Qualitative synthesis of experiences of early discharge, with a focus on paediatric febrile neutropenia: protocol

Febrile neutropenia describes the presence of fever, representing infection, in a patient who has poor immunity due to low neutrophils. It is the commonest life-threatening complication of treatment of children with cancer, and can occur multiple times during the course of managing a malignancy. (1) A large number of patients with febrile neutropenia have no significant sequelae of the condition, whilst a smaller number are at high risk of medical complications including organ failure and death.

Standard care in the UK usually involves intravenous (IV) antibiotics and at least 48 hours as an inpatient. (2) However, research has begun to focus on whether treatment can be reduced safely for those patients who are considered to be at low risk of complications of febrile neutropenia. (1) This may provide benefits of improved quality of life, reduction in hospital acquired infection, cost savings and reduced pressures on the healthcare service. (3–6) However, there remains some concern that reductions in therapy, particularly outpatient treatment, may not be acceptable to patients, their parents or the health care professionals providing for them.

A synthesis of primary qualitative work in this area could provide an in depth narrative of the different perspectives of those involved in services for paediatric febrile neutropenia. Thorough exploration of the existing literature may allow us to outline the issues that act as barriers or facilitators to acceptance of outpatient therapy for different groups. The resultant nuanced account should provide sufficient insight to allow the development of subsequent theory outlining the factors influencing the acceptance of early discharge in febrile neutropenia, and the features of services that might make them more successful from the perspectives of different stakeholders. Thus, the findings from a qualitative synthesis would complement findings from quantitative research in this area and help to inform those designing services, commissioners and policy makers.

Therefore, in this synthesis we aim to explore the data in existing studies that report what paediatric patients, their parents and their healthcare professionals perceive about early discharge in febrile neutropenia. However, we anticipate that the subject-specific qualitative data available will not be sufficient to explore all potential barriers and facilitators, or the differences in perspectives between patients, their parents and their healthcare professionals. To account for this, we will expand our review to consider other qualitative data that might reasonably inform theories about the experience of early discharge in paediatric febrile neutropenia.

In particular, we will explore the literature surrounding experiences of early discharge in two additional areas (see Figure 1). The first area of exploration will be that of adult febrile neutropenia, where many of the concerns related to complications of febrile neutropenia and experiences of oncological services might be similar. For example, patients, their carers and healthcare professionals may feel particularly anxious about early discharge with febrile neutropenia because of previous bad experiences with severe infections, or because of previous education about the potential severity of an episode of febrile neutropenia. The second area of exploration will be that of other paediatric chronic conditions with life-threatening exacerbations, where there may be similar social implications of early discharge strategies. For example, parents may struggle with the practicalities of taking a child home, including giving medications or attending frequent follow-up appointments, or feel anxious about the responsibility of caring for their child during an acute exacerbation of illness.
Aims and objectives:

**Box 1 – Specific synthesis questions**

1. What are the experiences and perceptions of patients, parents and healthcare professionals of early discharge in paediatric febrile neutropenia?
2. What are the experiences and perceptions of patients, carers and healthcare professionals of early discharge in adult febrile neutropenia?
3. What are the experiences and perceptions of patients, parents and healthcare professionals of early discharge in other paediatric chronic conditions with potentially life-threatening exacerbations?
4. What are the barriers and facilitators to acceptance of early discharge in these populations?
5. How do the perspectives in these situations differ and how does this impact on the process of early discharge?

This synthesis aims to explore perceived experiences and understanding of early discharge, with a focus on paediatric febrile neutropenia. We will explore how these concepts differ between groups and how they form barriers and facilitators to acceptance of early discharge. In particular, we will focus on the views of patients, their carers, and the healthcare professionals providing services to them. The specific research questions for this qualitative synthesis are outlined in Box 1.
Following the assessment of this broad and more contextual literature, we will aim to develop higher level theory about the experience of early discharge in paediatric febrile neutropenia and the factors which influence the acceptance of this as a management strategy. This synthesis will complement an ongoing quantitative systematic review (PROSPERO CRD42014005817) and contribute to ongoing multi-methods research in this area.

Methods

Methodology:

Although quantitative synthesis in the form of systematic reviews, with meta-analyses as a significant subgroup, has become an essential concept for those involved in health research, similar methodology in the qualitative paradigm has only recently been developed. When considered, qualitative synthesis clearly has great potential to benefit the health sciences, not just through increasing the numbers of patients involved and thus giving more confidence in the conclusions drawn (as is often described as the greatest benefit of quantitative synthesis), but also in allowing the development of higher level theories and further analysis of complex constructs, so as to benefit healthcare practitioners and policy makers in the development of services. Finally, just as in quantitative synthesis, it can be used to identify key gaps in the literature so as to guide future research endeavours.

We have chosen to use meta-ethnography to perform this qualitative synthesis. This methodology was first described by Noblit and Hare in 1988.(7) Although initially used to combine only ethnographic studies, it is now used to synthesise many different theoretical and methodological approaches. This pragmatic approach sits well with the overarching philosophy of the thesis within which this work sits, and is likely to yield the highest volume of included studies when we suspect there may be minimal good quality literature.

Another benefit of meta-ethnography is that although it aims to describe the various themes in the studies included, it also aims to translate those concepts into each other and thus create higher-level theory, which may be more generalizable. The constant comparison of the similarities and differences in studies and their findings is particularly applicable to our work, as we know that the literature selected is likely to provide both overarching themes and interesting contrasts in perceptions of early discharge in different contexts. By using this approach which is interpretive as well as aggregative, we aim to inductively produce a model of experiences and understanding of early discharge.

Search and retrieval strategy:

We will search MEDLINE, CINAHL, EMBASE, British Nursing Index, and PsychInfo. The initial Medline search strategy is included in Appendix 1.

As eligible studies are likely to be poorly indexed and we are searching particularly for theoretical richness, we will use a CLUSTER approach to searching.(8) This involves using key reports as nodes from which to explore the literature, in a systematic and explicit way. The main steps involved in cluster searching are outlined in Appendix 2.

Prominent researchers within the field will be contacted to seek further studies (See Appendix 3). Published and unpublished studies that are available in completed report form will be sought. Incomplete studies and primary data only will not be sought. A time limit of three months for eliciting further studies will be applied to ensure that the results of this review are available to inform further aspects of the overarching multi-methods research.

Screening for eligibility

One reviewer will screen the title and abstract of all studies for inclusion. A second reviewer will independently screen 1000 papers or 10% of those identified through the search, whichever is greater. The kappa statistic for agreement will be calculated and if this shows significant disagreement (K<0.4), all other studies will be screened by a second reviewer. Where it is not possible to identify whether a study should be included from the title and abstract, then full text of the paper will be sought and then assessed using the study eligibility
Disagreements regarding which studies to include will be resolved by consensus or, if this proves impossible, by recourse to an independent adjudicator.

**Inclusion and exclusion criteria:**

Studies will be included in the synthesis if they meet the following criteria:

**Study design:** All studies using qualitative methodology will be eligible for inclusion, including but not limited to ethnography, phenomenology, and grounded theory.

Further, studies using qualitative methods but which do not state an explicit methodology will be included, provided that they present qualitative data. This may include, but is not limited to, studies using focus group discussions, interview studies and observational studies. Similarly, mixed methods studies will be eligible for inclusion if they provide sufficient qualitative data.

**Study Participants:** Patients, their parents/carers, healthcare professionals, commissioners and/or policy makers.

**Topic of Interest:** Early discharge from hospital. This must be defined by the study. There will be details of the difference between early discharge and routine care, although routine care may be described with reference to a historical group.

**Context (any of):**

a) Paediatric febrile neutropenia  
b) Adult febrile neutropenia  
c) Other paediatric chronic conditions with life-threatening exacerbations. This might include, but is not limited to, asthma, diabetes mellitus, inborn errors of metabolism and neurodegenerative conditions at risk of respiratory exacerbations.

**Outcome of Interest:** Experiences or perceptions (where early discharge has not been experienced)

**Exclusions:**

i) Studies of early discharge in the neonatal period of healthy term newborns or babies following admission to neonatal critical care services will not be included. These studies will be excluded as they describe a very different context to that of febrile neutropenia. New parents are likely to describe different experiences and concerns compared to those with a previously well child who is now suffering from a life-threatening illness. Furthermore, the design of services in neonatal care is unique, particularly in relation to community-based follow-up and therefore is not comparable to that of febrile neutropenia.

ii) Studies exclusively using methods to quantitatively define preferences will be excluded. These may use Visual Analogue Scores, Time Trade Off analyses, Willingness-to-Pay or other methods. Studies that use one or more of these methods but also provide qualitative data will be eligible for inclusion in the review.

iii) Studies using a survey design will not be included, unless they also provide qualitative data using another method.

**Language:** Studies will be limited to those written in the English language for three reasons. Firstly, these are most likely to reflect the cultural experiences of the group in which we plan to apply the results, that is paediatric haematology and oncology patients with febrile neutropenia in the UK. Secondly, the benefit of qualitative research is to allow participants to express their experiences and perceptions, the clarity of which could be lost through translation and thus the results of the synthesis could become inaccurate. And finally, the researchers speak only English and therefore the decision to exclude non-English papers also represents a pragmatic approach.

**Quality assessment of primary studies and data extraction:**
The quality of the primary studies will be assessed using the QARI tool (Appendix 5) and the components of this assessment will be presented in both narrative and tabular form. General study information will be extracted using a standardised data extraction form (Appendix 6). Data extraction will be performed by one author and checked by a second.

**Data analysis and synthesis:**

<table>
<thead>
<tr>
<th>Box 2: Phases of meta-ethnography (9)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1: Reading the studies</strong></td>
</tr>
<tr>
<td>o Studies are read to develop an understanding of their position and context before being compared with others. Repeated re-reading of studies to identify key findings.</td>
</tr>
<tr>
<td><strong>Phase 2: Determining how studies are related</strong></td>
</tr>
<tr>
<td>o Determining the relationships between individual studies by compiling a list of the key findings in each study and comparing them with those from other studies. If findings are oppositional, a refutational synthesis should be undertaken.</td>
</tr>
<tr>
<td><strong>Phase 3: Translating the studies into one another</strong></td>
</tr>
<tr>
<td>o Determining the similarities and differences of key findings in one study with those in other studies and translating them into one another. The translations represent a reduced account of all studies. (First level of synthesis)</td>
</tr>
<tr>
<td><strong>Phase 4: Synthesizing translations</strong></td>
</tr>
<tr>
<td>o Identification of translations developed in phase 3, which encompass each other and can be further synthesized. Expressed as ‘line of argument’. (Second level of synthesis)</td>
</tr>
</tbody>
</table>

Our analysis will follow an adapted version of Noblit and Hare’s phases (see Box 2). This will be an iterative process, driven by the studies identified through the systematic searches. Qualitative data from the reports will be transferred to ATLAS.ti software and thematically coded by one researcher, with review by other members of the group. Codes will be compared and grouped and translated to provide the initial level of synthesis by one researcher and reviewed at meetings with other researchers. The resulting account will then be further explored and compared to identify a small number of higher theoretical constructs and will aim to create the lines of argument. The final theoretical constructs will be presented in both narrative and diagrammatical forms, demonstrating clear progression from data to theory.

We will aim to explore the broader context and implications of each study. We will consider the role of health service design and how this might influence the experience of early discharge, as well as social, cultural and economic structures and patient factors that could contribute to certain barriers and facilitators. We will look for patterning of the data for themes which suggest how different groups of participants might perceive similar experiences and how these perceptions could influence acceptance of services.

Specifically the broader literature will be explored for themes that might provide concepts and theory that can be translated to the context of paediatric febrile neutropenia. In reports of studies of adult febrile neutropenia, we will expressly look for themes related to aspects of the febrile neutropenia diagnosis and the experiences of oncological services that might influence perceptions of early discharge. Meanwhile, in studies of experiences in chronic childhood conditions, we will explicitly examine the data for the influences of social circumstances and care in the paediatric setting as potentially transferrable concepts.

The conceptual contribution of each report will be explored in relation to the final theory. Furthermore, we will consider the complex issue of quality within qualitative research, and aim to integrate the findings of the quality assessment within the analysis. In particular, we will evaluate whether studies which appear to be of
higher quality contribute concepts to the final theory that are not evident within poorer quality studies, and whether specific quality attributes explain any differences. This is consistent with the iterative and reflexive approach which characterises qualitative methodologies.

We will also examine the literature base to establish how it is conceptually organised and to identify any particular dominance in regards to geography, professional interest and theoretical standpoints. Furthermore, we will seek to identify areas where the body of research is incomplete, with a view to indicating potential future areas for exploration. The strengths and limitations of the synthesis process will be explicitly explored adding reflexivity to the review.

**Reporting and dissemination of results:**

The qualitative synthesis itself will be reported according to the ENTREQ guidelines and will be submitted for publication in a scholarly journal.(10) Lay and professional summaries of the project will be available from the authors. Areas of uncertainty and suggestions for further research will be outlined within the final report.
References


Appendices

1. Search Strategy
2. Process of Cluster searching
3. Email to Elicit Unpublished studies
4. Study Eligibility decision form
5. QARI Appraisal Tool
6. Data extraction Tool for General Study Information
Appendix 1 – Search Strategy

To be confirmed. Ongoing work in this area.

Overview of Search strategy: *(all with English language filter)*

<table>
<thead>
<tr>
<th></th>
<th>Medline</th>
<th>Embase</th>
<th>CINAHL</th>
<th>British Nursing Index</th>
<th>PsychInfo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatric FN</td>
<td>FN and length of stay</td>
<td>FN and length of stay</td>
<td>FN and early discharge</td>
<td>Febrile neutropenia</td>
<td>(Early discharge AND child) or febrile neutropenia</td>
</tr>
<tr>
<td>Adult FN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Childhood conditions</td>
<td>Early discharge and children</td>
<td>Early discharge and children</td>
<td>Early discharge and children</td>
<td>Early discharge</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2 – Process of CLUSTER searching (8)

### Steps to enhance exploration of content

<table>
<thead>
<tr>
<th>Step</th>
<th>Procedure</th>
<th>Source(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Identify at least one key “pearl” citation, agreed through consensus by the review team</td>
<td>Preliminary Literature Search of bibliographic databases</td>
</tr>
<tr>
<td>2</td>
<td>Check Reference list for any additional relevant citations by the Authors</td>
<td>Full text of pearl citations</td>
</tr>
<tr>
<td>3</td>
<td>Recheck for additional relevant records by the Authors</td>
<td>Reference management database</td>
</tr>
<tr>
<td>4</td>
<td>Search for lead author (and other authors as appropriate). Seek to identify Contact email, Publications list, Institutional repository</td>
<td>Google</td>
</tr>
<tr>
<td>5</td>
<td>Conduct citation searches on key pearl citation (and other publications as appropriate)</td>
<td>Web of Science/Google Scholar</td>
</tr>
<tr>
<td>6</td>
<td>Conduct searches on project name/identifier (if available)</td>
<td>Google Scholar</td>
</tr>
<tr>
<td>7</td>
<td>Make contact with Lead Author (particularly regarding related publications, unpublished articles, reports, book chapters etc.)</td>
<td>Personal Web pages</td>
</tr>
</tbody>
</table>

### Steps to enhance identification of theory

<table>
<thead>
<tr>
<th>Step</th>
<th>Procedure</th>
<th>Source(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Follow up key pearl citation and other cluster documents for citation of theory</td>
<td>Full text of pearl citations</td>
</tr>
<tr>
<td>9</td>
<td>Recheck for mentions of Theory in titles, abstracts, keywords</td>
<td>Reference management database</td>
</tr>
<tr>
<td>10</td>
<td>Optionally, perform iterative searches for theory mentioned in combination with Condition of Interest</td>
<td>Original set of bibliographic databases</td>
</tr>
</tbody>
</table>

### Steps to broaden the search to other relevant information

<table>
<thead>
<tr>
<th>Step</th>
<th>Procedure</th>
<th>Source(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Follow up key pearl citation and other cluster documents for citations to project antecedents and related projects</td>
<td>Full text of pearl citations</td>
</tr>
<tr>
<td>12</td>
<td>Conduct named project and citation searches for relevant projects identified from cluster documents</td>
<td>Web of Science/Google Scholar</td>
</tr>
<tr>
<td>13</td>
<td>Seek cross case comparisons by combining project name/identifier for cluster with project name/identifiers for other relevant projects</td>
<td>Original set of bibliographic databases</td>
</tr>
</tbody>
</table>
Appendix 3 – Email to elicit unpublished studies

Dear ______,

We are performing a qualitative synthesis about experiences of early discharge in paediatric febrile neutropenia. We anticipate that the qualitative data available will not be sufficient to explore all potential barriers and facilitators to early discharge in the area of paediatric febrile neutropenia, or the differences in perspectives between patients, their parents and their healthcare professionals. We will therefore expand our review to find other qualitative data that might reasonably provide data to inform theories about the experience of early discharge in paediatric febrile neutropenia.

In particular, we will explore the literature surrounding experiences of early discharge in two additional areas. The first area of exploration will be that of adult febrile neutropenia, where many of the concerns related to complications of febrile neutropenia and experiences of oncological services might be similar. For example, patients, their carers and healthcare professionals may feel particularly anxious about early discharge with febrile neutropenia because of previous bad experiences with severe infections, or because of previous education about the potential severity of an episode of febrile neutropenia. The second area of exploration will be that of other paediatric chronic conditions with life-threatening exacerbations, where there may be similar social implications of early discharge strategies. For example, parents may struggle with the practicalities of taking a child home, including giving medications or attending frequent follow-up appointments, or feel anxious about the responsibility of caring for their child during an acute exacerbation of illness.

We are contacting you, as an expert within this field, to enquire if you know about any ongoing or unpublished work within this area. In particular, we are looking for studies that meet the following criteria:

<table>
<thead>
<tr>
<th>Study design:</th>
</tr>
</thead>
<tbody>
<tr>
<td>All studies using qualitative methodology and/or methods will be eligible for inclusion, including but not limited to ethnography, phenomenology, and grounded theory.</td>
</tr>
</tbody>
</table>

| Also, studies using qualitative methods but do not state an explicit methodology will be included, provided that they present qualitative data. This may include, but is not limited to, studies using focus group discussions, interview studies and observational studies. Similarly, mixed methods studies will be eligible for inclusion if they provide sufficient qualitative data. |

| Study Participants: Patients, their parents/carers, healthcare professionals, commissioners and/or policy makers. Topic of Interest: Early discharge from hospital |
| Context (any of): |
| a) Paediatric febrile neutropenia |
| b) Adult febrile neutropenia |
| c) Other paediatric chronic conditions with life-threatening exacerbations. This might include, but is not limited to, asthma, diabetes mellitus, inborn errors of metabolism and neurodegenerative conditions at risk of respiratory exacerbations. |

| Outcome of Interest: Experiences or perceptions (where early discharge has not been experienced) |
| Language: English language studies only |
Exclusions:

i) Studies of early discharge in the neonatal period of healthy term newborns or babies following admission to neonatal critical care services will not be included.

ii) Studies exclusively using methods to quantitatively define preferences will be excluded. These may use Visual Analogue Scores, Time Trade Off analyses, Willingness-to-Pay or other methods. Studies that use one or more of these methods but also provide qualitative data will be eligible for inclusion in the review.

iii) Studies using a survey design will not be included, unless they also provide qualitative data using another method.

Should you know of any appropriate studies, we would greatly appreciate if you could share this information. If you have any questions about whether a study might be eligible for inclusion within this qualitative synthesis, please do not hesitate to contact us.

Many thanks for your time and consideration,

Yours sincerely,
Appendix 4 - Study Eligibility decision form

1. Does the study use qualitative methodology?
   Yes  Unclear  No

2. Is the study in the context of one of:
   a) Paediatric febrile neutropenia
   b) Adult febrile neutropenia
   c) Other paediatric chronic conditions with life-threatening exacerbations (this might include, but is not limited to, asthma, diabetes mellitus and neurodegenerative conditions at risk of respiratory exacerbations)?
      Yes  Unclear  No

3. Does the study include patients, their parents or carers and/or healthcare professionals?
   Yes  Unclear  No

4. Does the study assess experiences or perceptions of early discharge from hospital?
   Yes  Unclear  No

5. Is the study in English?
   Yes  Unclear  No

6. Is the study of early discharge in the neonatal period of healthy term newborns or babies following admission to neonatal critical care services? (note: this is an exclusion criterion)
   Yes  Unclear  No

7. Is a complete report or publication available?
   Yes  Unclear  No

Final decision:
Include  Unclear (need more information – define what)  Exclude
Appendix 5 – QARI appraisal tool (11)

1. Congruity between the stated philosophical perspective and the research methodology
   a. Does the report clearly state the philosophical and theoretical premises on which the study is based?
   b. Does the report clearly state the methodological approach adopted on which the study is based?
   c. Is there congruence between the two?

2. Congruity between the research methodology and the research question or objectives
   a. Is the study methodology appropriate for addressing the research question?

3. Congruity between the research methodology and the methods used to collect data
   a. Are the data collection methods appropriate to the methodology?

4. Congruity between the research methodology and the representation and analysis of the data?
   a. Are the data analysed and represented in ways that are congruent with the stated methodological position?

5. Congruity between research methodology and the interpretation of results
   a. Are the results interpreted in ways that are appropriate to the methodology?

6. Locating the researcher culturally or theoretically
   a. Are the beliefs and values, and their potential influence on the study declared?

7. Influence of the researcher on the research, and vice-versa, is addressed
   a. Is the potential for the researcher to influence the study and for the potential of the research process itself to influence the researcher and her/his interpretations acknowledged and addressed?

8. Representation of participants and their voices

9. Ethical approval by an appropriate body

10. Relationship of conclusions to analysis, or interpretation of the data
Appendix 6 - Data extraction Tool for General Study Information (11)

General information
- Person performing data extraction
- Date of data extraction
- Study number
- Author
- Title
- Citation
- Country of origin
- Source of funding

Study information
- Methodology (underpinning theory/philosophy)
  - Ethnography
  - Phenomenology
  - Grounded Theory
  - Discourse analysis
  - Other (Give further details)
- Methods
  - Interview (structured/semi-structured/unstructured)
  - Focus groups
  - Observation
  - Other (Give further details)
- Phenomenon of interest
- Setting
  - Paediatric Febrile Neutropenia
  - Adult Febrile Neutropenia
  - Other paediatric chronic condition with potentially life-threatening exacerbations
    - Give further details
- Participants
  - Patients/parents/carers/healthcare professionals
  - Number of participants
  - Age
  - Gender
  - Further participant details
- Data analysis
  - Software used
  - Techniques used
    - Contextual analysis
    - Comparative analysis
    - Thematic analysis
    - Discourse analysis
    - Content analysis
    - Other (give further details)
- Authors’ main conclusions

Other information/Comments