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Meta-ethnography of experiences of early discharge, with a focus on paediatric febrile neutropenia

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Abstract

Purpose (stating the main purposes and research question) Many children have no significant sequelae of febrile neutropenia. A systematic review of clinical studies demonstrated patients at low risk of septic complications can be safely treated as outpatients using oral antibiotics with low rates of treatment failure. Introducing earlier discharge may improve quality of life, reduce hospital acquired infection and reduce healthcare service pressures. However, the review raised concerns that this might not be acceptable to patients, families and healthcare professionals.

Methods This qualitative synthesis explored experiences of early discharge in paediatric febrile neutropenia, including reports from studies of adult febrile neutropenia and from other paediatric conditions. Systematic literature searching preceded meta-ethnographic analysis, including reading the studies and determining relationships between studies, translation of studies and synthesis of these translations.

Results Nine papers were included. The overarching experience of early discharge is that decision-making is complex and difficult and influenced by fear, timing and resources. From this background, we identified two distinct themes. First, participants struggled with practical consequences of treatment regimens, namely childcare, finances and follow-up. A second theme identified social and emotional issues, including isolation, relational and environmental challenges. Linking these, participants considered continuity of care and the need for information important.

Conclusions Trust and confidence appeared interdependent with resources available to families—both are required to manage early discharge. Socially informed resilience is relevant to facilitating successful discharge strategies. Interventions which foster resilience may mediate the ability and inclination of families to accept early discharge. Services have an important role in recognising and enhancing resilience.

Keywords Febrile neutropenia · Meta-ethnography · Qualitative synthesis

Introduction

Febrile neutropenia (FN) is the most common life-threatening complication of treating children with cancer [1]. Usual care

in the UK involves inpatient intravenous antibiotics for at least 48 h [2]. This is consistent with febrile neutropenia management internationally, when discharge usually occurs at some point between 24 h and 5 days from presentation, unless there are other significant concerns (e.g. during certain courses of chemotherapy/bone marrow transplantation) [3]. A recent systematic review found outpatient treatment with oral antibiotics is safe for those patients considered low-risk and has low rates of treatment failure [3]. Introducing these treatment regimens may improve quality of life, reduce hospital acquired infection and save resources [4–7]. However, the review raised concerns about the acceptability of outpatient treatment or earlier discharge to patients, parents or healthcare professionals [3].

Performing a qualitative synthesis alongside a systematic review of effectiveness can help explain the results of the quantitative review [8–10]. Qualitative synthesis can provide

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analytical depth and further nuanced interpretations, identify key areas for future research and inform those designing, commissioning and implementing services. Meta-ethnography, initially designed to thematically combine ethnographic studies, is now used to synthesise qualitative findings from different methodologies and the processes for performing this continue to develop [9, 11, 12]. The constant comparison of similarities and differences in study findings provides both overarching themes and contrasts in perceptions in different contexts. New concepts and theories are developed, thus optimising the contribution of the original research to the field and gaining new interpretations of the data [11].

This interpretive synthesis aims to inductively provide an in-depth narrative of the different perspectives of those involved in early discharge services, focusing specifically on paediatric FN and on the viewpoints of patients, their family carers and healthcare professionals. It aimed to explore differences between groups and how barriers and facilitators to acceptance of early discharge are formed.

Preliminary searches confirmed that the subject-specific qualitative material available would not be of sufficient volume to perform an in-depth exploration of potential barriers and facilitators. We therefore expanded the searches to consider other qualitative material that might reasonably inform theories about the experience of early discharge in paediatric FN. The first area of exploration was adult FN, where many of the concerns related to complications of FN and experiences of oncological services might be similar. For example, patients, their carers and healthcare professionals may feel anxious because of previous bad experiences with severe infections or education about the potential severity of FN. The second area of exploration was other paediatric chronic conditions with life-threatening consequences, where there may be similar social implications of early discharge strategies. For example, the practicalities of taking a child home, including giving medications or attending frequent follow-up appointments, or with the responsibility of caring for their child during an acute exacerbation of illness.

Methods

A synthesis protocol was registered with PROSPERO, the international prospective register of systematic reviews, prior to commencing this work (PROSPERO CRD 42014013084). This study is reported in accordance with ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) guidelines [13].

Electronic searches of MEDLINE, CINAHL, EMBASE, British Nursing Index and PsychInfo were performed. The search strategy required at least two of the key concepts of children, FN and early discharge (Supplementary File 1). As eligible studies were likely to be poorly indexed and we were

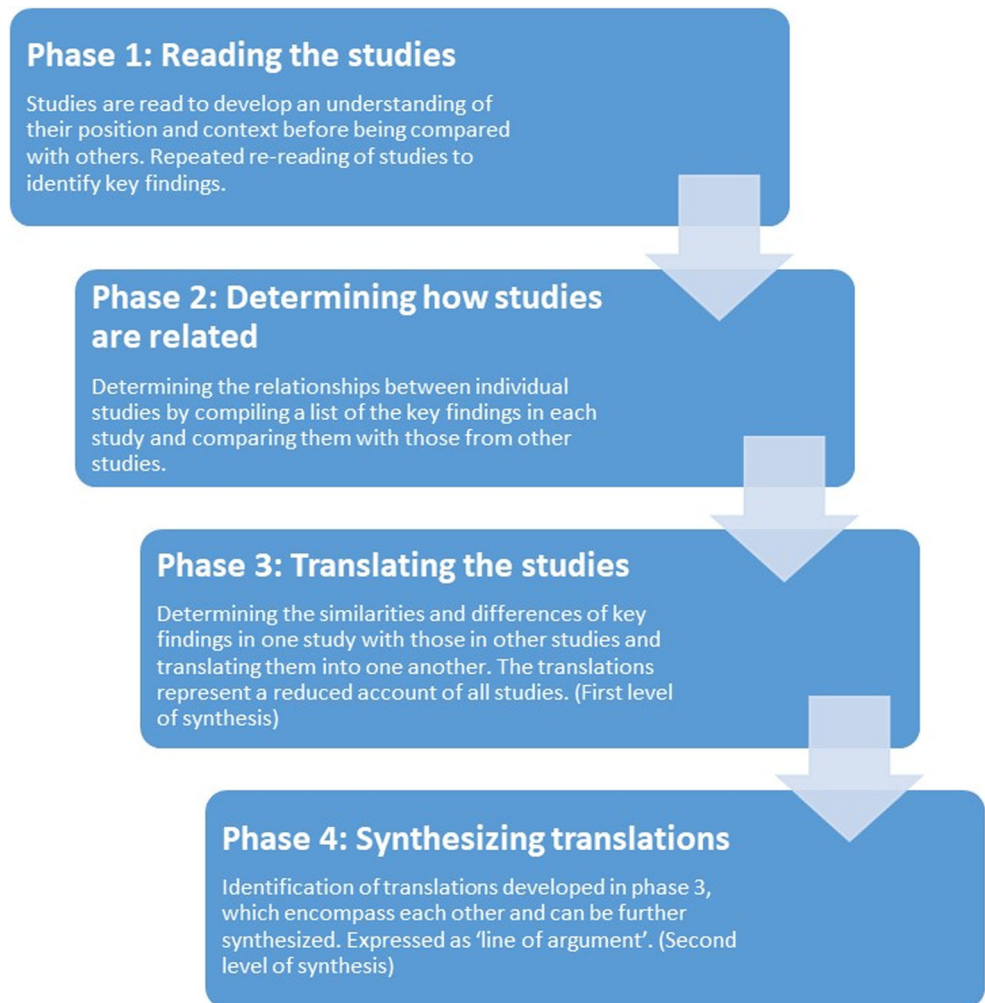
searching particularly for theoretical richness, a CLUSTER (Citations, Lead authors, Unpublished materials, Scholar searches, Theories, Early examples and Related projects) approach to searching was used [8]. This involved using key reports as nodes from which to explore the literature, in a systematic and explicit way (see Supplemental File 4). The reference lists of all included and relevant excluded papers were searched. All authors were contacted to request details of other works in this area.

Eligible studies provided qualitative data about experiences or perceptions of patients, parents, carers, healthcare professionals, commissioners or policy makers in relation to early discharge in the settings of paediatric FN, adult FN or other paediatric chronic conditions with life-threatening consequences, excluding neonatal and psychiatric conditions.

All studies using qualitative methodology were eligible for inclusion, including but not limited to ethnography, phenomenology and grounded theory. Studies that used qualitative methods but which did state an explicit methodology were also eligible to be included, provided they presented qualitative data. This included, but was not limited to, studies using focus group discussions, interview studies and observational studies. Similarly, mixed methods studies were eligible for inclusion if they provided sufficient qualitative data. We included English language studies only.

JM screened the title and abstract of all studies. JC independently screened 1000 titles and abstracts. Full texts were assessed for eligibility by two reviewers (JM/JC). Disagreements were resolved or referred to KA. General study data were extracted and quality assessed using the QARI tool (Supplementary File 2) by JM and JC [14].

Analysis followed an adapted version of Noblit and Hare's phases of meta-ethnography using the ATLAS.ti software (Fig. 1) [15]. The adaptation, developed by Flemming et al., is a simplification of the methodology described by Noblit and Hare that removes three stages originally described (Getting started, Deciding what is relevant to the initial interest and Expressing the synthesis) [9, 15]. This adapted version also provides a more concise description of the phases. In practice, this adapted version is of little difference from the originally described methodology. Qualitative data from the reports were transferred to the ATLAS.ti software and read repeatedly to ensure full understanding. The context was fully explored and study content thematically coded for key findings, with review by all authors to ensure accuracy of coding (phase 1). Codes were compared, grouped and translated to provide the initial level of synthesis and reviewed at authors' meetings (phases 2–3). This process confirmed that the codes and findings showed little evidence of stark contradiction between studies, meaning a refutational synthesis was not appropriate. However, the studies were not completely similar, showing differences between different social and clinical settings, rendering a reciprocal approach inappropriate. We therefore used

Fig. 1 Phases of meta-ethnography

a 'line of argument' synthesis, drawing on both the similarities and differences between studies to form the overarching synthesis. The resulting account was further explored and compared to identify a small number of higher theoretical constructs and to create the lines of argument (phases 3–4).

The context and implications of each study were considered including the role of health service design as described in the manuscripts (for example, 'hospital at home' schemes), as well as social, cultural and economic structures and patient factors, to identify patterning and themes within the material. Specifically, the broader literature was explored for themes that might provide concepts and theory that can be translated to the context of paediatric FN. In reports of adult FN, we looked for themes related to aspects of the FN diagnosis and the experiences of oncological services that might influence perceptions of early discharge. In studies of chronic childhood conditions, we examined the data for the influences of social circumstances and care in the paediatric setting as potentially transferrable concepts. The conceptual contribution of each report was explored, so as to more explicitly demonstrate the similarities and differences between studies. We considered

the complex issue of quality within qualitative research and aimed to integrate the findings of the quality assessment within the analysis.

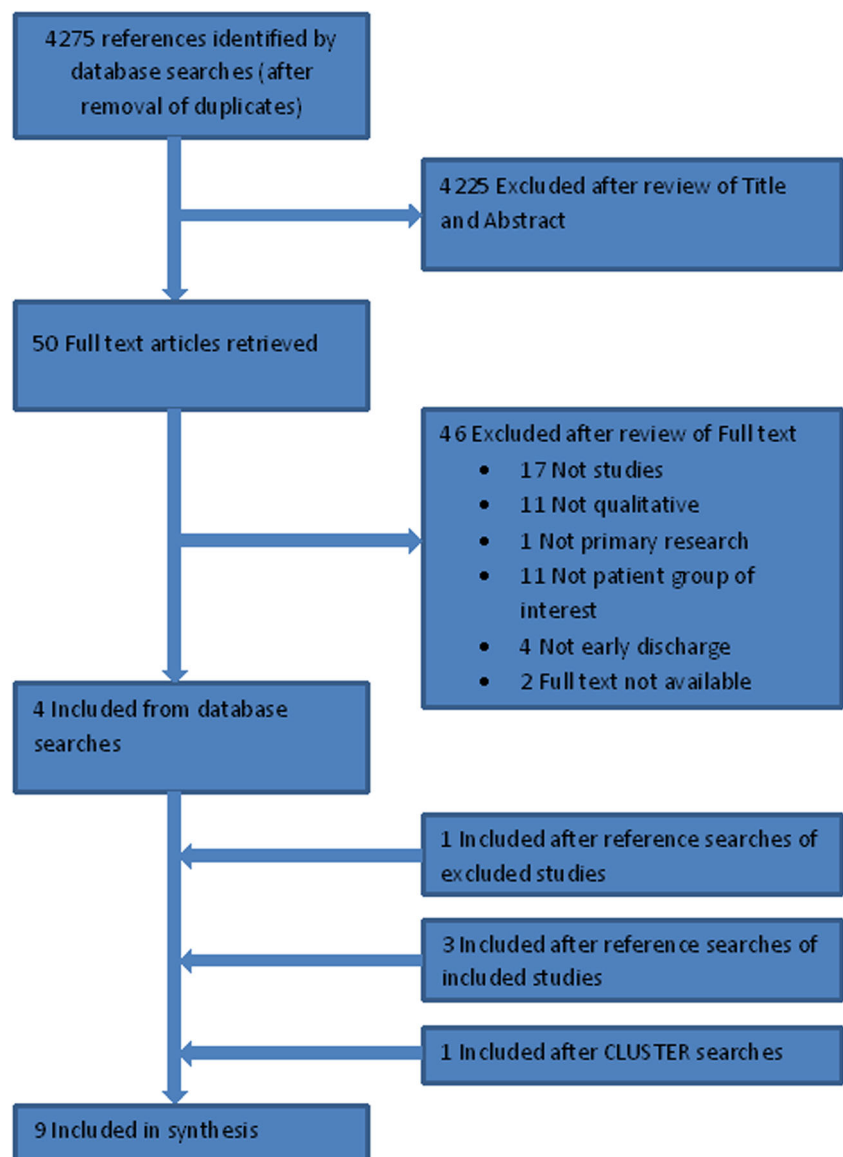
Results

Study details

A total of 4275 titles and abstracts were assessed, 50 full-text articles retrieved and 46 excluded (Fig. 2, Supplementary File 3). Four further studies were included from reference lists and one from CLUSTER searching (Supplementary File 4) [16]. The reviewers' decisions showed acceptable agreement ($\kappa = 0.44$).

Nine papers were included in the synthesis, published between 1977 and 2011 (Table 1) [17–25]. We recognise that this time span covers a period of changing attitudes and structures within healthcare, particularly a general move to shorter periods of hospitalisation. However, we consider that experiences and perceptions of reduced therapy regimens could

Fig. 2 Flow diagram for study selection



reasonably be considered to relate to the general concept of shortened admissions, rather than an absolute reduction in time. In this way, reductions in admissions from 30 to 25 days might be argued to raise similar concerns to reductions from 3 to 2 days.

Two-thirds of the included studies were performed within the UK, with the remainder from North America. Those who described their funding received academic support only.

One study was specific to paediatric FN [17]. One study did not specify the context, although the paper refers to ‘caregivers’ which suggests an adult setting [19]. This study did not explicitly focus on adult FN nor did it exclude it. As no other paper covered adult FN, this paper was included. The remainder of the studies focused on children with conditions other than FN. Most studies used semi-structured interviews, one reported observational ethnographic methods, another used focus group discussions.

Most studies included parents or caregivers within the participant group. Three studies explored the views of children, another briefly discussed a single child’s comment. Twenty-six children had been interviewed across the studies; the majority were aged 5–12 years. The literature included few teenagers or young adults. One study included adult patients and three involved healthcare professionals, mostly nursing staff and general practitioners. No studies considered the views of commissioners or policy makers.

Quality assessments

The quality of the included studies was variable (see Supplemental File 2). The theoretical premises of the studies were rarely described nor was their impact on the methodologies used acknowledged. Only one study gave a clear theoretical basis to their work, the remainder were largely descriptive.

Table 1 Included study details

Study	Country of origin	Methods	Phenomenon of interest	Setting	Population	Methods of analysis
Diorio et al., 2011 [13]	Canada	Interview	Parent preferences for treatment of febrile neutropenia and the key drivers of parental decision-making	Paediatric febrile neutropenia	155 parents	Thematic analysis
Freund and Siegel, 1986 [14]	USA	Observations through practice	Global issues of readjustment that may occur in any family with a child undergoing the transplant procedure. Notably also—the psychosocial concerns faced by the patient and the family in the transition from the hospital to the home environment	Paediatric bone marrow transplantation	83 patients, of whom 56 had leukaemia, 13 had aplastic anaemia and 14 had SCID	Thematic analysis
Fuji et al., 2013 [15]	USA	Focus group discussions	Perceptions of care transitions, their role within the process, barriers to effective care transitions and strategies to overcome these barriers	Unclear	18 patients and/or caregivers, 13 hospital-based providers, 7 non-physician community providers	Content analysis
Hally et al., 1977 [16]	UK	Multi-methods—quantitative data, interviews, questionnaires	Describe a home nursing scheme	Paediatric home nursing scheme	53 (of 61 eligible) families, 18 GPs from six practices and number of nurses unclear (?4)	Descriptive
Sartain et al., 2000 [17]	UK	Semi-structured interviews, augmented with drawing techniques for children	To explore children's parents' and health professionals' experience of childhood chronic illness	Other paediatric chronic condition with potentially life-threatening exacerbations	6 children, 10 parents and one healthcare professional associated with each family	Grounded theory
Sartain et al., 2001 [18]	UK	Structured and semi-structured interviews	Experiences of hospital and home care	Hospital at home service	11 children age 5–12 (6 hospital care, 5 hospital at home). Parents—20 in hospital care, 20 in hospital at home	Content analysis
Smith and Daughtry, 2000 [19]	UK	Semi-structured interviews	To identify any gaps in nursing services for acutely sick children and their families following discharge and to suggest ways to improve integration and communication between hospital and primary care to facilitate a 'seamless web of care' for families	Children's ward in medium sized DGH with both medical and surgical patients	20 parents who had needed help/support from a healthcare professional in the first 48 h following discharge	'Burnard's (1991) method for analysing interview transcripts in qualitative research'
Tatman et al., 1992 [20]	UK	Semi-structured interviews and questionnaires	Views of parents and GPs of a paediatric home care service	Other paediatric chronic condition with potentially life-threatening exacerbations	46 parents of 47 children. In-depth detail of the families' social context given within paper	Descriptive analysis
While, 1992 [21]	UK	Semi-structured interviews	Experiences of hospitalisation and home care	Other paediatric chronic condition with potentially life-threatening exacerbations	9 children, number of adults unclear—suggestion of 40 but not clearly stated	Content analysis

The methods of data collection, analysis and interpretation seemed appropriate to the research question and reflected the participants' voice. Most papers' conclusions were also clearly supported by their data.

Analysis

The overarching experience of patients, parents and healthcare professionals is that decision-making in early discharge is complex and difficult. This experience is influenced by common factors, including fear, timing and resources. We identified two distinct themes within the decision-making. First, families struggled with some practical aspects associated with maintaining treatment regimens, namely childcare, finances and attendance at follow-up. Second, parents discussed various social and emotional issues raised by early discharge, including social benefits and isolation, relational and environmental issues. Linking these themes, participants noted the importance of continuity of care and the need for information if they accepted early discharge. Participants described strategies that might circumvent some of the practical challenges faced and alleviate some feelings of isolation experienced. This model is represented in Fig. 3; supporting evidence is given in Table 2.

Complexities of decision-making and influences on this

Factors influencing the complex decision-making around early discharge could not be simply split into barriers and facilitators, as we had initially presumed. Instead, certain factors could at times help families to accept an early discharge regime and at others prevent this.

Participants described conflicting feelings about outpatient care and a delicate balance between accepting and declining early discharge options. There were obvious difficulties in assigning importance to different aspects of the decision-making and in balancing what is best for the child physically and emotionally, whilst simultaneously considering the needs of different family members. Parents discussed the challenge of seeking reassurance about concerns without feeling they were placing excessive demands on the healthcare service. The dilemma of incongruent patient, family and healthcare worker priorities was also acknowledged.

Various factors influenced the decisions made by participants. Fear, particularly related to potential deterioration in the outpatient environment, was one such factor. This was occasionally explicitly stated but was also seen in parental requests for more information about what to do in the case of such eventualities. Patient safety risks of remaining in hospital were not discussed, although this may reflect the fact that most of

Fig. 3 Overarching model of qualitative synthesis

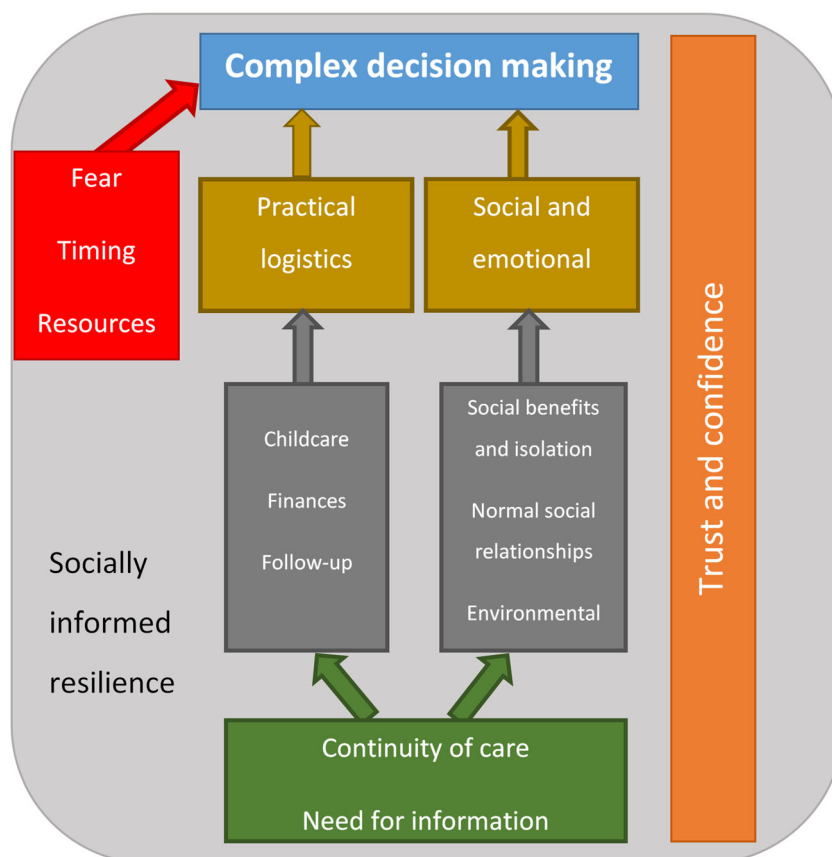


Table 2 Themes and subthemes with supporting evidence

Themes and subthemes	Sample evidence
Practical logistics	
• Child care	‘The more kids you have the harder it is to be in hospital’ ^a [13] ‘It [home nursing] also avoided special arrangements for other siblings and the disruption entailed in visiting the hospital.’ ^b [16]
• Finances	‘Six parents (30%) commented on the financial cost of staying in hospital with their children. Extra expenditure included meals for parents, telephone calls, and buying things (such as toys and magazines) to keep their child preoccupied’ ^b [18] ‘...we saved a fortune, when you’re in hospital you spend more money than you ever dream you will, so we didn’t have all that expense, which was good again.’ ^a [18] ‘The respondents also felt that time and money had been saved and, in particular, they referred to savings as regards travelling to hospital.’ ^b [21] ‘Parents reported that the cost of fuel, parking, and meals necessary during clinic visits were higher than the cost of staying in hospital for several days’ ^b [13]
• Follow-up	‘The nurse comes once a day but we have to come back three times a week. That’s not good.’ ^a [13] ‘Forget it, I’ll just stay in the hospital if I have to be here every day.’ ^a [13]
Social and emotional issues	
• Social benefits and isolation	See Table 3
• Normal social relationships	‘...I missed going to school and playing with my friends...’ ^c [17] ‘I don’t get to see half of my friends because I was in hospital. I miss out on loads of stuff at school’ ^c [17] ‘Just over half of the children interviewed said that it was nice to remain at home with the family...’ ^b [21]
• Environmental influences	‘There was a lot of things that I missed from home that I had, so the things at home that I can play with and amuse myself but I haven’t got at the hospital’ ^c [17] ‘Stephen tried to minimize the disruption actively by taking his own duvet into hospital and by setting up his computer games in hospital’ ^b [17] ‘You may as well be at home where you’ve got your creature comforts, you’ve got your own bed...’ ^a [18] ‘We would have definitely preferred to have been at home, and I think when you’re in your own surroundings, it’s far better, it makes a difference.’ ^a [18] ‘I can still look after him at home and in your own environment really, and plus for X he’s in his own surroundings, he doesn’t like change, he’s got his own toys around, he’s got his own bed and things like that, so it’s benefited him and it’s also benefited us’ ^a [18] ‘One parent (parent 21) stated that home care allowed the child to have “decent” meals and enabled him to do what he wanted with all his toys available for play...’ ^b [21]
• Staff experiences	‘Separation anxiety and a reluctance to give up the care of the child are frequent manifestations experienced by staff during the period the family is preparing to take the child home.’ ^b [14] ‘It is important for them to learn that the child is home, well cared for, and recovering satisfactorily’ ^b [14] ‘The staff must be assisted to acknowledge feelings of loss and to resolve them so as not to complicate the process of transition for the patient and family’ ^b [14]
Continuity of care	‘It might be a nice thing if the hospitals would call to ask, “How is everything going?...Do you have any questions?”’ ^c [15] ‘The feelings of anxiety and isolation following discharge were exacerbated if parents did not have a named person to contact when they needed reassurance and specific advice.’ ^b [19] ‘I would have felt happier if I had had a point of contact at the hospital because obviously they were familiar with him. They knew what had been wrong with him’ ^a [19] ‘The nurses who visit are never just “in and out”; they have always had time to stop and talk and have always been incredibly supportive.’ ^a [21]
Need for information	‘While definitive answers may not be possible, the provision of at least a tentative timetable would provide patients and families with a framework that enables them to begin to plan for the future.’ ^b [14] ‘Nurses described needing notice for advance planning to evaluate and reinforce medication and aftercare education, reconcile medications for discharge with pharmacists and physicians, complete and verify understanding of patient discharge teaching, and provide transfer information to staff at the receiving agency.’ ^b [15] ‘Patients described the need for additional education and follow-up post-discharge.’ ^b [15] ‘I would have just liked them to talk to me a bit more and explain what to do if she has another fit, because I still don’t know what to do.’ ^a [19] ‘... the general practitioner wrote: “The home care team largely communicated fairly well, but as I had little information from the hospital as to the overall plan I found dealing with arising problems difficult.’ ^b [20]
Complex decision-making and influences on this	
• Fear	‘[It’s a] hard [decision] because my child likes being home but as a parent I feel scared [at home].’ ^a [13]

Table 2 (continued)

Themes and subthemes	Sample evidence
	<p>• Parents were also concerned about children contracting infections either from other children at home or from other children during clinic visits, while they are neutropenic. Interestingly, very few parents mentioned concerns about nosocomial infections during hospital admissions^{a,b} [13]</p> <p>• The child too may feel anxious about the parents' capacity to keep the child "well" at home^b [14]</p> <p>• Resuming total responsibility for their recovering child once at home produced inordinate amounts of stress and anxiety to the interviewed parents, not least because they felt isolated from any professional support.^b [19]</p>
• Timing	<p>• Part of me wants early discharge, but I remember the last time ending up in ICU.^a [13]</p> <p>• You've caught me at a good time, when my son's health is good...if it was a worse time maybe my answers would have been different.^a [13]</p>
• Resources	<p>• Two years ago, hospital is the only one I would have considered, but we've become much more confident in our ability to administer medication.^a [13]</p> <p>• The more you can do in hospital, the more you want to do at home^a [21]</p> <p>• ...we had to disrupt other people to help us, get like his parents to help us get there and bring things for me, money for food and that.^a [18]</p>

^a Words of parents^b Words of report author(s)^c Words of children

these studies were performed in non-neutropenic patients. Families of neutropenic children could have greater concerns about nosocomial infections that this finding suggests.

Another influence is that of timing. Prior experiences influenced decisions made by parents, as did the health status of the child at the time of the episode. Families' ongoing reinterpretation of the biographical experience of having a child with cancer may be as important as the chronological time, the child's age or the specific stage of treatment.

An additional factor influencing decision-making about early discharge is that of resources—physical, social and psychological. For parents, having the practical resources to care for their child and the confidence to use these skills facilitated acceptance of outpatient care. The main social resources mentioned were other family members, including grandparents, and close friends who were nearby and willing to provide practical support. Psychological resources included optimism, confidence and a sense of control. Families who responded to a treatment schedule by accepting and adapting to the stressful situation seemed to tolerate any regimen more easily.

Practical logistics

The included studies outlined three main logistical challenges for patients and families receiving outpatient care. The first surrounds the care of other children within the household; outpatient treatment was preferable to parents as it avoided the need for additional childcare.

Second, additional financial costs occurred in inpatient and outpatient settings, including food and payments to access television in hospital, and travelling to clinic when an outpatient. Parents in both locations mentioned parking costs at the hospital as a logistical issue.

The final logistical challenge for patients is in attendance at follow-up. Parents whose children were treated as outpatients and were required to visit the clinic regularly found this to be a particularly negative aspect of treatment and sometimes preferred to stay as inpatients. Where frequent clinic attendance was not required, participants preferred outpatient management.

Social and emotional issues

Few studies discussed the social, cultural and economic context of their participants. Nonetheless, the material demonstrated their influence on the experience of care. Families who were economically less well-off reported more practical challenges related to finances. Depending on their social organisation, families had different experiences of childcare challenges, the social benefits and isolation of various regimes and had different social resources to call upon during the illness episodes.

The concepts of social benefit and isolation were used about both inpatient and outpatient care (Table 3). Participants in hospital felt staff were too busy to be available and did not enquire about deeper feelings regarding early discharge. Meanwhile, parents at home reported there was a lack of follow-up; they would have appreciated knowing who to call with a problem, or if staff contacted them at home to enquire about the child. Some children also experienced a feeling of abandonment and social isolation in hospital. However, others described social benefits from being in hospital and some preferred this to home.

Participants may be describing two forms of isolation—‘isolation from normal social life’ and ‘isolation from medical support’. This explains the similar feelings within both locations, but is refuted by the description of the first form within families at home. Therefore, we conclude that isolation is a complex but singular concept. It is difficult to assess whether the participants’ responses about isolation are a result of objective increases or decreases in social contact or whether they reflect altered perceptions due to a change in need for social input during the increased stress of an illness.

In FN, many inpatients are placed in ‘source isolation’ to prevent the spread of infection to other patients. This situation may exacerbate feelings of social isolation as families are less likely to interact with other inpatients and thus experience less of the social benefits available on a ward.

Other social and emotional issues discussed relate to the interruption of normal social relationships, including with siblings, school friends and playmates. Early discharge provides a more favourable environment for the maintenance of these relationships. The importance of familiar surroundings, toys and meals to the emotional well-being of children was strongly emphasised by parents and young people.

Social and emotional aspects of early discharge experienced by staff were discussed in only one paper. Staff worried

about the safety of children discharged early and were keen to follow-up with families after discharge. This concern was recognised as potentially causing complications to the process of early discharge.

Continuity of care and need for information

Participants described wanting ongoing care after discharge, highlighting the importance of ensuring community and hospital-based teams communicate and that someone contacts families following discharge to follow-up on progress. Participants did not want to come into hospital for this contact but preferred to be at home. There was praise of nurses from ‘hospital at home’ schemes with a clear dislike of coming into clinic regularly. Parents stated they would prefer contact from professionals they already knew, particularly those already involved in this episode [23].

Contiguous with the desire for continued care in the community was the message that families needed more information during the process of early discharge. Families needed more information about the problems their child had and how to expect their condition to change following discharge. They would like information regarding what to do if something went wrong at home (for example a further seizure or fever) and who to contact if concerned. One report told of inconsistency of information from healthcare teams and how this influenced the parent’s perception of early discharge; the provision of information influenced the emotional well-being of parents.

For staff, the need for continuous care with good transfer of information was also particularly important. Communication between teams was mentioned as a challenge, by both the discharging inpatient team and the receiving outpatient team across a number of the included reports.

Table 3 Themes of social benefits and isolation/abandonment expressed by various participants receiving both inpatient and outpatient care

	Inpatient care	Outpatient care/early discharge
Social benefits	<p>‘... and you can meet loads of friends as well here, like I met Laura last Monday when I came in, I met her and then I’ve known her every time I come in I’m always in the bed next to her.’^a [17]</p> <p>‘They [the children] had the opportunity to make friends and play.’^b [21]</p> <p>‘Two children made friends’^b [18]</p>	<p>‘They [parents] perceived HAH [Hospital at Home] as causing less social disruption...’^b [18]</p> <p>‘If you’re staying with your child you may as well be at home... you’ve got family around...’^c [18]</p> <p>‘Just over half of the children interviewed said it was nice to remain at home with the family...’^b [18]</p>
Isolation/abandonment	<p>‘I don’t get to see half of my friends because I was in hospital’^a [17]</p> <p>‘I missed going to school and playing with my friends...’^a [17]</p> <p>‘...you know when you’re in hospital...., you’re sort of isolated in a sense...’^c [18]</p>	<p>‘Like it being in hospital because, it’s like dead boring here [at home] and you’ve got people to play with you [at the hospital]... and I meet people...’^a [17]</p>

^a Words of children

^b Words of report author(s)

^c Words of parents

It is interesting that staff would like the opportunity to follow up children after discharge and parents report they would appreciate such a service; however, this continuity is not present within these studies. Potential barriers may include time and resource constraints and a culture within services of not contacting patients who have been recently discharged—preferring that families travel to clinic. Consideration needs to be given to the fact that families may resent returning for frequent clinic appointments but all stakeholders would like more contact following discharge. Services should reflect on whether some appointments could be replaced with telephone contact alongside, or instead of, hospital at home visits.

Contributions to the synthesis

The study by Diorio et al. was the only paediatric FN paper [17]. This provided subject-specific information, including the practical challenges of a paediatric haematology and oncology service, particularly frequent clinic follow-up for outpatient management of FN. However, the study was limited to a single centre and to the perspectives of parents.

Diorio et al. did not allude to social isolation or abandonment; this may be due to the brevity of an episode of FN and thus minimal impact on the family's social environment. Alternatively, the degree of social change that has previously happened within the child's illness may mean families are more adaptable to changes in their support structure. Finally, long-term relationships with staff and other families within the service may result in considerable social support both within and outside the hospital.

Participants of this study appeared less positive about outpatient care than other studies, where early discharge was generally preferred. This finding is difficult to explain; it may be a study-specific phenomenon, dependent on the centre and participants involved, or a disease-specific issue, where other families with FN might have similar attitudes to these regimens.

The most notably different report is that of Fuji et al. [19]. This study, including adult patient participants, described many similar themes to that of the paediatric studies, including abandonment, continuity of care and the need for information. It also contributed valuable data about staff experiences. We explored whether the exclusion of this paper would change the overarching theory of this review and found it did not.

There was no evidence that the quality of a study influenced the themes it contributed to the synthesis; lower quality studies contributed similar themes, in similar quantities and with similar depth to higher quality studies. There was no apparent difference in the studies from the UK compared to North America or from any particular professional or theoretical interest.

Discussion

Possible mechanisms/explanations

The concepts of trust and confidence offer an overarching theoretical explanation for the findings. Participants need to trust both their healthcare professionals and themselves when accepting an early discharge programme and require confidence in their own caring skills as well as confidence that healthcare professionals are contactable and give appropriate advice once discharged.

The issues of trust and confidence appear to be interdependent with the resources available to families—both are required in order to manage an early discharge regime. Trust and confidence enable families to recognise resources available to them and to mobilise those resources. Meanwhile, families who might otherwise have the trust and confidence to thrive in an early discharge situation need resources to be available so as to fully achieve the potential for outpatient care.

This suggests that socially informed resilience is particularly relevant to early discharge strategies. Resilience has been defined in many ways, but the overarching themes are that resilience describes a process (rather than a personality trait) in which individuals, families and communities respond to adversity in an adaptive way that enables them to continue to function adequately [26]. Resilience is a spectrum of time and situation dependent responses—a person may have resilience within their work but meanwhile not be functioning well at home. Resilience takes into account psychological influences, in this case trust and confidence, alongside the context in which they have to be realised, such as physical and social resources.

Resilience is a common response to adversity [27]. Adversity may range from prolonged exposure to personal adversity, such as chronic disease, to single catastrophic events, including natural disasters. An episode of FN might be considered as a single acute event which occurs on the background of prolonged adversity experienced by the family of a child with cancer. It is important to consider whether individuals regard an episode of FN as an adverse event and, if they do, what they perceive its severity to be. These perceptions may be vital in defining the need to employ resilient processes and the extent to which resources may need to be accessed.

Research describes various biological, psychological and social predictors of resilience. Gender and age both affect responses to adversity [27]. Ethnicity also plays a role in resilience; however, the social and cultural influences are more difficult to control for when assessing this factor [27]. High levels of perceived social support can foster resilience, whilst multiple life stressors may reduce it [27]. Positive family relationships, flexibility and adaptability within adverse

situations are known attributes of family resilience, as are positive relationships with healthcare professionals [28].

Financially, any loss of income may result in a less resilient response, independent of the initial or final income [27]. In childhood cancer, where the additional costs of caring for a child average £367 per month and families often have a loss of income as parents reduce working hours, families may be less able to demonstrate resilience during an episode of FN [29].

Resilience can be supported through encouraging developmental resilience, strengthening family and social relationships, increasing the availability of resources and ensuring that services are designed to promote resilience [26, 27]. In FN, this might include fostering relationships of trust and encouraging families to identify the resources already available to them, whilst providing additional resources of pre-discharge information and practical home nursing support.

Finally, the desire to improve resilience to adversity should not take place without also aiming to deal with that adversity. This may include improving practical assistance, such as free parking, transport or parental meals in hospital, and considering the structure of outpatient strategies to reduce the burden on families by reducing clinic visits where possible and ensuring easy access to professional advice. By providing accessible and appropriate services, the amount of resilience needed to deal with episodes of FN and the resultant treatment may be reduced.

Reflexivity

Overall, this review provides a preliminary theoretical framework for considering early discharge for children with FN. Our roles as both clinical academics and non-clinician researchers provide different perspectives and interpretations of the research, which have been incorporated in the analysis. We consider the proposed model to be credible to those working with this population. Further research aiming to represent the voices of young people and healthcare professionals and to assess contextual influences on decision-making is certainly needed in order to support any change in clinical practice.

A specific strength of this synthesis is in its structured scientific methodology and transparent approach to the work. Our use of a wide breadth of literature to inform this particular clinical problem has enabled the formulation of an initial theoretical construct and will shape future qualitative research.

The key limitation is the difficulty in clarifying some issues, because of the restricted material available. In particular, the voices of participants are potentially skewed as key perspectives are missing or minimally represented. Further, there is insufficient disease-specific data to allow complete confidence in our conclusions about the experience within paediatric FN.

Conclusions

Decisions about early discharge are complex and influenced by fear, resources and timing. Practical logistics alongside social and emotional issues are key factors considered in decision-making. There is a clear need for increased continuity of care and a desire for more information by families considering early discharge. Socially informed resilience provides a theoretical explanation for the experiences and perceptions found within this meta-ethnography. The ways in which resilience is fostered and negotiated may mediate the ability and inclination of families to care for their children within their home during episodes of FN. Services will need to consider how to recognise and encourage action to enhance resilience within the communities they serve.

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Compliance with ethical standards

Conflict of interest statement The authors have no conflicts of interest to declare. ICMJE forms have been completed and submitted to *Supportive Care in Cancer* with this manuscript.

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