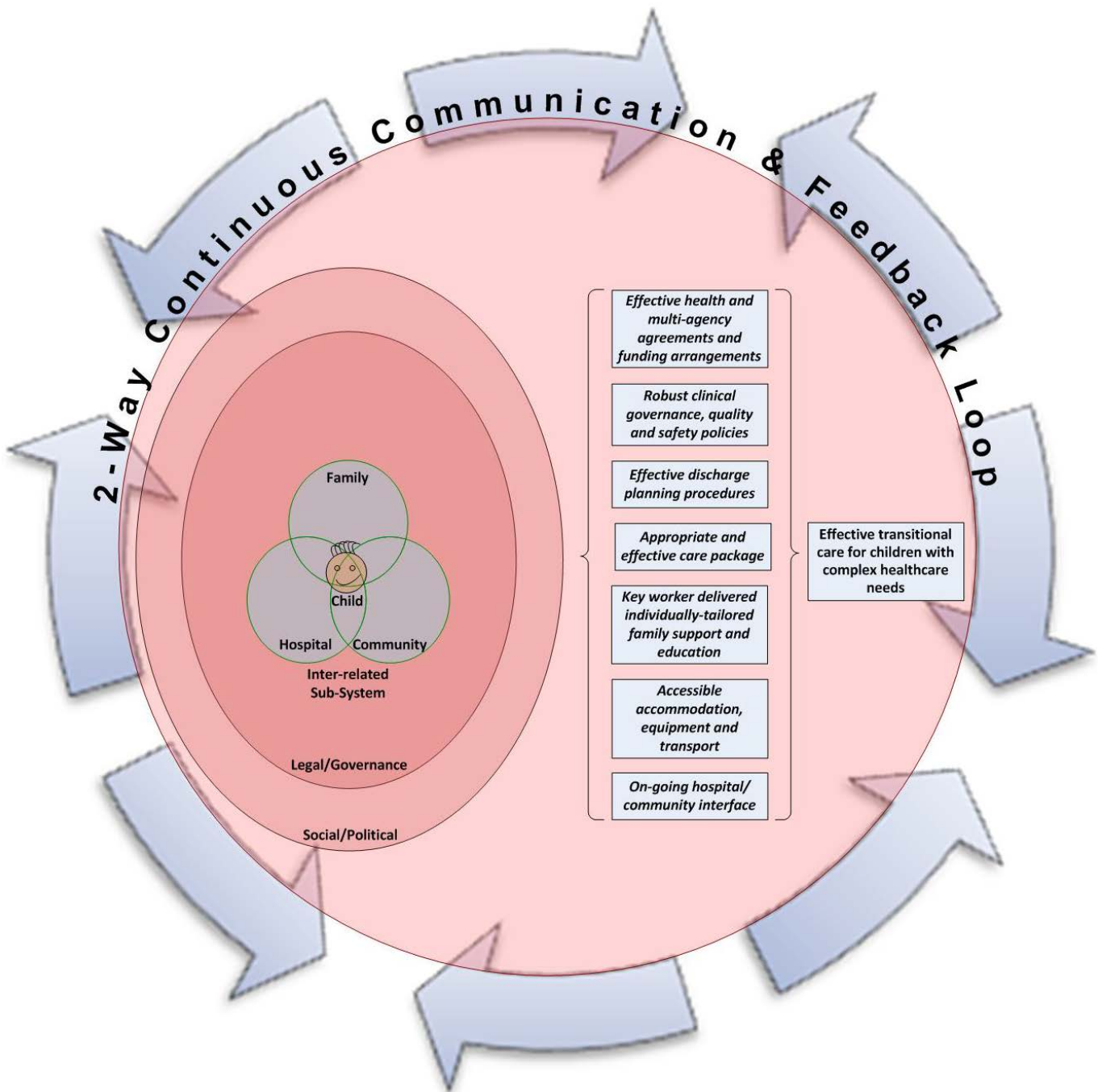


Figure 6. Five Level Health System Model and critical success factors for the successful transition of the child with complex healthcare needs from hospital to home.

Supplemental Information Files

Supplemental Information file 1. Excluded studies.

Supplemental Information file 2. Outcome of quality appraisal process of empirical studies.

Supplemental Information File 3. Analytical model underpinning theory development