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Provision of care for children with medical complexity in tertiary hospitals in England: qualitative interviews with health professionals

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ABSTRACT

Background Due to medical and technological advancements, children with medical complexity are a growing population. Although previous research has identified models of care and experiences when caring for this population, the majority are the USA or Canadian based. Therefore, the aim was to identify models of care for children with medical complexity and barriers and facilitators to delivering high-quality care for this population from a 'free at point of care' national health service.

Method Qualitative semistructured interviews were conducted with hospital clinicians across England and analysed using a thematic framework approach.

Results Thirty-seven clinicians from 11 hospital sites were interviewed. In 6 of the hospital sites, there were 14 services identified. Majority of services had a variety of components, some shared and some unique to the individual service. Clinicians faced barriers and facilitators when caring for this population as demonstrated across five categories.

Conclusions There is limited guidance and evidence on the most effective and efficient models for providing care for this population. It is not possible to determine what a service should look like as there is no consensus on the most appropriate model of care as shown in this study. Due to their complex needs, this population require coordination to ensure high standards of care. However, this was not always possible as clinicians faced barriers such as time constraints, silo thinking and a lack of available housing.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Children with medical complexity are an increasing population. However, little is known from a UK-based perspective on types of existing services and experiences when caring for this population.

WHAT THIS STUDY ADDS

⇒ This paper has identified the components of existing UK services for children with medical complexity. It also explored experiences of clinicians when caring for this population.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The variety in models of care identified for this population suggest there is no one-pathway that fits all. Therefore, an evaluation of existing UK-based services is required. There were also gaps when services interacted with community services, indicating a need to reduce fragmentation across social and healthcare. Time constraints and other institutional policies meant that clinicians struggled to provide holistic care, a necessary component. To address this, changes to paediatric services and medical training are necessary.

BACKGROUND

Children with medical complexity are defined as potentially having 'a congenital or acquired multisystem disease, a severe neurological condition with marked functional impairment, and/or technology dependence for activities of daily living'.[1] Due to advances in care and treatments, this is a growing population with an increased life expectancy,[2] leading children's hospitals to begin implementing complex care models.[3] However, most published literature is based in the USA and Canada with little evidence from the UK. Given the differences in payment, funding and structure of health services in the UK,[4,5] it is important to understand how services are caring for this growing population of children.[1] Even the literature from the USA and Canada is not consistent—one study identified two types of models known as the chronic care model and medical home model.[2] Whereas a more recent paper identified three types of care—primary care-centred, consultative-centred or comanagement-centred and episode-based models.[3] These are not relevant for a UK setting where most paediatric expertise is located in secondary and tertiary care. It is noted that current health systems are not designed to meet the needs of this population[6] with the English National Health Service (NHS) Long Term Plan[7] and other reports[8 9] highlighting the need to redesign children's health services. Previous research[10] has found that UK paediatricians have reported pressures from the increase in numbers of children with medical complexities and resistance from organisations to adopt models found in the USA and Canada as paediatricians are trained to operate an acute model of care. Due to this, further research examining the experiences of UK clinicians when caring for this population is required.

The complex care needs of these patients and their families have left staff reporting lacking in confidence when caring for this population, leading to conflict and breakdowns in care. In other instances, where family members and caregivers have interacted with health services, they have faced challenges when attempting to navigate a fragmented system, primarily based on an acute care model.[11] Implications may include emotional, physical burdens, poor care coordination and delayed transfers of care. Recent research has also found that these families face greater financial and social hardships than previously known[12], illustrating a need for further investigation into current provision of care.

This study aimed to identify existing models of care for this population in England and explore the barriers and facilitators when addressing needs from the perception of healthcare professionals.

METHODS

An exploratory phenomenological qualitative study using semistructured interviews to identify the models of care for children with medical complexity in England, and the barriers and facilitators to delivering high-quality care for this population.

Patient and public involvement

Patients were not involved in this study. However, the semistructured interview topic guide (see online supplemental file 1) was piloted and discussed in patient and public involvement (PPI) meetings. These meetings involved the Martin House Research Centre Family Advisory Board made up of parents of young people with life-limiting conditions and complex healthcare needs. EVM frequently attended PPI meetings to discuss process and have input from families. Findings will be disseminated in a series of presentations in key meetings, reports and publications.

Sample and recruitment

Purposeful sampling was used to recruit clinicians via the medical directors of all tertiary paediatric hospitals or the paediatric clinical directors of other trusts with Paediatric Intensive Care Units (PICUs). Directors were contacted via email between September 2021 and January 2022 and asked to forward study details to potential participants.

Data collection

The semistructured interview topic guide (see online supplemental file 1) was developed, piloted and discussed with team members. After informed consent for participation and potential future publication had been obtained, the telephone or video-call interviews were carried out by a female researcher (EVM, experienced in interviewing and unknown to clinicians prior to the interview) in a secure setting. Probes and follow-up questions were used to better our understanding. Fieldnotes including any interviewer assumptions or bias were noted during and after the interview. All interviews were recorded and transcribed verbatim. Transcripts and findings were not returned to participants for comment due to time constraints. Data saturation[13] was agreed on once no new codes were developed.

Data analysis

Data were analysed using a thematic framework approach[14] guided by relevant analytical frameworks. To identify the models of care, the Effective practice and Organisation of Care taxonomy[15] (EPOC) was used as it allowed models to be categorised based on their shared conceptual and practical components in a visual way. Guidance from the EPOC[15] framework and its main domains such as delivery, financial and governance arrangements were used to inductively and deductively code to later form categories. To identify barriers and facilitators, the social-ecological model[16 17] was applied, illustrating the relationships between social/policy, community, institutional and individual factors which influence human behaviour and relationships.

Table 1 Participant characteristics

Participant characteristics	
No of participants	37
Hospital type	9 tertiary hospitals
	2 non-tertiary hospitals (PICUs)
Gender	30 female
	7 male
Job type	26 medical staff Specialties ranged from paediatric nephrologist, palliative care, neurodisability to intensive care consultant
	8 nursing staff Specialties ranged from clinical nurse specialist, senior sister to coordinator
	2 occupational therapy staff
	1 support worker staff

Table 2 Categories found

Categories	Subcategories
Delivery arrangements	► Length of time a service has existed ► Where is the care provided ► Who provides the healthcare ► Coordination of care and management of care processes ► Information and communication technology
Financial arrangements	
Governance arrangements	
Implementation strategies	► Interventions targeted at other specific types of practice, condition or setting ► Interventions targeted at healthcare organisations

The analysis process was carried out by a member of the research team (EVM) overseen by LF and JH involving a series of five steps using Miles and Huberman's[14] framework analysis guidance. (1) After anonymisation, all transcripts were read and reread by a member of the research team (EVM) to begin the familiarisation process; (2) Thoughts were discussed with the research team as initial deductive (using the EPOC framework) and inductive coding derived from the data using the software NVivo V.12 began (carried out by EVM); (3) After discussions among the research team (LF, JH and EVM), initial codes were revised and later applied to an analytical framework. A total of 10 transcripts were applied to the analytical framework using an Excel Microsoft spreadsheet; (4) The framework containing codes and supporting quotes were presented (by EVM) to two members of the research team (LF and JH). After a series of iterations, finalised codes were applied and later interpreted; (5) Interpreting the data involved noting concepts and potential categories. Shared characteristics and concepts began to progress, illustrating connections. Finalised categories were then discussed with the research team until agreed on. The types of services were later categorised into models of care. Due to the limited and inconsistent terminology, not always appropriate for UK health systems, types of models were identified by the research team.

RESULTS

Twenty-two hospitals were originally contacted, 11 tertiary hospitals and 11 non-tertiary hospitals with PICUs. Thirty-seven participants completed interviews from 11 hospitals; sample characteristics are shown in table 1. Mean interview length was 50 min (range: 30–60 min).

Models of care

There were a total of four main categories identified, based on the topic list (a total of sixteen) found in the EPOC[15] framework as shown in table 2.

Fourteen services were identified from six of the tertiary paediatric hospital sites, with five hospitals having no services, two had one service and four had two or more services. Each was then categorised into one of the six models (given by the research team) as shown in table 3.

The services and types of models identified illustrated in tables 4–7, each has shared components such as length of time they have existed or financial arrangements. However, there were key differences as illustrated in the category, coordination and management of care processes. For example, services found under the complexity and coordination models focused on pulling services together whereas services found under the transition model focused

Table 3 Types of models

Type of model	Description of model	No of services
Complex and coordination model	Model that coordinates and manages care processes to improve care for example, social care, financial and housing	8
Upskilling model	Model that upskills professionals and/or families of those caring for children with medical complexity	2
Community model	Model that operates as an in-reach service and honorary contract, primarily focused on safeguarding	1
Palliative care model	Model that focuses on providing end of life care planning	1
Transition model	Model that assists in transitioning children with medical complexity from paediatric services to adult services	1
Intensive care model	Model that is based within the intensive care unit to coordinate care using a designed goal sheet and checklist	1

The six models, their categories and key components are illustrated in tables 4–7.

Table 4 Delivery arrangements

Model name	Complex and coordination model	Upskilling model	Community model	Palliative care model	Transition model	Intensive care model
Category: delivery arrangements						
Subcategory: Length of time a service has existed	Most had been running for 10 or more years	Running for 10 or more years	Running for 1 or more years	Running for more than 5 years	Running for more than 5 years	Running for 1 or more years
Subcategory: Where the care is provided	Provided in an acute setting at a tertiary children's hospital	Provided in an acute setting at a tertiary children's hospital. One service is an integrated service primarily based within the community, working with professionals and families to provide training. The other service provides post-discharge training and follow-up visits	Provided in an acute setting at a tertiary children's hospital run by a General Practitioner (GP) located in the hospital, frequently linking with community services	Provided in an acute setting at a tertiary children's hospital	Provided in an acute setting at a tertiary children's hospital	Provided in an acute setting at a tertiary children's hospital
Subcategory: Who provides the care?	Majority of services consist of multidisciplinary teams (MDTs) except for two services which are single-disciplinary works closely with community team members	Single-disciplinary team works closely with community team members	Single-disciplinary team although works closely with community nursing teams linked to the hospital, this was limited as it was thought to be on 'their terms' due to their honorary contract forbidding admission rights (P23)	MDT works closely with community teams although wishes to strengthen	Single-disciplinary team works closely with community team members	MDT working with community members is described as 'a challenge' due to their large patient cohort (P36)
Subcategory: Coordination and management of care processes	All services actively pull services together to improve care, for example, social care, financial and housing arrangements, the coordination process was compared with as being a 'conductor of an orchestra' (P03) Majority of services described carrying out holistic assessments, one professional described their interactions with specialties as, 'it's just about reminding them that it's not about one body system. It's about the whole system' (P13) with another service adopting an 'overarching view of the child' (P14). Many of the services explicitly described their services as having a family support element in which families valued being able to 'offload' (P20) holistic outlook	Both services problem-solve and provide dedicated clinical training for professionals, parents, and caregivers. holistic outlook	Coordinates patients' care by attending discharge planning meetings and various MDTs, ensuring 'parents can meet their health needs' (P23) holistic outlook	Provides end of life and advanced care planning holistic outlook	Assists patients transition from paediatrics to adult services holistic outlook	Coordinates care, ensuring staff are up-to-date and needs were met using their designed goal sheet and checklist holistic outlook
Subcategory: Information and communication technology	Two of the teams had designed a document to illustrate the holistic needs of their cohort. To help inform others, one team had designed a document to be used by professionals			Use of holistic document	Use of holistic document. In addition to this, a summary letter is also used to detail the transition to adult services. However, interactions with other staff members did not always go as planned as rarely would they 'get a lot of letters back' (P09)	Use of holistic document containing a goal sheet and checklist to provide a 'holistic whole patient' approach (P36)

Table 5 Financial arrangements

Model name	Complex and coordination model	Upskilling model	Community model	Palliative care model	Transition model	Intensive care model
Category: financial arrangements						
	Receives internal funding Many reported receiving limited funding, one service runs on a 5-day basis as they 'didn't really have quite enough money and resources' (P01)	Receives internal funding	Receives funding from not-for-profit-enterprise Reported receiving limited funding as healthcare services were 'all about money… Budgets are really tight' and as their service is not viewed as making 'money' as it treats conditions which cannot be 'cured' (P23)	Receives internal funding Reported receiving limited funding as 'everywhere is struggling' (P16)	Receives internal funding	Does not currently receive funding as it is a developing model

Table 6 Governance arrangements

Model name	Complex and coordination model	Upskilling model	Community model	Palliative care model	Transition model	Intensive care model
Category: governance arrangements						
	Each service has governance meetings. Many of the teams used clinical incident reporting to ensure the safety of patients and monitoring of performance via feedback measures	Use of governance meetings and monitoring of performance via feedback measures	Use of governance meeting and monitoring of performance via feedback measures	Unknown	Use of governance meetings and monitoring of performance via feedback measures	Use of governance meetings, monitoring of performance via feedback measures and requests a member of staff actively promotes their service

Table 7 Implementation strategies

Model name		Complex and coordination model	Upskilling model	Community model	Palliative care model	Transition model	Intensive care model
Category: implementation strategies							
	Subcategory: Interventions targeted at healthcare organisations	Many services had adapted their working model as one team changed their outlook from a 'medical approach' to one which was more social (P03) four of the services used family and professional voices to inform their service design					Adapted their working model, using voices of family members and professionals to inform their service design to produce a 'good pathway' (P36) after consultation of a long-stay patient questionnaire
	Subcategory: Interventions targeted at other specific types of practice, condition or setting	Referral criteria is used. The most common type of criteria used by services is based on the needs of a patient followed by multiteam or multisystem involvement, two services also base their criteria around length of stay	Referral criteria is used, based on the needs of a patient relevant to their output	No referral criteria is used as they are relatively new and do not have admission rights	Referral criteria is used, based on the needs of a patient relevant to their output	No referral criteria are used as they are relatively new	No referral criteria used as they are relatively new

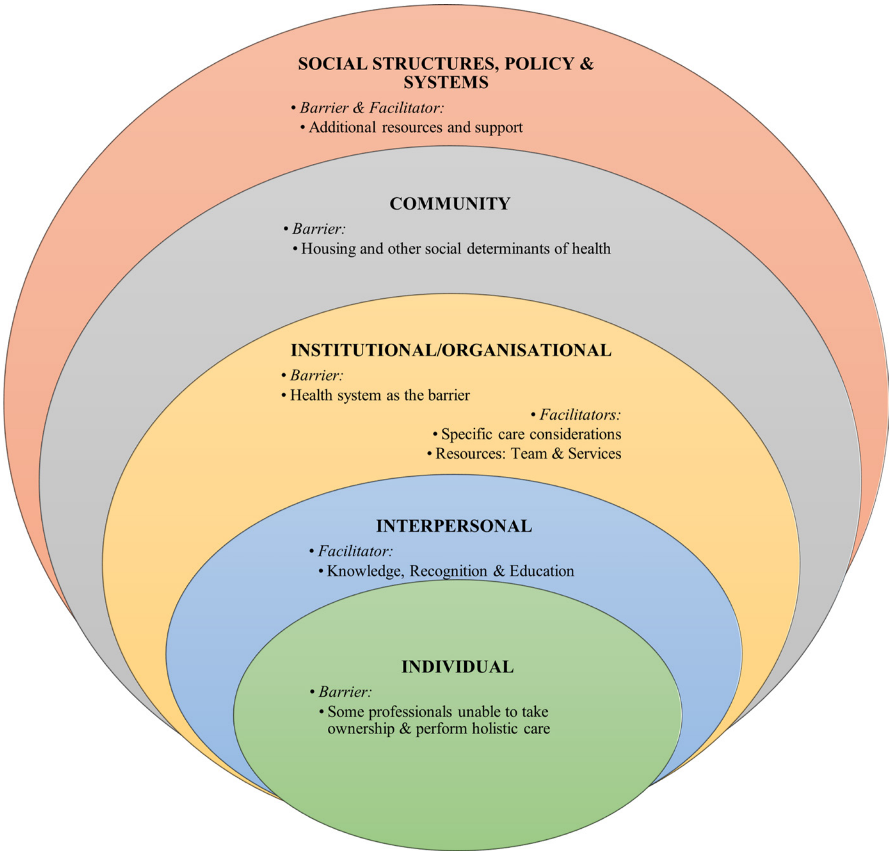

Figure 1 Social-ecological model with categories.

on assisting with transition from paediatric to adult services only.

Barriers and facilitators

Figure 1 (see figure 1) displays the categories identified within the barriers and facilitators to providing high-quality care to this population using the social-ecological model.[16 17] The barriers and facilitators found were relevant to all to the six types of models and organisations where no services were provided. Table 8 illustrates the categories found and their supporting quotes.

Individual

Perceived barrier: some professionals unable to take ownership & perform holistic care

Clinicians faced constraints when attempting to provide holistic care and take ownership of this group. Constraints related to individual characteristics such as multiple team involvement, too focused on their area of expertise, low-confidence levels and fears triggered by media influence.

Due to the high number of medical and social needs when caring for this population, a variety of team members from different specialties are often involved. Clinicians thought that this made it 'easy' to defer 'ownership' of the patient (P01) as there was not a named lead or one singular team leading care.

There were other individualised factors which clinicians sometimes perceived others from providing person-centred care, a necessary component according to many. For some, clinicians focused too heavily on their own professional skillset, at times, becoming too specialised and ignoring other social and medical factors.

> There's people who are specialist in a certain bit of the body and that's what they see their job is to deal with (P35)

In one example, a clinician reflected on their weekly multidisciplinary meetings and found that some would simply refer to one aspect of the patient's care as opposed to a person-centred model, illustrating that it would happen on a regular basis.

> He was just purely focused on the drug dosage of this child, that was the thing he was focused on. But he wasn't willing to think about the wider picture of this child … Other meetings that I've been to is that they're just very diagnostically focused … they don't have a wider role in term of thinking about the patient or the family (P27)

Due to acute pressures and time constraints, practising person-centred care was made more difficult for some and would actively encourage focusing on one area.

Table 8 Social-ecological model categories and quotes

Social-ecological model	Categories	Type	Exemplar quote
Social structures, policy and systems	Additional resources and support	Barrier and facilitator	‘Money is always a big barrier to anything’ (P11) ‘Having money to do it’ (when asked what the facilitators were) (P35)
Community	Housing and other social determinants of health	Barrier	‘The community teams … The provision isn’t there to support these patients’ (P13) ‘There’s an awful lot of housing issues to get around’ (P04)
Institutional/organisational	Health system as the barrier	Barrier	‘It’s fixed commitments in our diary that makes it sometimes very difficult to be responsive when the service is needed’ (P22) ‘The systems that we have set up in the healthcare system don’t necessarily support us working together cohesively’ (P07)
	Specific care considerations	Facilitator	‘It’s just that communication and coordination that we need’ (P38) ‘I really think there is so much in providing space for communication’ (P05)
	Resources: teams and services	Facilitator	‘I’ve definitely kind of suggested that I think we need it, there isn’t currently a medical lead’ (P15) ‘We need that complex discharge team’ (P11)
Interpersonal	Knowledge, recognition and education	Facilitator	‘There is absolutely definitely opportunities in many of the jobs that you do as a junior doctor to learn about medical complexity but there’s maybe not quite a clear path for the training’ (P24) ‘There needs to be a training pathway’ (P23)
Individual	Some professionals unable to take ownership and perform holistic care	Barrier	‘There is a speciality for every single thing and the problem with that is no-one looks after the whole child’ (P17) ‘People resist getting involved because it’s easier, it’s human nature, you don’t really want to be responsible for something you know you can’t make better’ (P16)

> They’re busy and so they deal with their bit and it’s sometimes that actually they’re not able to think about the whole child (P35)

In other cases, the complex decision-making and uncertainty surrounding caring for this population left some clinicians feeling fearful or unable to appropriately care for them due to lacking in experience or confidence. To help lessen fears, it was thought that building a ‘bank of experience of looking after them’ (P27) was necessary. Interpersonal anxieties surrounding caring for this population were heightened by the level of media coverage on high-profile cases as in recent years, a ‘spotlight on children’s health, Children with Complexity and life limiting, life threatening, conditions’ discouraged clinicians from feeling ‘comfortable’ (P34).

Interpersonal

Perceived facilitator: knowledge, recognition & education

On an interpersonal level, clinicians expressed the importance of understanding the needs of this cohort. To achieve this, ‘expertise’ (P26) such as training, education and recognition were seen as facilitators. For some, to gather investment and improve quality of care, the ‘education of people’ (P06) was at the forefront of producing change.

> I think the facilitators are interest, more than anything else (P26)

It was thought that many clinicians did not recognise this growing population and the complexities involved in their care. To facilitate change within health systems and ways of caring for this patient group, perceptions needed to be challenged.

> I think recognition is the biggest, I think that’s the most important one (P14)

Institutional/organisational

Perceived barrier: health system as the barrier

On an institutional level, the UK health system was viewed as a perceived barrier to high-quality care as it was not believed to be designed to meet the needs of children with medical complexity. Clinicians had not been allocated enough time to perform person-centred care and felt as though their organisation lacked in an appropriate pathway, which encouraged silo thinking.

It was argued that the health system itself was not designed to meet the needs of these children as there were not pathways which were child specific. The uniqueness and complexity of conditions meant that there was currently not one pathway suitable, as though they 'don't fit in', with one clinician describing it as their 'biggest challenge' (P03). Due to the environment of an acute system, this prevented some clinicians from providing high-quality care as they battled with time constraints and overwhelming workloads. These pressures left clinicians experiencing feelings of guilt and distress as illustrated in the quotation below.

> The biggest barrier is actually how busy staff are and that actually really upsets me because I think everybody goes to work to do a good job and the reality is we have so many children to see in a short period of time (P38)

When attempting to navigate the health system and care pathway of this population, clinicians were met with communication barriers. Due to the number of conditions this patient group may have, it often involves different team members from a variety of specialties. Therefore, the need for effective communication is important. However, the health system design was believed to encourage silo thinking as specialties did not share information with others outside of their department.

> Parts of the organisation and parts of the NHS not communicating well with each other. So, you know, we are still working in silo (P10)

In one hospital, attempts were made to delegate time and coordination (a previously identified barrier) to this patient group through the creation of a coordinator role. However, this was met with criticism as a 'a very small amount of time' was introduced and was ultimately viewed as 'setting someone up to fail' (P37). Similarly, many of the existing identified complex NHS services found in this article were found to lack in capacity, requiring additional funding or staff members. In one instance, one service only had 'three' available staff members working for both the service and the wider hospital meaning that it was 'not consistent' (P06). In another, funding and staff capacity was an issue.

> We're actually looking for more money at the moment because there's a lot more we can do. We just need more man hours (P04)

Perceived facilitator: specific care considerations

To assist in improving care conditions for this population, many agreed that specific care considerations were required. These consisted of continuity, coordination of care, efficient communication or discharge planning. To assist in their implementation, clinicians hoped that these considerations would be made a requirement by their organisation.

To facilitate coordination of care, effective communication and continuity were highlighted by many, with one clinician describing communication as 'high up' on the list of facilitators (P03). The need for efficient communication related to two aspects of their care, one referred to communication with family members and the other, internal communication among clinicians. However, this meant that hospitals would have to allocate time to provide this. In some instances, clinicians referred to a dedicated individual to assist in building relationships with families and acknowledging this unique patient group. It was also thought that this would be helpful in improving continuity of care.

> I think it needs somebody who is expert within communication, liaison, understanding the needs of these complex patients. (P26)

To improve the standards of care provided, clinicians were thought to require knowledge of extensive guidance surrounding discharge planning and other internal processes as part of their care considerations.

> Complexity requires multiple processes, multiple meetings and multiple levels of communication, multiple levels of understanding (P10)

The introduction of organisational changes involving resources consisting of teams, partnerships and dedicated services were viewed as facilitators. To care for this population, collaboration among teams and an awareness of services was necessary.

> You have to work alongside every discipline and every specialty within the Trust and building up those good rapports, not only within the Trust but then locally… Because that's really building up those good relationships for the families but also for the professionals to know that they're supported and there's plans (P03)

Clinicians must interact with various professionals, both internal and external to coordinate their care. Therefore, strong collaboration and working relationships were seen as beneficial in allowing both clinicians and families to feel secure. To some, this was already viewed as part of their natural skillset as paediatricians.

> I think paediatricians are very good at multidisciplinary teamworking and that's something certainly that in my job we do an awful lot of that's definitely a facilitator (P34)

In addition to collaboration with services, many of the clinicians believed that a dedicated service would act as a facilitator, some involving a medical lead.

> There isn't a clinical lead … We really need that. (P16)

In some instances, clinicians believed that interdisciplinary team members should be part of a dedicated service.

> If you wanted a gold standard service … You'd want a clinician, you'd want a specialist nurse, you'd want a social worker (P11)

To some, nursing staff were thought to be another key element of a complex service as they would have allocated time and resources.

> Nursing body, nursing team who are dedicated to children with complex needs (P18)

Community

Perceived barrier: housing and other social determinants of health

Referring to the community, outside of the hospital, clinicians described existing barriers such as housing and other social determinants of health as preventing clinicians from providing high-quality care.

The healthcare services available in the community was viewed as stretched, impacted by COVID-19 and staff shortages. Unfortunately, this left clinicians unable to 'progress with these families' (P03) as care packages were unavailable. Further implications included a delay in discharge as parents would not be supported at home.

The shortage of available housing was another external barrier preventing clinicians from coordinating an individual's care. Due to the complexity of the care required for this patient group, it frequently involves patients requiring housing adaptations. However, the lack of suitable homes meant that families and patients were at risk of a delayed discharge or even homelessness.

> These are families that are complex in the nature of potentially being homeless, not having appropriate accommodation (P06)

> It's housing that takes ages because if there's no houses, there's no houses. There's nowhere to discharge this child. (P21)

Social structures, policy and systems

Perceived barrier & facilitator: additional resources and support

Interestingly, additional financial resources and support from organisations caring for this population were viewed as both a barrier and facilitator. Many of the clinicians described their organisations as 'struggling' and lacking in available funding. However, still argued that funding was an 'obvious' (P16) facilitator and a necessary component.

> There has to be the financial driver as well [when asked what the facilitators are] (P37)

Despite the economic driver acting as a facilitator, adequate funding was viewed as something 'the NHS doesn't have' (P18). Therefore, the possibility of introducing dedicated services or a clinical lead was unimaginable for many.

> With the block contracts and the money that's needed for new posts. That's certainly definitely one of the problems that I can't imagine is just happening in [hospital]. [when asked about the possibility of a clinical lead] (P34)

By adopting a wider approach, viewing it from an organisational perspective, one clinician highlighted the long hospital stays of this patient group and the discharge priorities of the trust. If possible, cost-saving measures such as discharging patients as quickly and safely may be achievable if investment was implemented.

> Funding point of view, these children spend a lot of time in hospital and it's expensive to keep these children in hospital. And actually, what the trusts wants us to be doing is discharging them as quickly and as safely as we can just because it's less money for the trust [when asked what the facilitators are] (P11)

DISCUSSION

This study highlights that many tertiary children's hospitals in England do not have specific services for children with medical complexity. Those organisations that do have specific services for children with medical complexity used a variety of models to provide this care—six different models found across fourteen services in six organisations. Key components of these models included implementation, financial and care coordination strategies. The variation in types of models identified illustrates the unique requirements of this population. This study has also identified contemporary views of professionals on the perceived barriers and facilitators to providing high-quality care to this population applied across the social-ecological framework, ranging from individual to societal.

Models of care

The majority of models from the current study could be classified as episode based[3], one of the three main categories found when exploring US models of care. This model type treats a specific health episode or transition period in an acute setting using a holistic outlook, deemed as the most appropriate type due to the varying needs of this patient group.[18 19] However, we found key components between our models that differentiated them, that is, focus on transition to adulthood or palliative care. Those classified as episode based under our study also differed from the previously reported disadvantage, inconsistent care teams[3] as ours had assigned team members. Another main challenge of this episodic model, shown in the current study too, is that some professionals are unable to ensure continuity of care outside of the hospital setting.[20] To address this issue, there were instances of services wishing to further develop their team for example, additional team members, but these were mainly hampered by funding issues. This was unsurprising as healthcare decision-making to invest in a complex care service may be heavily influenced by financial availability[20] despite suggestions of implementing higher standards of care to lower high costs.[21] High financial outputs refer to recent reports that found children with medical complexity account for 57% of Canadian hospital resources and costs[22] and in England, lack of bed space to meet this growing patient group has been noted[23] .

Although growing concerns and calls for change surrounding high healthcare use and costs, children with medical complexity still experience challenges when interacting with health services. Due to their healthcare needs and fragility, the risk of implications such as a medication errors or miscommunications across medical settings are heightened.[24] Each of the identified services made attempts to reduce poor outcomes using several governance strategies, an example shown under the intensive care model using a checklist to coordinate and ensure medication safety. Previous research has found a significant gap in evidence of models successfully transitioning patients into adult services.[3] In this study, a transition model was identified, adding to the limited evidence base.

Barriers and facilitators to providing high-quality care

The barriers and facilitators found illustrated the experiences of clinicians involved in caring for children with medical complexity, ranging from individual to social structures, policy and systems. Prior international studies[11 25] have reported families facing challenges when attempting to navigate a fragmented health system, similar to findings in this study, but from a health professional perspective when caring for this patient group. Clinicians reflected on barriers such time constraints and personal development as they lacked appropriate training or experience. Limited time to care for and training in complexity has been found in previous US[26] and UK[10] studies. Despite recommendations of holistic care as a facilitator, clinicians described individual and organisational barriers which prevented them from doing so. These barriers are not uncommon as previous literature has found that paediatric nurses faced institutional restrictions when attempting to integrate person-centred care into their practice.[27] To assist in limiting such barriers, clinicians in our study agreed that some form of financial investment involving a clinical lead or multidisciplinary team to assist in coordination would be beneficial. This is also evident in previous research as this patient group has been identified as having significant amounts of healthcare costs[21] and require several professionals[28], strengthening the suggestion of investment. Such incentives are thought to create space for clinicians to provide necessary person-centred care, coordination and recognition to improve health and quality of life[6 29] as instances of when a programme has introduced forms of coordination, parents' concerns have been reduced.[30 31]

Outside of the hospital setting, housing and community resources were thought to impact the quality of care. In some instances, COVID-19 was seen as impacting staff availability and exposing fragmentation across services, further illustrating existing inequalities between social care and the NHS.[32] Due to the complex nature of this group, many require some form of medical assistance surrounding their functional mobility and therefore, accessible housing is considered a necessary component of their care.[33] However, in this study, clinicians reported a shortage of appropriate housing. There have been previous calls for the government to invest in the growing landscape of disabled children across the UK, particularly those with complex needs, to provide housing.[33 34] It is evident such calls have not been adequately addressed as illustrated throughout this study.

Implications for services

Due to the variation in models identified, guidance is required to determine the most effective service to later implement. In existing identified models, services faced implications relating to linking with community services and faced financial concerns. Existing and future services must emphasise the importance of collaborating with community services, finding new ways to strengthen relationships. Throughout our study, clinicians emphasised the importance of coordination and introducing roles such as clinical leads through investment. However, it is understood that not all hospitals have the capacity to introduce a complex service for this population. Despite this, paediatric services must find ways adapt to meet the needs of this growing landscape. This may involve implementing some of the facilitators such as training and recognition.

Implications for research

Future research could examine the implementation of the identified facilitators as an intervention across a variety of hospital sites. In this instance, it was not possible to evaluate the impact of the identified models of care. Therefore, findings may encourage others to design a programme evaluation to determine the impact of the identified models of care.

Strengths and limitations

This study provides an in-depth exploration of the complexities when caring for this population using in-depth semistructured interviews and is one of the few UK-based studies, to our knowledge, that focuses on current models of care, barriers and facilitators for this population. The use of the EPOC framework provided an organised and conceptualised interpretation of the existing models. Similar to the other framework used, social-ecological model, as a variety of factors were identified as barriers or facilitators, ultimately promoting necessary changes. The interviews were conducted during the wave of COVID-19, offering a unique insight into the pressures of the health and social care sector. Due to the number of hospital sites recruited, a large variety of professions were included. Although extensive efforts were made to recruit clinicians from non-tertiary children's hospitals, they were under-represented in our sample. It is likely that there are existing complex community-based services that were not included in this study.

CONCLUSIONS

Children with medical complexity should be a priority for hospital-based teams, however, both the lack of a dedicated service in some organisations and the range of different models of care found in this study suggests a lack of knowledge of appropriate models for providing care for this population. However, clinicians did agree that changes to training, knowledge and recognition this population would be a beneficial strategy. Paediatric services have the opportunity to redesign training to ensure holistic care and dedicated coordination are part of their practice, as clinicians struggled to implement this under current acute models. Outside of the acute care settings, future social care investment such as suitable accessible housing and other community services is needed.

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