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A qualitative study of the needs of injured children and their families after a child's traumatic injury

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Title: A qualitative study of the needs of injured children and their families after a child's traumatic injury.

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ABSTRACT

Objective: To explore the needs of children and their families after a child's traumatic injury.

Design: Qualitative interview study.

Participants: 32 participants; 13 children living at home after a traumatic injury, their parents/guardians (n=14) and five parents whose injured child did not participate.

Setting: Two Children's Major Trauma Centres in England.

Results: Interviews were conducted a median 8.5 months (IQR 9.3) post injury. Injuries affected the limbs, head, chest, abdomen, spine or multiple body parts. Education and training were needed to help children and families understand the injury, how best to look after it and prepare for discharge. Information delivery needed to be timely, clear, consistent and complete, include the injured child, but take into account individuals' capacity to absorb detail. Quick and easy access to information was key, irrespective of the method of delivery. Similarly, services needed to be timely and easily accessible with flexible protocols and eligibility criteria to include injured children. Treatment (particularly therapy) needed to be structured, goal directed and of sufficient frequency to return injured children to their full function. A central point of contact is required after hospital discharge for advice, reassurance and to co-ordinate on-going care. Positive partnerships with professionals helped injured children and their families maintain a sense of hope and participate in joint decision-making about their care.

Conclusion:

Injured children and their families' needs focussed on education and training, effective information and communication, access to flexible specialist services, support to co-ordinate care, and positive relationships with professionals to provide flexible, patient centred care.

ARTICLE SUMMARY

Strengths and Limitations

- To improve the generalisability of the results we used a purposeful sampling for maximum variation, rather than a sample of convenience and we believe the participants in this study are broadly representative of children with severe trauma injuries and their families. [1]
- To our knowledge this is a first study to examine post-discharge needs for a broad range of injuries and ages from the perspectives of both the injured children and their parents.
- Age specific needs have previously been identified for adolescents. [2] Our initial intention was to explore age specific needs, but the data analysis showed that the identified needs were generic across all ages.
- However, more age-related needs may have been identified if there were greater numbers of participants across the different age ranges and interview probes placed more emphasis on issues relevant to age.

INTRODUCTION

Injury is a leading cause of death and disability in children and young people, [3] which can affect quality of life and result in a significant burden of care over the child's life span. [4] Centralised major trauma systems in England have successfully improved survival, [5] but rehabilitation has not matched the improvements in acute care. [6] Under the UK's major trauma system, an assessment of patients' need for rehabilitation should be completed in hospital and when appropriate at the point of discharge. [7] However, recovery and rehabilitation continue beyond the acute hospital admission and it is equally important to identify needs during the remainder of recovery. Furthermore, health and education services are generally aimed at children with development disabilities or long-term conditions rather than those acquired from an injury. [8] Children with newly acquired injuries are unlikely to have access to standardised pathways of care or long-term therapists who are well versed in their needs. In order to develop such services, it is critical to understand injured children's rehabilitation needs.

The literature on injured children's needs has focussed on specific types of injures, primarily traumatic brain injuries; [2,9–15] the needs of parents or family members rather than the injured child, [11,13,15,16] or the specific needs of adolescents. [2,10] The aim of this study was therefore to explore the needs of injured children and their families for children of all ages and a broad range of injuries to obtain information to inform the delivery of patient-centred services.

METHODS

Study design and setting

This was a qualitative interview study conducted at two Children's Major Trauma Centres in England between March 2018 and August 2019. The study was approved by the National Health Service, North West - Greater Manchester South Research Ethics Committee (REC reference 17/NW/0615) and the Health Research Authority. The University of Manchester was the study sponsor.

Participants

Admission records were screened for 1) children aged 6-15 years admitted to a specialist Major Trauma Centre with moderate to severe traumatic injury (Injury Severity Score>8) who were discharged from the Centre within the previous 12 months. 2) Parents or guardians of injured children who fulfilled the criteria. Parents of younger children aged two to 5 years at the time of injury were also included. Participants were not included if they had been discharged within the previous two weeks (as it was felt that they would have insufficient experience of being home to fully contribute: Babies/infants (less than two years old), children with isolated burn injuries (as they were managed in separate care pathway), non-accidental injuries, or those for whom there were significant safeguarding concerns. A purposeful approach to sampling was used to account for perspectives from a range of injuries (in terms of severity and the types of injury), genders, ages and times since injury.

Data collection

Potential participants were invited to take part by post or face-to-face contact with trauma co-ordinator using age appropriate study information packs. Consent was obtained from the parents and assent from the children before the interview started. All interviews were conducted by SJ who is a clinical researcher/major trauma co-ordinator and has completed training in interviewing children. A flexible interview format was used and participants were given the choice of conducting interviews; jointly (child and their parent/guardian together) or separately, on the telephone or in person. A semi-structured topic guide was used to explore the child's and when appropriate, parent's or family's needs. Interview questions related to participants perceptions of the care and support they received after hospital discharge. The semi-structured nature of the interviews allowed participants to explore other topics which they considered relevant such as inpatient care. Interviews were digitally recorded and transcribed verbatim. Data collection ceased once data saturation and sufficient variation in the sample were attained.

Analysis

The interviews were audio-recorded and the anonymised transcriptions were thematically analysed using Excel and NVivo 11. [17] SJ became familiar with the data by re-reading transcripts to identify and develop potential themes. Initial themes and sub-themes were based on their relevance to the research question [18] and were refined through discussions with the research team (SJ, ST, JY). SJ reviewed the full transcripts to identify quotes which represented the existing themes and could be coded as such. A theoretical thematic analysis was used in which the researcher used her knowledge and interest in the area to guide the coding. This was most suitable approach because a specific research question had been defined. [18] However, some quotes resulted in the development of emergent themes which came solely from the data. An example of which was 'partnerships between professionals and patients. The research team met regularly to discuss the interpretations, alternative explanations for emergent findings and agree on the themes. Data within emergent findings was reviewed to check the relevance to the research question and that there was sufficient data to justify new themes.

Patient and public involvement

The Women and Children's Patient and Public Involvement Team from Manchester Academic Health Science Centre provided feedback on the study documents (Patient information sheets, consent and assent forms).

RESULTS

Twenty-six interviews were conducted involving 32 participants; 13 children and their parents/guardians (n=14) and five parents whose injured child did not participate. Interview duration ranged 11 to 76 minutes. The format for the interviews is summarised in Table 1 and the characteristics of injured children in Table 1.

Table 1 Interview structure

Interview format	**Participants**	**Method**	**Number of participants**
5 Parents only	5 mothers	3 Telephone 2 In person	5
5 Dyads (joint interviews with child & their parent/guardian)	5 children & their parents (4 mothers & 1 guardian)	All in person	10
7 Dyads (child & their parent interviewed separately)	7 children & their parents (7 mothers)	All in person	14
1 Triad (child interviewed separately, mother and father together)	1 child & their parents (1 mother & 1 father)	All in person	3
Total number of participants			32

Table 2 Characteristics of injured children (13 participants, 5 who did not participate but whose parents were interviewed)

Characteristics	
Gender	Male 11 Female 7
Age at time of interview (years)	Range 5 to 15 (Median 12.0, IQR 2.8)
Injury mechanisms	4 Road traffic accidents 3 Sport 1 Fall >2 metres 5 Fall <2 metres 5 Other mechanism
Type of injury	1 Isolated head injury 1 Isolated spinal injury 3 Isolated abdominal injuries 1 abdomen & chest 6 Injuries to limb(s) 6 Multiple injuries
Time since injury (months)	Range 1 to 12.5 (Median 8.5, IQR 9.3)

Most participants, particularly the children were unfamiliar with the concept of 'needs' as this is an abstract concept coined by healthcare professionals, thus they seldom talked specifically about their needs. However, needs were implicit in all participants' narratives about how their healthcare was delivered, regardless of whether they were satisfied with their care or whether their needs had been met. Each participant described their own unique experiences and although these varied, they often pointed towards the same types of needs. The focus of the interviews was after hospital discharge, but the researcher gave participants the flexibility to discuss matters which were important to them including hospital care.

Four overarching themes emerged; Education and training needs, Information needs, Service needs, and Positive partnerships between children, families and professionals.

1. Education and training needs

Education needs

Both injured children and their parents had to assimilate a large amount of information about the accident and injury(ies). For most this was a completely unfamiliar situation and they recognised that they had a lot to learn. Professionals needed to help by educating them about their injury and how to manage it. Parents highlighted the need to be warned or advised about the prognosis and forewarned about symptoms (such as pain, seizures, hallucinations, difficulty concentrating, fatigue) which sometimes occurred unexpectedly. It was also important to understand the reason why they occurred (Box 1: quote 1a, 1b, 1c).

Training needs

Participants identified that they needed training, particularly in preparation for hospital discharge. This included issues such as how to look after wounds and scars; mobilise; and return to activities and school. They needed opportunities to develop coping strategies and to practice on-going care and treatments while in hospital to develop competence. This gave them confidence to execute these tasks at home. For more severely injured children this need went beyond merely practicing in the hospital environment. The opportunity to practice at home during weekend leave made the eventual return home more manageable (Box 1: quote 1d).

Box 1: Quotes regarding education and training needs

Sub-theme	**Quote and participant**
Education needs	1a) *"…They did say to us that they would be… …a miracle if they managed to save his eye. That was our worst-case scenario."* (Parent 11) 1b) *"These sudden pains didn't start for a while after. I didn't know they were coming……and then…..I felt like, "what's this? ……why is she getting these and is it.... fine that she should be exercising?"* (Parent 16) 1c) *"if there would have been any side effects, or things, to look out for, you know?....like I suppose like you get on any medicine"* (Parent 26)
Training needs	1d) *"That really did help……I just felt prepared then. It was like "right, we can do it at the hospital, we can do it at home."* (Parent 12)

2. Information needs

Information needs

Participants needed timely information to be provided in sufficient detail to understand *"what was going on"*. Delays in receiving information predominately related to administration (particularly referrals and transfer of health records), meetings and short notice of operation cancellations. Several found the systems in place outdated (Box 2: quote 2a). The desired level of detail varied, but all participants needed information to be clear and consistent. They often explained how helpful they found well-executed explanations from professionals (Box 2: quote 2b).

Consistency of information was essential, but it was often conflicting. Participants attributed this to the use of medical jargon in written and verbal reports, the number of professionals involved in care and the different approaches between health professionals/hospitals (Box 2: quote 2c). This conflicting information and advice caused *"tension"* and *"confusion."* Participants reported that they were sometimes left not knowing what to expect or the best way of managing the injuries. They recommended closer liaison between health professionals.

Related to consistency of information, was participants' need for up-to-date information. They needed to be informed clearly and consistently about any changes in diagnosis, prognosis, management plan or expected symptoms throughout all stages of their care. Information was often considered insufficient. Gaps in information delivery were attributed to health professionals not spending enough time with participants, not knowing specific facts or presenting the information which they considered the most important. For example, one family only became aware of the full details of their child's head injury when they reviewed the consent form for a procedure (Box 2: quote 2d).

Effective communication and information sharing

Participants were asked about how information was provided for them, and what they wanted and needed. Irrespective of the format, participants identified that information needed to be available quickly and easily. Most parents considered written information to be useful, particularly copies of clinic and referral letters and other relevant correspondence. This enabled them to monitor progress of care and to play an active role in their child's care. Written information was frequently needed to share information with other health professionals and external agencies (such as schools) who often required "*a written letter from doctor.*" Several found it difficult to absorb written information (such as leaflets and booklets) given their emotional state, although several acknowledged these were valuable *"to refer back to"*. However, many parents preferred to liaise directly with health care professionals in person or via texts, phone-calls and emails as their primary source of communication and information (Box 2: quote 2e). Similarly, injured children preferred to ask their parents questions rather than professionals. However open conversations with professionals which included, and were directed towards the injured child were valued (Box 2: quote 2f). The use of visual aids, such as x-rays and scans also helped participants understand the injury, particularly when there were no visible physical signs. One child used his abdominal scan to help his peers understand the severity of his injury.

Dissatisfaction with information and communication arose when participants were repeatedly asked the same questions by health professionals; when information was not shared between health professionals, and when participants were not advised of the outcomes of investigations or test results, or changes to care plans.

Box 2: Information needs

Sub-theme	**Quote and participant**
Information needs	2a) *"I don't understand why a hospital can't just get in the modern world and email people……or phone them up and do a referral. Why they have to type and dictate a letter and it takes two weeks for it to get to the person they need it to get to."* (Parent 7)

	2b) *"they [the injuries] seemed quite complicated at first……because there was a lot….. They listed them,………, so they laid it out clearly….., They just kind of explained each one to me......And …showed me some x-rays."* (Child 10). 2c) *"I think the difficulty is in the hospital, there's loads of registrars doing ward rounds and stuff that don't have a consistent approach. So they… would come to you and tell you different things."* (Parent 8) 2d) *"It said … "fractured skull". We were like,…, "it's the first we've heard of it"….. So, that was kind of disappointing really, that we hadn't heard that."* (Parent 18)
Effective communication and information sharing	2e) *"We can just email at any stage if we've got any questions, which is fantastic. Anything I'm worried about, just email and they'll…respond straightaway."* (Parent 9) 2f) *"I thought that was really good actually. A lot of the time they speak to [Injured child] rather than to me? Because he's the injured one and worrying."* (Parent 23)

3. Service needs

Participants were clear about what they needed from services. They needed services to be accessible, timely, sufficient, structured and co-ordinated. Although many positive experiences and satisfaction were expressed, this was not universal. The types of difficulties outlined were not limited to one type of service: unmet needs for accessible services were described for most types of service.

Accessible and timely services

After hospital discharge, services needed to be provided locally or at the participants' homes, often 'out of hours' or with 'open appointments' to enable participants to obtain care or assessments when needed (Box 3: quote 3a). However, many factors made services difficult to access. Participants described lengthy or difficult journeys to their healthcare provider; a lack of 7-day services and strict eligibility criteria which excluded children (but with no specialist children's services were available), or children's services which excluded those with acquired problems in favour of children with chronic conditions (Box 3: quote 3b). Additionally, rigid protocols prevented access to services such as school transport and equipment. For example, one injured child could only receive one set of equipment although they lived in two homes as their parents were separated. Services could not accommodate this commonplace living arrangement and would only supply one set of equipment.

The timing of services was very important; participants often experienced long waiting lists for services to start (particularly therapy) and cancelled operations. They were concerned about the negative impacts this had on the injured child's physical and psychological recovery and well-being (Box 3: quote 3c). A couple of participants proposed that appointments could be quicker if telephone consultations were available, or if primary and secondary care services worked more closely together to prioritise injured children more appropriately (Child 21 and Parent 22).

Dose and structure of treatment

Participants also needed services to provide sufficient treatment. Many described unmet needs relating to low staffing levels (particularly hospital nurses), lack of children's mental health services and insufficient doses of therapy, mostly physiotherapy (Box 3: quote 3d). Another issue was that treatment (often physiotherapy or occupational therapy) needed to have a greater scope of ambition for the injured child's recovery. Rehabilitation goals whether set with therapists or autonomously were considered essential to gauge improvement, inspire motivation and provide a focus for the future (Box 3: quote 3e). However several participants reported that therapy finished before the injured child had reached their goals to return to physical education, competitive sport or other activities (i.e. they had not reached their rehabilitation potential). In order to deal with these unmet rehabilitation needs, participants devised their own exercise and rehabilitation regimes; requested physiotherapy reviews or funded therapy privately. Participants needed rehabilitation to be clearly structured because the injury(ies) disrupted their usual routines.

Co-ordination of care

Care and rehabilitation of children with severe traumatic injuries often involves input from multiple professionals and services over an extended period to manage complex, sometimes sensitive problems. Participants very clearly articulated the need for this complex, multi-agency, multi-facetted, often long-term care to be co-ordinated by a health care professional. They highlighted the need for help to co-ordinate timely provision of appropriate equipment, appointments (such as out-patient clinics), care packages and return to education (whether school or home schooling) and other activities (Box 3: quote 3f).

Co-ordinating on-going care after discharge, such as clinic appointments and referrals was a particular issue for most participants, regardless of the severity of injury or the number of specialist services involved. They valued help to ensure referrals and appointments were made; attempts to streamline appointments to minimise the number of trips and disruption to schooling and employment; prompt notification of appointments; timely reminders and help to re-arrange appointments if necessary. When this co-ordination was not available, participants described unsatisfactory experiences (Box 3: quote 3g).

Most participants acknowledged that they needed a named contact to be involved throughout their hospital stay, through discharge and for on-going care. They needed to provide the co-ordination described above, plus information, advice, on-going monitoring of recovery and needs, reassurance and emotional support (Box 3: quotes 3h and 3i).This named contact was often a trauma coordinator, but participants also found their GP a helpful point of reference and a means of accessing other services. Part of the co-ordinators role also needed to 'signpost' children (and their families) to access appropriate on-going care. Participants reported how problems and symptoms, particularly post-traumatic distress and mental health problems often only became apparent after hospital discharge. To address such problems, participants needed to know what sources of help were available and how to access them. They described how they needed *"to be put in touch with the right people"*.

This signposting role extended beyond health care services. There was a particular need to co-ordinate multi-agency care (usually for the more severely injured children) as participants did not have the knowledge, skills or experience to negotiate the highly complex and variable systems, particularly when community or education services were involved. Many met and unmet needs were highlighted regarding return to education (whether at school or at home) after a traumatic injury and these are addressed in a separate publication.

Box 3: Service needs, partnerships between patients and professionals

Sub-theme	**Quote and participant: Service needs**
Accessible and timely services	3a) *"We had an open appointment arrangement with the physio, where we could ring up if there was a problem."* (Parent 6)

	3b) *"They [district nurses]… told me that they don't deal with anybody under the age of eighteen."* (Parent 8) 3c) *"We were thrown into two weeks of, is he having brain surgery, is he not? And it happened, you know, twice, two cancellations. And that is such a huge thing for your heart to cope with."* (Parent 18)
Dose and structure of treatment	3d) *"We could just see that it [physiotherapy] wasn't gonna be what [injured child] needed. She needed more…… she wasn't even gonna start for at least a couple of weeks"* (Parent 9). 3e) *"That really helped. We set some [goals] in hospital, didn't we? Something to do in the future like……….., what do you want to do for your birthday? So I was like, I'd always wanted to go, like, Harry Potter World or something."* (Child 21).
Co-ordination of care	3f) *"I don't think I could have coped, if I'd had to ring up all them people and sort all her [injured child's] care package out, I couldn't have coped."* (Parent 2) 3g) *"well we've got his appointment through. As I say, we were expecting it. They said it would be within six weeks, but it's actually 13…it'll be 13 weeks since the accident."* (Parent 26) 3h) *"When I rang the nurse though, they were really reassuring, and they sort of said "I don't think it's anything too much to worry about, but mention it to the neurosurgeons". So, it did allay my fears a bit."* (Parent 19) 3i) *"he just reassured me a lot and answered a lot of questions that I had about going …back to school and sorting things out"* (Child 21)
Main Theme	**Quote and participant**

Partnerships between patients and professionals	4a) *"They [hospital staff] kept us positive and…yeah, didn't make us feel that, God, this was, you know, absolutely disastrous, but she was gonna get better."* (Parent 9) 4b) *"I think the fact it was a children's hospital and they knew exactly what they were doing… You feel confident."* (Parent 26) 4c) *"Originally I couldn't even get [injured child] there [Psychology Department]. But the therapist from CAMHS built up such a good relationship."* (Parent 12) 4d) *"we just discussed it as a whole family and [trauma co-ordinator] …everything that was worrying [Injured Child]… . And then she just literally said "right. I can fix that, that, that, that and that, but I can't do this… but I know somebody who might be able to, so let me look into it, leave it with me."* (Parent 21) 4e) *"They [the council] were supposed to provide some equipment for the bath. And it never materialised. They came out, they brought the wrong bath board. And then they said they'd come out again. But they didn't."* (Parent 12)

4. Partnerships between patients and professionals

Participants explained how they needed positive, supportive, trusting partnerships with the professionals involved in their care. A positive outlook from professionals helped to boost morale and gave a sense of hope and helped the injured children and their families feel emotionally supported (Box 3: quote 4a). This also related to the need to be able trust the skills, competence and reliability of the professionals and organisations involved in the injured child's care, which gave them confidence and reassurance (Box 3: quote 4b). This trust was also needed to persuade the injured children to adhere to aspects of treatment which they disliked and enabled professionals and participants to work effectively together (Box 3: quote 4c).Several children disliked certain aspects of their treatment (e.g. wearing an eye patch or orthotic devices) and were reluctant to adhere to them. To minimise this problem, children and their families needed to *"feel heard"*, be involved in discussions and decisions about their care, to jointly solve problems by exploring alternative treatment options and finding mutually agreeable solutions or compromises (where possible) (Box 3 quote 4d).However not all relationships between services and participants were positive. There were several reports of inadequate, possibly incompetent care. Examples included incorrect application of orthotics, medical errors, failure to adhere to major trauma pathways, referrals which were not made, delayed appointments etc. In these cases, participants felt they had not been listened to by health professionals, nor involved in discussions/decisions about their care. Consequently, they could not rely on some aspects of service provision (Box 3 quote 4e).

DISCUSSION

The results of this study showed that injured children and their families' needs focus on education and training; effective communication; access to services; support to co-ordinate care; and positive partnerships with professionals.

Participants' unmet need for clear, consistent and complete information across the full recovery continuum echoes findings from previous studies. [11,12,19] However, participants needs and preferences varied, so consideration was needed to individualise the information and ensure it is available in a range of different formats, as well as ensuring the injured child and other family members are included in honest and open discussions. Additionally, clearer information to manage expectations may be required when details are unknown or subject to change, particularly care plans. Although written information was often useful, this needed to be conveyed quickly (by email or text for example) and act as a supplement to verbal communication.

Access to services was a frequent unmet need. Most participants described a *"post code lottery"* when it came to rehabilitation. This is a common problem, [11,14,20,21] particularly for services relating to cognitive or mental health difficulties. [9,14,21] The haphazard and inadequate nature of trauma rehabilitation services has been recognised previously, [6,22] particularly as most services focus on children with chronic conditions. Moreover services for adults and children are often inequitable, for example adult hip fracture care is provided according to national guidance and linked to the payment of a best practice tariff, but the equivalent systems are not in place for children's femoral fractures. [23]

There is a clear need to develop comprehensive, streamlined rehabilitation services for children with acquired injuries, whose needs may (or may not) be temporary or change over time. This could be achieved by expanding the UK's major trauma networks to include specialist community-based paediatric trauma rehabilitation, but this would require sustained funding and training. [24,25] Work is currently underway to address these issues.

In agreement with previous studies, there was an overwhelming need for a single-point of contact during and after hospital discharge. [2,11,21,26,27] This was needed to help patients' access professional support and to co-ordinate the multiple professions, specialities, agencies and organisations involved in their care. A single point of contact is required over the long-term because on-going problems are highly prevalent for several years after severe injury, [27,28] but may not become apparent until after the child has been discharged from hospital, and attempts to return to their normal life. [9,14] Current clinical guidelines state that every patient with a moderate to severe injury should have their rehabilitation needs assessed [29] within 48 to 72 hours of hospital admission, and at discharge from hospital (for those previously recognised to have rehabilitation needs). [7] This is achieved through the completion of a ‘rehabilitation prescription’. Although this is a good starting point, the rehabilitation prescription has limitations, not least because it does not detect or address problems which develop after hospital discharge. A system is required which continues to screen for (and then treat and monitor) problems after hospital discharge. This may be most pragmatically addressed by a comprehensive needs assessment tool which can be completed by the patient/family at regular intervals throughout the full trajectory of recovery. Work to develop such a tool which is suitable for all ages of children, types of injury and stages of care is underway. Furthermore, a named co-ordinator/key worker is needed to provide long-term support and to co-ordinate care. This could contribute to the trusting positive partnerships that participants emphatically needed for more patient-centred care and enabling joint decision making. [30] A sense of hope was maintained through such partnerships and this is recognised as important aspect of trauma care to support the emotional recovery. [12,31] Although, some major trauma services provide this service, many only provided a specialist co-ordinator for hospital-based care. [21] Further work to develop and evaluate such services is clearly needed.

CONCLUSION

Severely injured children and their families require services that provide education and training; effective information and communication; access to timely, specialist services at sufficient dose; co-ordination of support and on-going care, and positive relationships between staff and patients.

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	Title page

Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	Abstract
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	Page 4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	Page 4
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and	Page 5,6

		transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	[#6](#6)	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	Page 5,6
Context	[#7](#7)	Setting / site and salient contextual factors; rationale	Page 5
Sampling strategy	[#8](#8)	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	Page 5,6
Ethical issues pertaining to human subjects	[#9](#9)	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 5
Data collection methods	[#10](#10)	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	5,6

Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	Page 5,6
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 7,8
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	Page 5,6
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Page 5,6
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	Page 5,6
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 9 to 21

Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	19,20,21
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	19,20,21
Limitations	#19	Trustworthiness and limitations of findings	3
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	22
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	22

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A qualitative study of the needs of injured children and their families after a child's traumatic injury

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ABSTRACT

Objective: To explore the needs of children and their families after a child's traumatic injury.

Design: Semi-structured qualitative interviews with purposeful sampling for different types of injuries and a theoretical thematic analysis.

Participants: 32 participants; 13 children living at home after a traumatic injury, their parents/guardians (n=14) and five parents whose injured child did not participate.

Setting: Two Children's Major Trauma Centres (hospitals) in England.

Results: Interviews were conducted a median 8.5 months (IQR 9.3) post injury. Injuries affected the limbs, head, chest, abdomen, spine or multiple body parts. Participants highlighted that throughout their recovery (during and after inpatient stay). Education and training were needed to help children and families understand and manage the injury, and prepare for discharge. Information delivery needed to be timely, clear, consistent and complete, include the injured child, but take into account individuals' capacity to absorb detail. Similarly, throughout recovery, services needed to be timely and easily accessible, with flexible protocols and eligibility criteria to include injured children. Treatment (particularly therapy) needed to be structured, goal-directed and of sufficient frequency to return injured children to their full function. A central point of contact is required after hospital discharge for advice, reassurance and to co-ordinate on-going care. Positive partnerships with professionals helped injured children and their families maintain a sense of hope and participate in joint decision-making about their care.

Conclusion: Throughout the full trajectory of recovery injured children and their families need patient-centred, accessible, flexible co-ordinated health services, with more effective

harmonious communication between professionals, the child and their family. There is a requirement for support from a single point of contact and a system that monitors the needs of the injured child and their family after hospital discharge.

ARTICLE SUMMARY

Strengths and Limitations

- To improve the generalisability of the results we used a purposeful sampling for maximum variation, rather than a sample of convenience and we believe the participants in this study are broadly representative of children with trauma injuries and their families.
- To our knowledge this is a first study to examine needs throughout recovery for a range of different injuries and ages from the perspectives of both the injured children and their parents.
- Different needs may have been identified if the interviews had involved more fathers and/or greater numbers of participants across the different age ranges.
- Joint interview formats may have influenced or limited the scope of the topics discussed by either the child or the parent, but a positive aspect of this format was that parents were able to provide insightful prompts, beyond the scope of the researcher.
- Self-reported needs are subjective and have not been quantified with any objective measurements.

INTRODUCTION

Injury is a leading cause of death and disability in children and young people, [1] which can affect quality of life and result in a significant burden of care over the child's life span. [2] Centralised major trauma systems have demonstrated improvements in survival from severe injury. [3] Despite the improvements in acute care, the rehabilitation which follows is an emerging priority for improvement. [4] There is a need to strengthen rehabilitation for trauma, as unmet rehabilitation needs represent a worldwide problem. [5]

It is important to improve children's care beyond the acute hospital admission to enable children to reach their full emotional, social, physical and vocational potential. [6] However, health and education services are generally aimed at children with development disabilities or long-term conditions rather than those acquired from an injury. [7] Children with newly acquired injuries are unlikely to have access to standardised pathways of care or long-term therapists who are well versed in their needs. The unique nature of each child's injury, situation and difficulties means that rehabilitation ought to be tailored to their specific needs. Thus, an effective starting point for rehabilitation is to understand the needs of the injured child and their family to enable an individualised approach to their care.

Previous research, including our work to review needs following childhood injury, [8] highlighted a range of needs; particularly support with psychosocial problems for injured child and their other family members, [8–16] as well as physical and practical problems, [13,17,18] support to facilitate the child's transitions from hospital to home, [19] and return to school. [20,21] The need for information about the injury and it's management are reoccurring themes in trauma related research. [9,19,22–25] However, the current evidence base focusses on the needs of children with traumatic head injuries. [8,13,16,26] Children and families with other types of injury have received little attention. Furthermore the research on the needs of injured children after traumatic brain injury mainly considers the needs of parents or family members rather than the injured child, [9,14,27,28] or the specific needs of adolescents. [24,29] This study aims to address this gap in the evidence by exploring the needs of injured children and their parents, including children of all ages (aged to 2 to 15 years), with a range of different injuries affecting different body parts. This will help to inform the delivery of patient-centred services.

METHODS

Study design and setting

This was a qualitative interview study conducted at two Children's Major Trauma Centres in England between March 2018 and August 2019. The study was approved by the National Health Service, North West - Greater Manchester South Research Ethics Committee (REC reference 17/NW/0615) and the Health Research Authority.

Participants

Major trauma co-ordinators in the participating centres screened admission records to identify potential participants to take part in the study. To be included participants needed to be:

1) children aged six to 15 years admitted to a specialist Major Trauma Centre with moderate to severe traumatic injury (Injury Severity Score>8) who were discharged from the Centre within the previous 12 months.

2) Parents or guardians of injured children who fulfilled the criteria.

3) Parents of younger children aged two to five years at the time of injury were also included.

The following exclusion criteria were applied:

1) Participants who had been discharged within the previous two weeks (as it was felt that they would have insufficient experience of being home to fully contribute).

2) Babies/infants (less than two years old).

3) Children with isolated burn injuries (as they were managed in separate care pathway).

4) Non-accidental injuries, or those for whom there were significant safeguarding concerns.

A purposeful approach to sampling was used to account for perspectives from a range of injuries, genders, ages and times since injury.

Data collection

Potential participants were invited to take part by using age appropriate study information packs which were either posted or provided in person by a trauma co-ordinator. Consent was obtained from the parents and assent from the children before the interview started. All interviews were conducted by SJ who is a clinical researcher/major trauma co-ordinator and has completed training in interviewing children. A flexible interview format was used and participants could choose: who participated (joint child and parent, or solely the child or parent), where the interview took place (home, hospital, neutral location) and how the interview was conducted (telephone, face-to-face). However, for interviews involving children a face-to-face format was recommended.

A semi-structured topic guide was used to explore the child's and when appropriate, parent's or family's needs (Appendix 1). Questions were simplified to suit children of younger ages. Interview questions related to participants' perceptions of the care and support they received throughout recovery (during inpatient care and after hospital discharge), but the semi-structured nature of the interviews allowed participants to explore other topics which they considered relevant. Interviews were digitally recorded and transcribed verbatim.

Analysis

Anonymised transcriptions were thematically analysed using Excel and NVivo 11. A theoretical thematic analysis was use to analyse the data, which was considered to be the most suitable method of analysis as a specific research question had already been identified. [30] When using a theoretical thematic approach, the analysis is driven by the researchers' knowledge and experience in the field. The researcher had insights into the needs of injured children and their families because of her clinical and research experience with this group and topic. [8] This knowledge was used to develop a coding framework of some main themes. Firstly, SJ became familiar with the data by re-reading the transcripts. She then coded the data to categorise it within the existing coding framework or determine whether codes pointed towards a new theme. The research team (SJ, ST, JY) met regularly to review the coded data, verify its relevance to main themes and discuss the interpretations, alternative explanations for emergent findings and agree on any new theme headings which were required. Data were coded as interviews were conducted. Data collection ceased once data saturation and sufficient variation in the sample were attained. Data saturation was deemed as the point at which coded data from new interviews only added to existing themes and no new themes were developed. Field notes were maintained for the interviews to contextualise and reflect on the data, such as how forthcoming children were in the interviews. Any actions required from the interviews were documented in the field notes.

Patient and public involvement

The Women and Children's Patient and Public Involvement Team from Manchester Academic Health Science Centre provided feedback on the study documents (Patient information sheets, consent and assent forms).

RESULTS

Twenty-six interviews were conducted involving 32 participants; 13 children and their parents/guardians (n=14) and five parents whose injured child did not participate. One child was too young to participate according to the study criteria, two children were not considered to be at an appropriate point in their psychological recovery, one child did not wish to take part and for one child it was logistically too difficult to arrange a face to face interview. Interview duration ranged 11 to 76 minutes. The format for the interviews is summarised in Table 1 and the characteristics of injured children in Table 2. All the interviews conducted in person took place in participants' homes, with the exception of two interviews which were conducted at the hospital (one parent interview and one parent-child dyad interview).

Table 1 Interview structure

Interview format	Participants	Method	Number of participants
5 Parents only	5 mothers	3 Telephone 2 In person	5
5 Dyads (joint interviews with child & their parent/guardian)	5 children & their parents (4 mothers & 1 guardian)	All in person	10
7 Dyads (child & their parent interviewed separately)	7 children & their parents (7 mothers)	All in person	14
1 Triad (child interviewed separately, mother and father together)	1 child & their parents (1 mother & 1 father)	All in person	3
Total number of participants			32

Table 2 Characteristics of injured children (13 participants, 5 who did not participate but whose parents were interviewed)

Characteristics	
Gender	Male 11 Female 7
Age at time of interview (years)	Range 5 to 15 (Median 12.0, IQR 2.8)
Injury mechanisms	4 Road traffic accidents 3 Sport 1 Fall >2 metres 5 Fall <2 metres 5 Other mechanisms
Type of injury	1 Isolated head injury 1 Isolated spinal injury 3 Isolated abdominal injuries 1 abdomen & chest injuries 6 Injuries to limb(s) 6 Multiple injuries
Time since injury (months)	Range 1 to 12.5 (Median 8.5, IQR 9.3)

Most participants, particularly the children were unfamiliar with the concept of 'needs' as this is an abstract concept coined by healthcare professionals, thus they seldom talked specifically about their needs. However, needs were implicit in all participants' narratives about how their healthcare was delivered, regardless of whether they were satisfied with their care or whether their needs had been met. Participants described their own unique experiences and although these varied, they often pointed towards the same types of needs. The focus of the interviews was after hospital discharge, but the researcher gave participants the flexibility to discuss matters which were important to them including hospital care. School-based service needs were identified in the analysis, but have been addressed in a separate paper due to the range and depth of information obtained relating to these needs. Parents and older children were able to give the most information about their needs.

Four overarching themes emerged; Education and training needs, information needs, service needs, and positive partnerships between children, families and professionals.

Education and training needs

Education needs

Both injured children and their parents had to assimilate a large amount of information about the accident and injury(ies). For most this was a completely unfamiliar situation and they recognised that they had a lot to learn. Professionals needed to help by educating them about their injury and how to manage it. Parents highlighted the need to be warned or advised about the prognosis and forewarned about symptoms (such as pain, seizures, hallucinations, difficulty concentrating, fatigue) which sometimes occurred unexpectedly. It was also important to understand the reason why they occurred (Box 1: quote 1a, 1b, 1c).

Training needs

Participants identified that they needed training, particularly in preparation for hospital discharge. This included issues such as how to look after wounds and scars, mobilise, and return to activities and school. They needed opportunities to develop coping strategies and to practice on-going care and treatments while in hospital to develop competence. This then gave them confidence to execute these tasks at home. For more severely injured children this need went beyond merely practicing in the hospital environment. The opportunity to practice at home during weekend leave made the eventual return home more manageable (Box 1: quote 1d).

Information needs

Information needs

Participants needed timely information to be provided in sufficient detail to understand *"what was going on"*. Delays in receiving information predominately related to administration (particularly referrals and transfer of health records), meetings and short notice of operation cancellations. Several found the systems in place outdated (Box 1: quote 1e). The desired level of detail varied, but all participants needed information to be clear and consistent. They often explained how helpful they found well-executed explanations from professionals (Box 1: quote 1f).

Consistency of information was essential, but it was often conflicting. Participants attributed this to the use of medical jargon in written and verbal reports, the number of professionals involved in care and the different approaches between health professionals/hospitals (Box 1: quote 1g). This conflicting information and advice caused *"tension"* and *"confusion."* Participants reported that they were sometimes left not knowing what to expect or the best way of managing the injuries. They recommended closer liaison between health professionals.

Related to consistency of information, was participants' need for up-to-date information. They needed to be informed clearly and consistently about any changes in diagnosis, prognosis, management plan or expected symptoms throughout all stages of their care. Information was often considered insufficient. Gaps in information delivery were attributed to health professionals not spending enough time with participants, not knowing specific facts or presenting the information which they considered the most important. For example, one family only became aware of the full details of their child's head injury when they reviewed the consent form for a procedure (Box 1: quote 1h).

Effective communication and information sharing

Participants were asked about how information was provided and what they wanted and needed. Irrespective of the format, participants identified that information needed to be available quickly and easily. Most parents considered written information to be useful, particularly copies of clinic and referral letters and other relevant correspondence. This enabled them to monitor progress of care and to play an active role in their child's care. Written information was frequently needed to share information with other health professionals and external agencies (such as schools) who often required *"a written letter from a doctor."* Several found it difficult to absorb written information (such as leaflets and booklets) given their emotional state, although several acknowledged these were valuable *"to refer back to"*. However, many parents preferred to liaise directly with health care professionals in person or via texts, phone-calls and emails as their primary source of communication and information (Box 1: quote 1i). Similarly, injured children preferred to ask their parents questions rather than professionals. However, open conversations with professionals which included and were directed towards the injured child were valued (Box 1: quote 1j). The use of visual aids, such as x-rays and scans also helped participants understand the injury, particularly when there were no visible physical signs. One child used his abdominal scan to help his peers understand the severity of his injury.

Dissatisfaction with information and communication arose when participants were repeatedly asked the same questions by health professionals; when information was not shared between health professionals, and when participants were not advised of the outcomes of investigations or test results, or changes to care plans.

Box 1: Education, training and information needs

Themes	**Quote and participant**
Education and training needs	1a) *"…They did say to us that they would be… …a miracle if they managed to save his eye. That was our worst-case scenario."* (Parent 11) 1b) *"These sudden pains didn't start for a while after. I didn't know they were coming……and then…..I felt like, "what's this? ……why is she getting these and is it…. fine that she should be exercising?"* (Parent 16) 1c) *"if there would have been any side effects, or things, to look out for, you know?….like I suppose like you get on any medicine"* (Parent 26) 1d) *"That really did help……I just felt prepared then. It was like "right, we can do it at the hospital, we can do it at home."* (Parent 12)
Information needs	1e) *"I don't understand why a hospital can't just get in the modern world and email people……or phone them up and do a referral. Why they have to type and dictate a letter and it takes two weeks for it to get to the person they need it to get to."* (Parent 7) 1f) *"they [the injuries] seemed quite complicated at first……because there was a lot….. They listed them,………, so they laid it out clearly….., They just kind of explained each one to me……And …showed me some x-rays."* (Child 10). 1g) *"I think the difficulty is in the hospital, there's loads of registrars doing ward rounds and stuff that don't have a consistent approach. So they… would come to you and tell you different things."* (Parent 8) 1h) *"It said … "fractured skull". We were like,…, "it's the first we've heard of it"….. So, that was kind of disappointing really, that we hadn't heard that."* (Parent 18)
Information needs: effective communication and information sharing	1i) *"We can just email at any stage if we've got any questions, which is fantastic. Anything I'm worried about, just email and they'll…respond straightaway."* (Parent 9) 1j) *"I thought that was really good actually. A lot of the time they speak to [Injured child] rather than to me? Because he's the injured one and worrying."* (Parent 23)

Service needs

Participants were clear about what they needed from services throughout their recovery. Whether inpatient or community based, they needed services to be accessible, timely, sufficient, structured and co-ordinated. Although many participants expressed positive experiences and satisfaction, this was not universal. The types of difficulties outlined were not limited to one type of service: unmet needs for accessible services were described for most types of community-based services.

Accessible and timely services

After hospital discharge, services needed to be provided locally or at the participants' homes, often 'out of hours' or with 'open appointments' to enable participants to obtain care or assessments when needed (Box 2: quote 2a). However, many factors made services difficult to access after hospital discharge. Participants described lengthy or difficult journeys to their healthcare provider and strict eligibility criteria which excluded children. (Box 2: quote 2b). Additionally, rigid protocols prevented access to services such as school transport and equipment. For example, one injured child lived in two homes as their parents were separated, but services could not accommodate this commonplace living arrangement and would only supply one set of equipment.

In order to be accessible, some services needed to be made available to family members as well as the injured child. Post-traumatic stress type symptoms and/or mental health issues were often experienced in injured child and their family members, including parents, grandparents and siblings (participants' experiences are reported in detail elsewhere). Although the hospital offered psychological support to the whole family, this holistic approach was more difficult to access in the community after hospital discharge (Box 2: quote

2c). However, several participants did not take up psychological support during inpatient stay, as difficulties often only became apparent after discharge when participants tried to return to 'normal 'life'.

The timing of services was very important; participants often experienced long delays for services to start (particularly community therapy) and cancelled operations. Such delays were difficult for families (Box 2: quote 2d). A couple of participants proposed that appointments could be quicker if telephone consultations were available after discharge, or if primary and secondary care services worked more closely together to prioritise injured children more appropriately (Child 21 and Parent 22).

Dose and structure of treatment

Whether during inpatient or community-based care, participants needed services to provide sufficient treatment throughout the continuum of recovery. In the hospital, a lack of nursing staff was highlighted as a key issue. However, there was a notable discrepancy between satisfaction with mental health and therapy services in the hospital and community setting, with such services generally regarded as comprehensive in the hospital, but lacking in the community. After discharge from hospital, participants described a lack of children's mental health services or professionals who deliver specific psychotherapy treatments for children. Similarly, in contrast to the hospital, community-based therapy was often regarded as insufficient (Box 2: quote 2e). Another issue was that treatment in the community (often physiotherapy or occupational therapy) needed to have a greater scope of ambition for the injured child's recovery. Rehabilitation goals, whether set with therapists or autonomously were considered essential to gauge improvement, inspire motivation and provide a focus for the future (Box 2: quote 2f). Several participants reported that community therapy finished before the injured child had reached their goals to return to physical education, competitive sport or other activities (i.e. they had not reached their rehabilitation potential). In order to deal with these unmet rehabilitation needs, participants devised their own exercise and rehabilitation regimes; requested physiotherapy reviews or funded therapy privately. Participants also needed rehabilitation to be clearly structured because the injury(ies) disrupted their usual routines.

Co-ordination of care and ongoing support

Care and rehabilitation of children with traumatic injuries often involved input from multiple professionals and services over an extended period to manage complex, sometimes sensitive problems. Participants very clearly articulated the need for this complex, multi-agency, multi-facetted, often long-term care to be co-ordinated by a health care professional. They highlighted the need for help to co-ordinate timely provision of appropriate equipment, appointments, care packages and return to education (whether this be school or home schooling) and other activities (Box 2: quote 2g).

Co-ordinating on-going care after discharge, such as clinic appointments and referrals were a particular issue for most participants, regardless of the severity or complexity of the injury or the number of specialist services involved. They valued: help to ensure referrals and appointments were made, attempts to streamline appointments to minimise the number of trips and disruption to schooling and employment, prompt notification of appointments, timely reminders and help to re-arrange appointments if necessary. When this co-ordination was not available, participants described unsatisfactory experiences (Box 2: quote 2h).

Most participants acknowledged that they needed a named contact to be involved throughout their hospital stay, through discharge and for on-going care. This professional needed to provide the co-ordination described above, plus on-going monitoring of recovery and needs, reassurance, emotional support and continued advice especially about new symptoms. (Box 2: quotes 2i and 2j). Where available this named contact was often a trauma co-ordinator, but participants also found their general practitioner a helpful point of reference and a means of accessing other services. Part of the co-ordinator's role also needed to 'signpost' children (and their families) to access appropriate on-going care. Participants reported how problems and symptoms, particularly post-traumatic distress and mental health problems often only became apparent after hospital discharge. To address such new problems, participants needed to know what sources of help were available and how to access them. They described how they needed *"to be put in touch with the right people"*. This signposting role extended beyond health care services.

There was a particular need to co-ordinate multi-agency care (usually for the more severely injured children) as participants did not have the knowledge, skills or experience to negotiate the highly complex and variable systems, particularly when community or education services were involved. Many met and unmet needs were highlighted regarding return to education (whether at school or at home) after a traumatic injury and these are addressed in a separate publication.

Box 2: Service needs

Themes	**Quote and participant: Service needs**
Service needs: Accessible and timely services	2a) *"We had an open appointment arrangement with the physio, where we could ring up if there was a problem."* (Parent 6) 2b) *"They [district nurses]… told me that they don't deal with anybody under the age of eighteen."* (Parent 8) 2c) *"I think we were offered everything we…. could have been. I think getting counselling for me mum [child's grandparent] was a bit harder….." [referring to experience after hospital]* 2d) *"We were thrown into two weeks of, is he having brain surgery, is he not? And it happened, you know, twice, two cancellations. And that is such a huge thing for your heart to cope with."* (Parent 18)
Service needs: Dose and structure of treatment	2e) *"We could just see that it [physiotherapy] wasn't gonna be what [injured child] needed. She needed more…… she wasn't even gonna start for at least a couple of weeks"* (Parent 9). 2f) *"That really helped. We set some [goals] in hospital, didn't we? Something to do in the future like……….., what do you want to do for your birthday? So I was like, I'd always wanted to go, like, Harry Potter World or something."* (Child 21).
Service needs: Co-ordination of care	2g) *"I don't think I could have coped, if I'd had to ring up all them people and sort all her [injured child's] care package out, I couldn't have coped."* (Parent 2) 2h) *"well we've got his appointment through. As I say, we were expecting it. They said it would be within six weeks, but it's actually 13…it'll be 13 weeks since the accident."* (Parent 26) 2i) *"When I rang the nurse though, they were really reassuring, and they sort of said "I don't think it's anything too much to worry about, but mention it to the neurosurgeons". So, it did allay my fears a bit."* (Parent 19) 2j) *"he just reassured me a lot and answered a lot of questions that I had about going …back to school and sorting things out"* (Child 21)

Partnerships between patients and professionals

Participants explained how they needed positive, supportive, trusting partnerships with the professionals involved in their care. A positive outlook from professionals helped to boost morale and gave a sense of hope and helped the injured children and their families feel emotionally supported (Box 3: quote 3a). This also related to the need to be able trust the skills, competence and reliability of the professionals and organisations involved in the injured child's care, which gave them confidence and reassurance (Box 3: quote 3b and 3c). This trust was also needed to persuade the injured children to adhere to aspects of treatment which they disliked and enabled professionals and participants to work effectively together (Box 3: quote 3d). Several children disliked certain aspects of their treatment (e.g. wearing an eye patch or orthotic devices) and were reluctant to adhere to them. To minimise this problem, children and their families needed to *"feel heard"*, be involved in discussions and decisions about their care, to jointly solve problems by exploring alternative treatment options and finding mutually agreeable solutions or compromises (where possible) (Box 3 quote 3e). However, not all relationships between services and participants were positive. There were several reports of perceived problems with care. Examples included the incorrect application of orthotics, medication error, issues with adherence to major trauma pathways, referrals which were not made, delayed appointments, etc. In these cases, participants felt they had not been listened to by health professionals, nor involved in discussions/decisions about their care. Consequently, they could not rely on some aspects of service provision (Box 3 quote 3f).

Box 3: partnerships between patients and professionals

Themes	Quote and participant
Partnerships between patients and professionals	3a) *"They [hospital staff] kept us positive and…yeah, didn't make us feel that, God, this was, you know, absolutely disastrous, but she was gonna get better."* (Parent 9) 3b) *"I think the fact it was a children's hospital and they knew exactly what they were doing… You feel confident."* (Parent 26) 3c) *"you know, the people who do these types of operations, they're good at their job" (Child 17)* 3d) *"Originally I couldn't even get [injured child] there [Psychology Department]. But the therapist from CAMHS built up such a good relationship."* (Parent 12) 3e) *"we just discussed it as a whole family and [trauma co-ordinator] …everything that was worrying [Injured Child]… . And then she just literally said "right. I can fix that, that, that, that and that, but I can't do this… but I know somebody who might be able to, so let me look into it, leave it with me."* (Parent 21) 3f) *"They [the council] were supposed to provide some equipment for the bath. And it never materialised. They came out, they brought the wrong bath board. And then they said they'd come out again. But they didn't."* (Parent 12)

DISCUSSION

The results of this study showed that injured children and their families' needs focus on education and training to help understand the injury and how to manage it, effective communication, access to sufficient services, support to co-ordinate care and positive partnerships with professionals.

Participants' unmet need for clear, consistent and complete information across the full recovery continuum echoes findings from previous studies [9,13,23] and is attributed to the range of professionals often involved in trauma care. [23] However, participants' needs and preferences varied, so consideration should be given to individualising the information and ensuring it is available in a range of different formats, as well as ensuring the injured child and other family members are included in honest and open discussions. Additionally, clearer information to manage expectations may be required when details are unknown or subject to change, [9] particularly care plans. Although written information was often useful, this needed to be conveyed quickly (by email or text for example) and act as a supplement to verbal communication. Electronic patient held records or portals have been shown to enhance information and communication exchange, [31,32] and may help to fulfil children's and family's needs for more immediate, accessible and consistent information.

Access to services was a frequent unmet need, which was most pronounced in the community setting. It is unsurprising that most participants described a *"post code lottery"* when it came to rehabilitation in the community setting. All the participants included in this study had been managed in specialist children's Major Trauma Centres. The resources, standards and clinical governance processes present in these centres only cover hospital-based care [4] and do not extend to the community setting, where there are few services specifically for injured children. Similarly, disparities in access to post-discharge rehabilitation for childhood traumatic injury have been reported in the United States. [6] Further research is required to better understand how injured children's community-based rehabilitation can be provided efficiently and effectively.

Inadequate service provision has been reported previously, [7,9,16,33] particularly for services relating to cognitive or mental health difficulties. [12,16,33,34] The current study reinforces this by highlighting that although psychological support during the inpatient stay was comprehensive, it was lacking after discharge, which is when difficulties often emerged. Psychological support services needed to extend throughout the full recovery trajectory and cater for the needs of the whole family unit. To achieve this, the capacity of children's community mental health services needs to expand by training more professionals, [35] and educating both parents [36] and professionals [10] about how to detect signs of post-traumatic stress, particularly as symptoms can present late in recovery. [15,37] In contrast to previous research, our participants placed more importance on the need for physical and practical support. This may reflect the variety of injuries included in our sample, rather than being limited to head injuries.

There is a clear need to develop comprehensive, streamlined rehabilitation services for children with acquired injuries, whose needs may be temporary or change over time. Expansion of the Major Trauma Networks to include all facets of rehabilitation for all ages could provide this support, but this would require sustained funding and training. Like previous studies, we found an overwhelming need for a single-point of contact during and after hospital discharge [9,29,33,38,39] to help patients access professional support and to co-ordinate the multiple professions, specialities, agencies and organisations involved in their care. Co-ordinators could work in conjunction with rehabilitation medicine consultants, [40] who would lead clinical decision making. This approach may achieve more streamlined rehabilitation and consistent communication. Some major trauma services provide a specialist co-ordinator, but this is often limited to hospital-based care. [33] However, support may be required over the long-term as on-going problems are highly prevalent for several years after severe injury, [39,41] but may not become apparent until after the child has been discharged from hospital and attempts to return to their normal life. [12,16] Ongoing support may contribute to trusting, positive partnerships that participants emphatically needed for more patient-centred care and to enable joint decision making. [42] In this study and previous research an important role of a known contact is to provide reassurance and maintain a sense of hope. [13–15,19,36,43] An important aspect of trauma care is to support the emotional recovery [43] of the child and their parents. [36]

A system is required that continues to screen for (and then treat and monitor) problems after hospital discharge. This may be most pragmatically addressed by a comprehensive needs assessment tool which can be completed by the child/family at regular intervals throughout the full recovery. Work is underway to develop such a tool that is suitable for all ages of children, types of injury and stages of care.

Strengths and Limitations

A common criticism of qualitative research is the limited generalisability of the results. [44] To address this, we used a purposeful sampling for maximum variation, rather than a sample of convenience and we believe the participants in this study are broadly representative of children with a range of traumatic injuries. [45] To our knowledge this is a first study to examine needs throughout recovery for a broad range of injuries and ages from the perspectives of both the injured children and their parents. However, the purposeful approach to sampling did not encompass attaining equal numbers of mothers and fathers. The majority of mothers who took part was an unexpected finding, which may have influenced the range of needs and experiences reported. Previous qualitative studies have shown a difference in themes identified for males and females. [46]

Due to involvement of children and sensitive nature of the interview topic (childhood injury) it was important to give participants the opportunity to take part in the interviews in the way that they felt most comfortable. We acknowledge that joint interview formats may have influenced or limited the scope of the topics discussed by either the child or the parent. [47] One positive aspect of joint interviews was that parents were able to provide insightful prompts, beyond the scope of the researcher.

Age specific needs have previously been identified for adolescents. [29] Our initial intention was to explore age specific needs, but the data analysis showed that the identified needs were generic across the ages investigated. More age-related needs may have been identified if there were greater numbers of participants across the different age ranges and interview probes placed more emphasis on issues relevant to age.

We acknowledge that self-reported needs are subjective and have not been quantified with any objective measurements. Self-reported, subjective data can be influenced by different forms of bias, [48,49] including social desirability bias. [49] For example, social desirability bias may have occurred because participants wanted to appear to be coping and thus may have under reported their level of need.

CONCLUSION

This research has helped to identify unmet healthcare needs of a new target population. Children with a range of injuries and their families need patient-centred, accessible, flexible co-ordinated health services throughout the full trajectory of recovery, with more effective harmonious communication between professionals, the child and their family. Trauma rehabilitation should be provided as a continuum of care, part of which should involve the ongoing monitoring of the injured child's and family's needs. Services between hospital and community setting need to be more seamless and equitable. This may be achieved by attaining evidence such as that presented here, about needs through the full trajectory of recovery, which can then be used to inform policy and commissioning.

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Data Sharing statement

All data relevant to the study are included in the article or uploaded as supplementary material.

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APPENDIX 1

	Guide to Questions
Generic needs	Tell me about what was different for **you/ you and your child** following your injury? What help did ***you/your child*** need after your injury?
Discharge specific needs	What was it like for ***you/ you and your child*** when you went home from the hospital? When ***you/your child*** went home from the hospital how did you feel? Did you feel ***you/you and your child*** prepared to go home? Was there anything that worried ***you/ you and your child*** about going home? Did ***you/you and your child*** need any support/help from hospital staff/health professionals when you went home from the hospital? Did you feel that you got the help ***you/you and your child*** needed? Did ***you/your child*** have any difficulties when you went home from the hospital? Was there anything that really helped or made things easier when **you/your child** went home? **Probes:** Equipment, modifications to home, home visits, advice leaflets, meetings before discharge, follow up appointments, phone calls from the hospital.
Key Worker	Did ***you/your child*** have a key worker (a health professional/nurse/physio/occupational-therapist/carer/doctor) who provided help or advice when you went home from the hospital? **If answers yes:** Did you find this helpful? Why was this helpful? What did the key worker do for you? **If answers no:** Do you think that a key worker would have been helpful? What help/support could have they provided?
Information needs	Was **your/your child's** injury explained to you in the hospital? Did you understand the explanation of ***your/your child's injury***? Did you understand how the injury would affect ***you/your child?***

	Were you provided with advice about **what you/your child** was allowed and not allowed to do following ***your/your child's injury?*** Was this easy to understand? Did you receive any advice or information when you were discharged from the hospital? Probe: information booklet, helplines, follow up appointments/ follow up phone calls. **If answers yes:** Was the information helpful/how? Were you given enough information? Was it easy to understand? Who gave you the information? **If answers no:** Was there you wanted to know when you went home from the hospital, which you were not told? Was there anything you had to find out for yourself?
Educational needs	How did ***you/your child*** deal with returning to school after their injury? Did **you/your child** have any difficulties returning to school? Did **your/your child's teachers** know that you/your child had suffered from an injury? **Probes:** Did they understand the injury/do anything differently? Was there anything that really helped **you/your child** when you returned to school? Were there any changes made or advice which made **your/your child's** return to school easier?
Social needs	Did **your** friends/family know about **your/your child's** injury? Do you think they understood what had happened to ***you/your child***? Were ***your friendships*** different in any way following ***your/your child's*** injury? Did your friends and family help ***you/your child after your child's injury***? Did ***your/your child's*** hobbies/play/sporting activities change following your injury?
Physical	Did **you/your child** have any physical problems following the injury? (Probes: will depend on the age of child: difficulties walking, talking, crawling, eating, speaking hearing, toileting, returning to their usual activities)

	Did **you/your child** need crutches/walking frame/wheel chair after your injury? Did ***you/your child*** have any treatment from therapists /health professionals to help with the physical problems after the injury? Therapists and Health Professionals are: physiotherapists/occupational therapists/dieticians/speech therapists/nurses/doctors. Did you need additional care/help at home? Probe: adaptions to the home, downstairs living. Was there any change to **your/your child's** appearance after their injury? **Probes:** scars, cuts & bruises, weight gain or loss, items your child had to wear: supports, casts, brace, breathing pipe.
Psychological	Were ***you or your child*** scared or worried after ***your/your child's injury?*** Did ***you or your child*** have any problems sleeping following their injury? Did ***your child's/your behaviour*** change following the injury?
Emotional needs	How did you feel after ***your/your child's injury?*** Did ***your/your child's*** injury affect you emotionally? Did you receive any emotional support from staff at the hospital or people in your local community? **Probes:** worried, concerns for the future, upset, scared.
Family/work needs?	Did **your/your child's** injury affect the family or family life? ***Probes:*** • Was there any change to the daily routine? • Was there any change to roles/responsibilities within the family? • Do you have other children? Was it difficult to look after them at the time of your child's injury? • Were you working at the time of your child's injury? Did their injury affect work in any way? • Was your place of employment supportive after your child's injury? • Did you need any support to look after your child ?
Current situation	What are things like for **you/your child now?** Are you receiving help from either the hospital or your community services?

	Have you/ your child regained their previous level of activities at home? And at school?
Unmet needs/met needs	Looking back over the time since the injury, is there anything that could have been done differently to help ***your/your child's*** recovery? With hindsight were there any services which you did not receive which you think would have helped you and your child/you? What really helped you after your injury/ you and your child after your child's injury. Probes: Advice/information/people (health professionals/family, friends/people in the community), equipment, support groups, follow ups.
Closing	Thank you for much for talking to me today. Do you have any questions or is there anything else you would like to tell me which we haven't covered?

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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The page numbers refer to the unmarked copy.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or	Title page

		data collection methods (e.g. interview, focus group) is recommended	
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	Abstract
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	Page 4
Purpose or research question	#4	Purpose of the study and specific objectives or questions	Page 4
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those	Page 7

		choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	Page 6
Context	#7	Setting / site and salient contextual factors; rationale	Page 5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	Page 5,6
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 5
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of	6,7

		procedures in response to evolving study findings; rationale	
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	Page 6, 7 & 32
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 9
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	Page 7
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Page 7
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	Page 7

Results/findings

Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 8 to 21
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	14,19, 21
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	22, 23, 24, 25, 26
Limitations	#19	Trustworthiness and limitations of findings	24, 25
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	27
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	27

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A qualitative study of the needs of injured children and their families after a child's traumatic injury

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Title: A qualitative study of the needs of injured children and their families after a child's traumatic injury.

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ABSTRACT

Objective: To explore the needs of children and their families after a child's traumatic injury.

Design: Semi-structured qualitative interviews with purposeful sampling for different types of injuries and a theoretical thematic analysis.

Participants: 32 participants; 13 children living at home after a traumatic injury, their parents/guardians (n=14) and five parents whose injured child did not participate.

Setting: Two Children's Major Trauma Centres (hospitals) in England.

Results: Interviews were conducted a median 8.5 months (IQR 9.3) post injury. Injuries affected the limbs, head, chest, abdomen, spine or multiple body parts. Participants highlighted needs throughout their recovery (during and after the hospital stay). Education and training were needed to help children and families understand and manage the injury, and prepare for discharge. Information delivery needed to be timely, clear, consistent and complete, include the injured child, but take into account individuals' capacity to absorb detail. Similarly, throughout recovery, services needed to be timely and easily accessible, with flexible protocols and eligibility criteria to include injured children. Treatment (particularly therapy) needed to be structured, goal-directed and of sufficient frequency to return injured children to their full function. A central point of contact is required after hospital discharge for advice, reassurance and to co-ordinate on-going care. Positive partnerships with professionals helped injured children and their families maintain a sense of hope and participate in joint decision-making about their care.

Conclusion: Throughout the full trajectory of recovery injured children and their families need family-centred, accessible, flexible, co-ordinated health services, with more effective

harmonious communication between professionals, the child and their family. There is a requirement for support from a single point of contact and a system that monitors the needs of the injured child and their family after hospital discharge.

ARTICLE SUMMARY

Strengths and Limitations

- To improve the generalisability of the results we used purposeful sampling for maximum variation, rather than a sample of convenience and we believe the participants in this study are broadly representative of children with trauma injuries and their families.
- To our knowledge this is a first study to examine needs throughout recovery for a range of different injuries and ages from the perspectives of both the injured children and their parents.
- Different needs may have been identified if the interviews had involved more fathers and/or greater numbers of participants across the different age ranges.
- Joint interview formats may have influenced or limited the scope of the topics discussed by either the child or the parent, but a positive aspect of this format was that parents were able to provide insightful prompts, beyond the scope of the researcher.
- Self-reported needs are subjective and have not been quantified with any objective measurements.
- No data is available relating to the ethnicity of the study participants. Therefore, we do not know if the sample reflects population diversity.

INTRODUCTION

Injury is a leading cause of death and disability in children and young people, [1] which can affect quality of life and result in a significant burden of care over the child's life span. [2] Centralised major trauma systems have demonstrated improvements in survival from severe injury. [3] Despite the improvements in acute care, the rehabilitation which follows is an emerging priority for improvement. [4] The imperative to strengthen children's trauma rehabilitation reflects the global issue of unmet rehabilitation needs. [5]

It is important to improve children's care beyond the acute hospital admission to enable children to reach their full emotional, social, physical and vocational potential. [6] However, health and education services are generally aimed at children with development disabilities or long-term conditions rather than those acquired from an injury. [7] Children with newly acquired injuries are unlikely to have access to standardised pathways of care or long-term therapists who are well versed in their needs. The unique nature of each child's injury, situation and difficulties means that rehabilitation ought to be tailored to their specific needs. Thus, an effective starting point for rehabilitation is to understand the needs of the injured child and their family to enable an individualised approach to their care.

Previous research, including our work to review needs following childhood injury, [8] highlighted a range of needs; particularly support with psychosocial problems for the injured child and their other family members, [8–16] as well as for physical and practical problems. [13,17,18] Support is required to facilitate the child's transitions from hospital to home, [19] and return to school. [20,21] The provision of information has been shown to reduce parents' anxiety [19] and increase participation in the care of their child. [22] In trauma related research the need for information about the injury and it's management are reoccurring themes. [9,23,24] However, the current evidence base focusses predominately on the needs of children with traumatic head injuries, [8,13,16,25] and mainly considers the needs of parents or family members rather than the injured child, [9,14,26,27] or the specific needs of adolescents. [28,29] As trauma involves the whole-body system it is important for clinicians to understand needs for different types of injuries. In addition to head injuries, children suffer from injuries to the limbs/pelvis, spine, abdomen and thorax, which occur in a variety of combinations. [30] Childhood head injuries often result in cognitive, behavioural and functional impairments. [11,25,31,32], whilst other types of injuries (orthopaedic, abdominal and thoracic injuries) cause mainly physical problems, such as pain, loss of mobility and breathing difficulties. Head injuries are often thought of as invisible injuries [9], which could also be the case for internal organ injuries, but orthopaedic injuries are often associated with visible physical signs, such as a cast or the use of mobility aids. All types of injuries have the potential to affect psychological health and/or to be life changing. [15]

This study aims to address this gap in the evidence by exploring the needs of injured children and their parents, including children with a wider range of ages and injuries affecting different body parts. This will help to inform the delivery of family-centred services.

METHODS

Study design and setting

This was a qualitative interview study conducted at two Children's Major Trauma Centres in England between March 2018 and August 2019. The study was approved by the National Health Service, North West - Greater Manchester South Research Ethics Committee (REC reference 17/NW/0615) and the Health Research Authority.

Participants

Major trauma co-ordinators in the participating centres screened admission records to identify potential participants to take part in the study. To be included participants needed to be:

1) children aged six to 15 years at the time of injury admitted to a specialist Major Trauma Centre with moderate to severe traumatic injury (Injury Severity Score >8) who were discharged from the Centre within the previous 12 months.

2) Parents or guardians of injured children who fulfilled the criteria.

3) Parents of younger children aged two to five years at the time of injury were also included.

The following exclusion criteria were applied:

1) Participants who had been discharged within the previous two weeks (as it was felt that they would have insufficient experience of being home to fully contribute).

2) Babies/infants (less than two years old).

3) Children with isolated burn injuries (as they were managed by separate care pathway).

4) Non-accidental injuries, or those for whom there were significant safeguarding concerns.

A purposeful approach to sampling was used to account for perspectives from a range of injuries, genders, ages and times since injury.

Data collection

Potential participants were invited to take part by using age appropriate study information packs which were either posted or provided in person by a trauma co-ordinator. Consent was obtained from the parents and assent from the children before the interview started. All interviews were conducted by SJ who is a clinical researcher/major trauma co-ordinator and has completed training in interviewing children. A flexible interview format was used and participants could choose: who participated (joint child and parent, or solely the child or parent), where the interview took place (home, hospital, neutral location) and how the interview was conducted (telephone, face-to-face). However, for interviews involving children a face-to-face format was recommended.

A semi-structured topic guide was used to explore the child's and when appropriate, parent's or family's needs (Appendix 1). Some of the questions in the topic guide are dealt with in companion papers addressing children's and family's experiences and educational needs which are in preparation and will be published in due course. Questions were simplified to suit children of younger ages. Interview questions related to participants' perceptions of the care and support they received throughout recovery (during inpatient care and after hospital discharge), but the semi-structured nature of the interviews allowed participants to explore other topics which they considered relevant. Interviews were digitally recorded and transcribed verbatim.

Analysis

Anonymised transcriptions were thematically analysed using Excel and NVivo 11. A theoretical thematic analysis was use to analyse the data, which was considered to be the most suitable method of analysis as a specific research question had already been identified.[33] When using a theoretical thematic approach, the analysis is driven by the researchers' knowledge and experience in the field. The researcher had insights into the needs of injured children and their families because of her clinical and research experience with this group and topic. [8] The results of the scoping review relating to the needs of injured children and their families were used to produce a preliminary framework of key themes. [8] Firstly, SJ became familiar with the data by re-reading the transcripts. She then coded the data to categorise it within the existing coding framework or determine whether codes pointed towards a new theme. The research team (SJ, ST, JY) met regularly to review the coded data, verify its relevance to main themes and discuss the interpretations, alternative explanations for emergent findings and agree on any new theme headings which were required. Data were coded as interviews were conducted. Data collection ceased once data saturation and sufficient variation in the sample were attained. Data saturation was deemed as the point at which coded data from new interviews only added to existing themes and no new themes were developed. Field notes were maintained for the interviews to contextualise and reflect on the data, such as how forthcoming children were in the interviews.

Patient and public involvement

The Women and Children's Patient and Public Involvement Team from Manchester Academic Health Science Centre provided feedback on the study documents (patient information sheets, consent and assent forms).

RESULTS

Twenty-six interviews were conducted involving 32 participants; 13 children and their parents/guardians (n=14) and five parents whose injured child did not participate. One child was too young to participate according to the study criteria, one child did not wish to take part, for one child it was logistically too difficult to arrange a face to face interview and two children were receiving psychological support and they and/or their parents did not feel they could manage the potential psychological impacts of an interview.

Interview duration ranged 11 to 76 minutes. The format for the interviews is summarised in Table 1 and the characteristics of injured children in Table 2. All the interviews conducted in person took place in participants' homes, with the exception of two interviews which were conducted at the hospital (one parent interview and one parent-child dyad interview).

Table 1 Interview structure

Interview format	Participants	Method	Number of participants
5 Parents only	5 mothers	3 Telephone 2 In person	5
5 Dyads (joint interviews with child & their parent/guardian)	5 children & their parents (4 mothers & 1 guardian)	All in person	10
7 Dyads (child & their parent interviewed separately)	7 children & their parents (7 mothers)	All in person	14
1 Triad (child interviewed separately, mother and father together)	1 child & their parents (1 mother & 1 father)	All in person	3
Total number of participants			32

Table 2 Characteristics of injured children (13 participants and 5 who did not participate but whose parents were interviewed)

Characteristics	
Gender	Male 11 Female 7
Age at time of interview (years)	Range 5 to 16 (Median 13.0, IQR 3.5)
Injury mechanisms	4 Road traffic accidents 3 Sport 1 Fall >2 metres 5 Fall <2 metres 5 Other mechanisms
Type of injury	1 Isolated head injury 1 Isolated spinal injury 3 Isolated abdominal injuries 1 abdomen & chest injuries 6 Injuries to limb(s) 6 Multiple injuries
Time since injury (months)	Range 1 to 12.5 (Median 8.5, IQR 9.3)

Most participants, particularly the children were unfamiliar with the concept of 'needs' as this is an abstract concept coined by healthcare professionals, thus they seldom talked specifically about their needs. However, needs were implicit in all participants' narratives about how their healthcare was delivered, regardless of whether they were satisfied with their care or whether their needs had been met. Participants described their own unique experiences and although these varied, they often pointed towards the same types of needs. The interviews focussed on care after hospital discharge, but the researcher gave participants the flexibility to discuss matters which were important to them including hospital care. School-based service needs were identified in the analysis, but have been addressed in a separate paper due to the range and depth of information obtained relating to these needs. This paper is in preparation. Parents and older children were able to give the most information about their needs.

Four overarching themes emerged; Education and training needs, information needs, service needs, and positive partnerships between children, families and professionals. Education and information needs are interrelated. Education/training needs focus on what children and families need to help them look after the injury, whilst information needs relate to how advice is delivered.

Education and training needs

Education needs

Both injured children and their parents had to assimilate a large amount of information about the accident and injury(ies). For most this was a completely unfamiliar situation and they recognised that they had a lot to learn. Professionals needed to help by educating them about their injury and how to manage it. Parents highlighted the need to be warned or advised about the prognosis and forewarned about symptoms (such as pain, seizures, hallucinations, difficulty concentrating, fatigue) which sometimes occurred unexpectedly. It was also important to understand the reasons why they occurred (Box 1: quote 1a, 1b, 1c).

Training needs

Participants identified that they needed training, particularly in preparation for hospital discharge. This included issues such as how to look after wounds and scars, mobilise, and return to activities and school. They needed opportunities to develop coping strategies and to practice on-going care and treatments while in hospital to develop competence. This then gave them confidence to execute these tasks at home. For more severely injured children this need went beyond merely practicing in the hospital environment. The opportunity to practice at home during weekend leave made the eventual return home more manageable (Box 1: quote 1d).

Information needs

Information needs

Participants needed timely information to be provided in sufficient detail to understand *"what was going on".* Delays in receiving information predominately related to administration (particularly referrals and transfer of health records), meetings and short notice of operation cancellations. Several found the systems in place outdated (Box 1: quote 1e). The desired level of detail varied, but all participants needed information to be clear and consistent. They often explained how helpful they found well-executed explanations from professionals (Box 1: quote 1f).

Consistency of information was essential, but it was often conflicting. Participants attributed this to the use of medical jargon in written and verbal reports, the number of professionals involved in care and the different approaches between health professionals/hospitals (Box 1: quote 1g). This conflicting information and advice caused *"tension"* and *"confusion."* Participants reported that they were sometimes left not knowing what to expect or the best way of managing the injuries. They recommended closer liaison between health professionals.

Related to consistency of information, was participants' need for up-to-date information. They needed to be informed clearly and consistently about any changes in diagnosis, prognosis, management plan or expected symptoms throughout all stages of their care. Information was often considered insufficient. Gaps in information delivery were attributed to health professionals not spending enough time with participants, not knowing specific facts or presenting the information which they considered the most important. For example, one family only became aware of the full details of their child's head injury when they reviewed the consent form for a procedure (Box 1: quote 1h).

Effective communication and information sharing

Participants were asked about how information was provided and what they wanted and needed. Irrespective of the format, participants identified that information needed to be available quickly and easily. Most parents considered written information to be useful, particularly copies of clinic and referral letters and other relevant correspondence. This enabled them to monitor progress of care and to play an active role in their child's care. Written information was frequently needed to share information with other health professionals and external agencies (such as schools) who often required "*a written letter from a doctor."* Several found it difficult to absorb written information (such as leaflets and booklets) given their emotional state, although participants acknowledged these were valuable *"to refer back to"*. However, many parents preferred to liaise directly with health care professionals in person or via texts, phone-calls and emails as their primary source of communication and information (Box 1: quote 1i). Similarly, injured children preferred to ask their parents questions rather than professionals. However, open conversations with professionals which included and were directed towards the injured child were valued (Box 1: quote 1j). The use of visual aids, such as x-rays and scans also helped participants understand the injury, particularly when there were no visible physical signs. One child used his abdominal scan to help his peers understand the severity of his injury.

Dissatisfaction with information and communication arose when health care professionals repeatedly asked the same questions, did not share information and/or did not advise participants of the outcomes of investigations, test results, or changes to care plans.

Box 1: Education, training and information needs

Themes	**Quote and participant**
Education and training needs	1a) *"…They did say to us that [it] would be… …a miracle if they managed to save his eye. That was our worst-case scenario."* (Parent 11) 1b) *"These sudden pains didn't start for a while after. I didn't know they were coming……and then…..I felt like, "what's this? ……why is she getting these and is it…. fine that she should be exercising?"* (Parent 16) 1c) *"if there would have been any side effects, or things, to look out for, you know?….like I suppose like you get on any medicine"* (Parent 26) 1d) *"That really did help……I just felt prepared then. It was like "right, we can do it at the hospital, we can do it at home."* (Parent 12)
Information needs	1e) *"I don't understand why a hospital can't just get in the modern world and email people……or phone them up and do a referral. Why they have to type and dictate a letter and it takes two weeks for it to get to the person they need it to get to."* (Parent 8) 1f) *"they [the injuries] seemed quite complicated at first……because there was a lot….. They listed them………, so they laid it out clearly….., They just kind of explained each one to me……And …showed me some x-rays."* (Child 10). 1g) *"Some people were saying he needs to wake up, he's going to turn day into night and it's not good for them… and some people were saying why are you waking him up………he needs to sleep, he needs to recover, and we were a bit like … what do we do? Are we going to wake him up or let him sleep?"* (Parent 6) 1h) *"It said … "fractured skull". We were like,…, "it's the first we've heard of it"….. So, that was kind of disappointing really, that we hadn't heard that."* (Parent 18)
Information needs: effective communication and information sharing	1i) *"We can just email at any stage if we've got any questions, which is fantastic. Anything I'm worried about, just email and they'll…respond straightaway."* (Parent 9) 1j) *"I thought that was really good actually. A lot of the time they speak to [Injured child] rather than to me? Because he's the injured one and worrying."* (Parent 23)

Service needs

Participants were clear about what they needed from services throughout their recovery. Whether inpatient or community based, they needed services to be accessible, timely, sufficient, structured and co-ordinated. Although many participants expressed positive experiences and satisfaction, this was not universal. The types of difficulties outlined were not limited to one type of service: unmet needs for accessible services were described for most types of community-based services.

Accessible and timely services

After hospital discharge, services needed to be provided locally or at the participants' homes, often 'out of hours' or with 'open appointments' to enable participants to obtain care or assessments when needed (Box 2: quote 2a). However, many factors made services difficult to access after hospital discharge. Participants described lengthy or difficult journeys to their healthcare provider and strict eligibility criteria which excluded children. (Box 2: quote 2b). Additionally, rigid protocols prevented access to services, such as school transport and equipment. For example, one injured child lived in two homes as their parents were separated, but services could not accommodate this commonplace living arrangement and would only supply one set of equipment.

In order to be accessible, some services needed to be made available to family members as well as the injured child. Post-traumatic stress type symptoms and/or mental health issues were often experienced by an injured child and their family members, including parents, grandparents and siblings (participants' experiences will be reported in detail in a pending publication). Although the hospital offered psychological support to the whole family, this holistic approach was more difficult to access in the community after hospital discharge (Box 2: quote 2c). However, several participants did not take up psychological support during inpatient stay, as difficulties often only became apparent after discharge when participants tried to return to 'normal life'.

The timing of services was very important; participants often experienced long delays for services to start (particularly community therapy) and cancelled operations. Such delays were difficult for families to cope with (Box 2: quote 2d). A couple of participants proposed that appointments could be quicker if telephone consultations were available after discharge, or if primary and secondary care services worked more closely together to prioritise injured children more appropriately (Child 21 and Parent 22).

Dose and structure of treatment

Whether during inpatient or community-based care, participants needed services to provide sufficient treatment throughout the continuum of recovery. In the hospital, a lack of nursing staff was highlighted as a key issue. However, there was a notable discrepancy between satisfaction with mental health and therapy services in the hospital and community setting, with such services generally regarded as comprehensive in the hospital, but lacking in the community. After discharge from hospital, participants described a lack of children's mental health services or professionals who deliver specific psychotherapy treatments for children. Similarly, in contrast to the hospital, community-based therapy was often regarded as insufficient (Box 2: quote 2e). Another issue was that treatment in the community (often physiotherapy or occupational therapy) needed to have a greater scope of ambition for the injured child's recovery. Rehabilitation goals, whether set with therapists or autonomously were considered essential to gauge improvement, inspire motivation and provide a focus for the future (Box 2: quote 2f). Several participants reported that community therapy finished before the injured child had reached their goals to return to physical education, competitive sport or other activities (i.e. they had not reached their rehabilitation potential). In order to deal with these unmet rehabilitation needs, participants devised their own exercise and rehabilitation regimes; requested physiotherapy reviews or funded therapy privately. Participants also needed rehabilitation to be clearly structured because the injury(ies) disrupted their usual routines.

Co-ordination of care and ongoing support

Care and rehabilitation of children with traumatic injuries often involved input from multiple professionals and services over an extended period to manage complex, sometimes sensitive problems. Participants very clearly articulated the need for this complex, multi-agency, multi-facetted, often long-term care to be co-ordinated by a health care professional. They highlighted the need for help to co-ordinate timely provision of appropriate equipment, appointments, care packages and return to education (whether this be school or home schooling) and other activities (Box 2: quote 2g).

Co-ordinating on-going care after discharge, such as clinic appointments and referrals were a particular issue for most participants, regardless of the severity or complexity of the injury or the number of specialist services involved. They valued help to ensure referrals and appointments were made, attempts to streamline appointments to minimise the number of trips and disruption to schooling and employment, prompt notification of appointments, timely reminders and help to re-arrange appointments if necessary. When this co-ordination was not available, participants described unsatisfactory experiences (Box 2: quote 2h).

Most participants acknowledged that they needed a named contact to be involved throughout their hospital stay, through discharge and for on-going care. This professional needed to provide the co-ordination described above, plus on-going monitoring of recovery and needs, reassurance, emotional support and continued advice especially about new symptoms. (Box 2: quotes 2i and 2j). Where available this named contact was often a trauma co-ordinator, but participants also found their general practitioner a helpful point of reference and a means of accessing other services. Part of the co-ordinator's role also needed to 'signpost' children (and their families) to access appropriate on-going care. Participants reported how problems and symptoms, particularly post-traumatic distress and mental health problems often only became apparent after hospital discharge. To address such new problems, participants needed to know what sources of help were available and how to access them. They described how they needed *"to be put in touch with the right people"*. This signposting role extended beyond health care services.

There was a particular need to co-ordinate multi-agency care (usually for the more severely injured children) as participants did not have the knowledge, skills or experience to negotiate the highly complex and variable systems, particularly when community or education services were involved. Many met and unmet needs were highlighted regarding return to education (whether at school or at home) after a traumatic injury and these are addressed in a separate manuscript, which is in preparation.

Box 2: Service needs

Themes	**Quote and participant: Service needs**
Service needs: Accessible and timely services	2a) *"We had an open appointment arrangement with the physio, where we could ring up if there was a problem."* (Parent 6) 2b) *"They [district nurses]… told me that they don't deal with anybody under the age of eighteen."* (Parent 8) 2c) *"I think we were offered everything we…. could have been. I think getting counselling for me mum [child's grandparent] was a bit harder….." [referring to experience after hospital]* (Parent 11) 2d) *"We were thrown into two weeks of, is he having brain surgery, is he not? And it happened, you know, twice, two cancellations. And that is such a huge thing for your heart to cope with."* (Parent 18)
Service needs: Dose and structure of treatment	2e) *"We could just see that it [physiotherapy] wasn't gonna be what [injured child] needed. She needed more…… she wasn't even gonna start for at least a couple of weeks"* (Parent 9). 2f) *"That really helped. We set some [goals] in hospital, didn't we? Something to do in the future like..........., what do you want to do for your birthday? So I was like, I'd always wanted to go, like, Harry Potter World or something."* (Child 21).
Service needs: Co-ordination of care	2g) *"I don't think I could have coped, if I'd had to ring up all them people and sort all her [injured child's] care package out, I couldn't have coped."* (Parent 2) 2h) *"well we've got his appointment through. As I say, we were expecting it. They said it would be within six weeks, but it's actually 13…it'll be 13 weeks since the accident."* (Parent 26) 2i) *"When I rang the nurse though, they were really reassuring, and they sort of said "I don't think it's anything too much to worry about, but mention it to the neurosurgeons". So, it did allay my fears a bit."* (Parent 19) 2j) *"he just reassured me a lot and answered a lot of questions that I had about going …back to school and sorting things out"* (Child 21)

Partnerships between patients and professionals

Participants explained how they needed positive, supportive, trusting partnerships with the professionals involved in their care. A positive outlook from professionals helped to boost morale and gave a sense of hope and helped injured children and their families feel emotionally supported (Box 3: quote 3a). This also related to the need to be able trust the skills, competence and reliability of the professionals and organisations involved in the injured child's care, which gave them confidence and reassurance (Box 3: quotes 3b and 3c). This trust was also needed to persuade the injured children to adhere to aspects of treatment which they disliked and enabled professionals and participants to work effectively together (Box 3: quote 3d). Several children disliked certain aspects of their treatment (e.g. wearing an eye patch or orthotic devices) and were reluctant to adhere to them. To minimise this problem, children and their families needed to *"feel heard"*, be involved in discussions and decisions about their care, to jointly solve problems by exploring alternative treatment options and finding mutually agreeable solutions or compromises (where possible) (Box 3 quote 3e). However, not all relationships between services and participants were positive. There were several reports of perceived problems with care. Examples included the incorrect application of orthotics, medication error, issues with adherence to major trauma pathways, referrals which were not made, delayed appointments, etc. In these cases, participants felt they had not been listened to by health professionals, nor involved in discussions/decisions about their care. Consequently, they could not rely on some aspects of service provision (Box 3 quote 3f).

Box 3: partnerships between patients and professionals

Themes	**Quote and participant**
Partnerships between patients and professionals	3a) *"They [hospital staff] kept us positive and…yeah, didn't make us feel that, God, this was, you know, absolutely disastrous, but she was gonna get better."* (Parent 9) 3b) *"I think the fact it was a children's hospital and they knew exactly what they were doing… You feel confident."* (Parent 26) *3c) "you know, the people who do these types of operations, they're good at their job" (Child 17)* 3d) *"Originally I couldn't even get [injured child] there [Psychology Department]. But the therapist from CAMHS built up such a good relationship."* (Parent 12) 3e) *"we just discussed it as a whole family and [trauma co-ordinator] …everything that was worrying [Injured Child]… . And then she just literally said "right. I can fix that, that, that, that and that, but I can't do this… but I know somebody who might be able to, so let me look into it, leave it with me."* (Parent 21) 3f) *"They [the council] were supposed to provide some equipment for the bath. And it never materialised. They came out, they brought the wrong bath board. And then they said they'd come out again. But they didn't."* (Parent 12)

DISCUSSION

The results of this study showed that injured children and their families' needs focus on education and training to help understand the injury and how to manage it, effective communication, access to sufficient services, support to co-ordinate care and positive partnerships with professionals.

Participants' unmet need for clear, consistent and complete information across the full recovery continuum echoes findings from previous studies [9,13,23] and is attributed to the range of professionals often involved in trauma care. [23] However, participants' needs and preferences varied, so consideration should be given to individualising information and ensuring it is available in a range of different formats, as well as ensuring the injured child and other family members are included in honest and open discussions. Additionally, clearer information to manage expectations may be required when details are unknown or subject to change, [9] particularly care plans. Although written information was often useful, this needed to be conveyed quickly (by email or text for example) and act as a supplement to verbal communication. Electronic patient held records or portals have been shown to enhance information and communication exchange, [34,35] and may help to fulfil children's and family's needs for more immediate, accessible and consistent information.

Access to services was a frequent unmet need, which was most pronounced in the community setting. It is unsurprising that most participants described a *"post code lottery"* when it came to rehabilitation in the community setting. All the participants included in this study had been managed in specialist children's Major Trauma Centres. The resources, standards and clinical governance processes present in these centres only cover hospital-based care [4] and do not extend to the community setting, where there are few services specifically for injured children. Similarly, disparities in access to post-discharge rehabilitation for childhood traumatic injury have been reported in the United States. [6] Further research is required to better understand how injured children's community-based rehabilitation can be provided efficiently and effectively.

Inadequate service provision has been reported previously, [7,9,16,36] particularly for services relating to cognitive or mental health difficulties. [12,16,36,37] The current study reinforces this by highlighting that although psychological support during the inpatient stay was comprehensive, it was lacking after discharge, which is when difficulties often emerged. Psychological support services needed to extend throughout the full recovery trajectory and cater for the needs of the whole family unit. To achieve this, the capacity of children's community mental health services needs to expand by training more professionals, [38] and educating both parents [39] and professionals [10] about how to detect signs of post-traumatic stress, particularly as symptoms can present late in recovery. [15,40] In contrast to previous research, our participants placed more importance on the need for physical and practical support. This may reflect the variety of injuries included in our sample, rather than being limited to head injuries.

There is a clear need to develop comprehensive, streamlined rehabilitation services for children with traumatic injuries, whose needs may be temporary or change over time. Expansion of the Major Trauma Networks to include all facets of rehabilitation for all ages could provide this support, but this would require sustained funding and training. Like previous studies, we found an overwhelming need for a single-point of contact during and after hospital discharge [9,28,36,41,42] to help patients access professional support and to co-ordinate the multiple professions, specialities, agencies and organisations involved in their care. Co-ordinators could work in conjunction with rehabilitation medicine consultants, [43] who would lead clinical decision making. This approach may achieve more streamlined rehabilitation and consistent communication. Some major trauma services provide a specialist co-ordinator, but this is often limited to hospital-based care. [33] However, support may be required over the long-term as on-going problems are highly prevalent for several years after severe injury, [42,44] but may not become apparent until after the child has been discharged from hospital and attempts to return to their normal life. [12,16] Ongoing support may contribute to trusting, positive partnerships that participants emphatically needed for more family-centred care and to enable joint decision making. [45] In this study and previous research an important role of a known contact is to provide reassurance and maintain a sense of hope. [13–15,19,39,46] An important aspect of trauma care is to support the emotional recovery [46] of the child and their parents. [39]

A system is required that continues to screen for (and then treat and monitor) problems after hospital discharge. This may be most pragmatically addressed by a comprehensive needs assessment tool which can be completed by the child/family at regular intervals throughout the full recovery. Work is underway to develop such a tool that is suitable for all ages of children, types of injury and stages of care.

Strengths and Limitations

A common criticism of qualitative research is the limited generalisability of the results. [47] To address this, we used purposeful sampling for maximum variation, rather than a sample of convenience and we believe the participants in this study are broadly representative of children with a range of traumatic injuries. [30] To our knowledge this is a first study to examine needs throughout recovery for a broad range of injuries and ages from the perspectives of both the injured children and their parents. However, the purposeful approach to sampling did not encompass attaining equal numbers of mothers and fathers. The majority of mothers who took part was an unexpected finding, which may have influenced the range of needs and experiences reported. Previous qualitative studies have shown a difference in themes identified for males and females. [48]

Due to involvement of children and sensitive nature of the interview topic (childhood injury) it was important to give participants the opportunity to take part in the interviews in the way that they felt most comfortable. We acknowledge that joint interview formats may have influenced or limited the scope of the topics discussed by either the child or the parent. [49] One positive aspect of joint interviews was that parents were able to provide insightful prompts, beyond the scope of the researcher.

Age specific needs have previously been identified for adolescents. [28] Our initial intention was to explore age specific needs, but the data analysis showed that the identified needs were generic across the ages investigated. More age-related needs may have been identified if there were greater numbers of participants across the different age ranges and interview probes placed more emphasis on issues relevant to age.

We acknowledge that self-reported needs are subjective and have not been quantified with any objective measurements. Self-reported, subjective data can be influenced by different forms of bias, [50,51] including social desirability bias. [51] For example, social desirability bias may have occurred because participants wanted to appear to be coping and thus may have under reported their level of need. Finally, we do have data about the ethnicity of the study participants. Therefore, we do not know if the sample reflects population diversity.

CONCLUSION

This research has helped to identify unmet healthcare needs of a new target population. Children with a range of injuries and their families need family-centred, accessible, flexible co-ordinated health services throughout the full trajectory of recovery, with more effective harmonious communication between professionals, the child and their family. Trauma rehabilitation should be provided as a continuum of care, part of which should involve the ongoing monitoring of the injured child's and family's needs. Services between hospital and community settings need to be more seamless and equitable. This may be achieved by attaining evidence such as that presented here, about needs through the full trajectory of recovery, which can then be used to inform policy and commissioning.

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Data Sharing statement

All data relevant to the study are included in the article or uploaded as supplementary material.

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APPENDIX 1

	Guide to Questions
Generic needs	Tell me about what was different for **you/ you and your child** following your injury? What help did ***you/your child*** need after your injury?
Discharge specific needs	What was it like for ***you/ you and your child*** when you went home from the hospital? When ***you/your child*** went home from the hospital how did you feel? Did you feel ***you/you and your child*** prepared to go home? Was there anything that worried ***you/ you and your child*** about going home? Did ***you/you and your child*** need any support/help from hospital staff/health professionals when you went home from the hospital? Did you feel that you got the help ***you/you and your child*** needed? Did ***you/your child*** have any difficulties when you went home from the hospital? Was there anything that really helped or made things easier when **you/your child** went home?

	Probes: Equipment, modifications to home, home visits, advice leaflets, meetings before discharge, follow up appointments, phone calls from the hospital.
Key Worker	Did ***you/your child*** have a key worker (a health professional/nurse/physio/occupational-therapist/carer/doctor) who provided help or advice when you went home from the hospital? **If answers yes:** Did you find this helpful? Why was this helpful? What did the key worker do for you? **If answers no:** Do you think that a key worker would have been helpful? What help/support could have they provided?
Information needs	Was **your/your child's** injury explained to you in the hospital? Did you understand the explanation of ***your/your child's injury***? Did you understand how the injury would affect ***you/your child?*** Were you provided with advice about **what you/your child** was allowed and not allowed to do following ***your/your child's injury?*** Was this easy to understand? Did you receive any advice or information when you were discharged from the hospital? Probe: information booklet, helplines, follow up appointments/ follow up phone calls.

	If answers yes: Was the information helpful/how? Were you given enough information? Was it easy to understand? Who gave you the information? **If answers no:** Was there you wanted to know when you went home from the hospital, which you were not told? Was there anything you had to find out for yourself?
Educational needs	How did ***you/your child*** deal with returning to school after their injury? Did **you/your child** have any difficulties returning to school? Did **your/your child's teachers** know that you/your child had suffered from an injury? **Probes:** Did they understand the injury/do anything differently? Was there anything that really helped **you/your child** when you returned to school? Were there any changes made or advice which made **your/your child's** return to school easier?
Social needs	Did **your** friends/family know about **your/your child's** injury? Do you think they understood what had happened to ***you/your child***? Were ***your friendships*** different in any way following ***your/your child's*** injury? Did your friends and family help ***you/your child after your child's injury***? Did ***your/your child's*** hobbies/play/sporting activities change following your injury?

Physical	Did **you/your child** have any physical problems following the injury? (Probes: will depend on the age of child: difficulties walking, talking, crawling, eating, speaking hearing, toileting, returning to their usual activities) Did **you/your child** need crutches/walking frame/wheel chair after your injury? Did ***you/your child*** have any treatment from therapists /health professionals to help with the physical problems after the injury? Therapists and Health Professionals are: physiotherapists/occupational therapists/dieticians/speech therapists/nurses/doctors. Did you need additional care/help at home? Probe: adaptions to the home, downstairs living. Was there any change to **your/your child's** appearance after their injury? **Probes:** scars, cuts & bruises, weight gain or loss, items your child had to wear: supports, casts, brace, breathing pipe.
Psychological	Were ***you or your child*** scared or worried after ***your/your child's injury?*** Did ***you or your child*** have any problems sleeping following their injury? Did ***your child's/your behaviour*** change following the injury?
Emotional needs	How did you feel after ***your/your child's injury?***

	Did ***your/your child's*** injury affect you emotionally? Did you receive any emotional support from staff at the hospital or people in your local community? **Probes:** worried, concerns for the future, upset, scared.
Family/work needs?	Did **your/your child's** injury affect the family or family life? ***Probes:*** • Was there any change to the daily routine? • Was there any change to roles/responsibilities within the family? • Do you have other children? Was it difficult to look after them at the time of your child's injury? • Were you working at the time of your child's injury? Did their injury affect work in any way? • Was your place of employment supportive after your child's injury? • Did you need any support to look after your child ?
Current situation	What are things like for **you/your child now?** Are you receiving help from either the hospital or your community services? Have you/ your child regained their previous level of activities at home? And at school?
Unmet needs/met needs	Looking back over the time since the injury, is there anything that could have been done differently to help ***your/your child's*** recovery? With hindsight were there any services which you did not receive which you think would have helped you and your child/you? What really helped you after your injury/ you and your child after your child's injury. Probes: Advice/information/people (health

	professionals/family, friends/people in the community), equipment, support groups, follow ups.
Closing	Thank you for much for talking to me today. Do you have any questions or is there anything else you would like to tell me which we haven't covered?

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		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data	Title page

		collection methods (e.g. interview, focus group) is recommended	
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	Abstract
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	Page 4&5
Purpose or research question	#4	Purpose of the study and specific objectives or questions	Page 5
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those	Page 7&8

		choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	Page 7&8
Context	#7	Setting / site and salient contextual factors; rationale	Page 5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	Pages 6&8
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 5&7
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of	5,7&8

		procedures in response to evolving study findings; rationale	
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	Page 7, 33-36
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 8, 9&10
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	Page 7&8
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Page 8
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	Page 8

Results/findings

Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 8 to 22
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	15,20, 22
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	23-27
Limitations	#19	Trustworthiness and limitations of findings	3, 25-26
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	28
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	28

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