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Physiotherapists' decision-making on paediatric intensive care: development of a conceptual model

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Abstract

Respiratory physiotherapy is a commonly used treatment for children in paediatric intensive care units (PICUs). A wide range of interventions are available, and practice varies. There is no literature exploring how physiotherapists make decisions regarding treatment choice and delivery in this vulnerable and complex population. The aim of this study was to understand physiotherapists' decision-making regarding delivery of respiratory physiotherapy in UK PICUs.

This was a qualitative study, involving virtual semi-structured interviews and focus groups with PICU physiotherapists. Sixteen interviews and two focus groups ($n=7$) were completed. They were audio-recorded and transcribed verbatim. Framework analysis was used.

From the interview analysis, five themes were developed within a 'Factors influencing decision-making' framework: physiotherapist knowledge, the physiotherapist, consideration of family, other health care professionals and external influences. Clinical knowledge and understanding were key factors in decision-making. Approaches evolved with experience, opportunities for reflection and learning, plus the development of intuition. Collaboration was integral to physiotherapists' decision-making, however this posed additional challenges. A 'Clinical decision-making' framework was developed from the focus groups, including three themes: information gathering, listening to the patient, and learning from experience. Active information gathering and comprehensive patient assessment were described. Listening to the patient and being able to react and adapt at the bedside were important processes involved in decision-making.

A conceptual model has been developed, which depicts physiotherapists' decision-making as complex, iterative and collaborative, with experience and expertise important factors. The findings have highlighted several areas that require consideration from a workforce and education perspective.

Keywords Respiratory physiotherapy, Clinical decision-making, Family-centred care

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Introduction

Approximately 20,000 children are admitted to UK paediatric intensive care units (PICUs) each year. Of these, 65% require respiratory support, with 30% admitted for respiratory conditions [1]. Children may present with respiratory distress due to an acute infection or exacerbation of inherited or acquired lung disease. The natural defence mechanisms, which contribute to effective airway clearance of the respiratory system, are essential to ensure removal of foreign particles and pathogens, preventing infection, and optimising respiratory function and ventilation. Whilst these mechanisms are sufficient in healthy individuals they are disrupted during critical illness, particularly in patients with respiratory disease or those requiring intubation and mechanical ventilation [2–5]. Respiratory physiotherapy is a commonly used treatment for children on PICU and aims to facilitate airway clearance and minimise complications associated with a PICU admission [6, 7]. Physiotherapists use a wide range of interventions with mechanically ventilated children and variability in practice has been demonstrated [8].

Clinical decision-making is described as the core competency of professional practice [9]. It enables clinicians to make informed and responsible decisions and address the problems faced by their patients. Several authors have studied physiotherapists’ decision-making in the adult respiratory setting [10–12]. Physiotherapists’ decision-making related to airway clearance techniques and mucoactive agents in critically ill adults has been investigated using focus groups [10]. The authors described decision-making as an iterative process in which physiotherapists utilise multiple sources of clinical information. Smith et al. (2007) used hermeneutic methodology to investigate specific factors influencing cardiorespiratory physiotherapy decision-making in adult acute care [11]. Decision-making was identified as a dynamic, complex and multidimensional process. A mixed-methods study highlighted that although cardiorespiratory physiotherapists’ decision-making was similar to the hypothetico-deductive model and five-rights nursing model, it was more complex, iterative, and reflexive than these individual models suggest [12]. There is currently no literature exploring how physiotherapists make decisions regarding treatment in PICU. Greater understanding is important given the complex PICU environment, including high patient turnover, patients receiving multiple therapies and interventions, and distressed parents/families,

together with the necessity for quick decisions and timely treatments.

Despite the popularity of respiratory physiotherapy in PICU, evidence to support its effectiveness in ventilated children remains inconclusive [13, 14]. There are currently few high-quality studies, with heterogeneity in the physiotherapy interventions and populations studied. Important gaps in the literature include lack of representative populations, the effects of multiple physiotherapy treatments, and the impact on long-term outcomes [13, 14].

A mixed-methods study was developed to provide a detailed understanding of respiratory physiotherapy on PICU. Aiming to advance the knowledge base and identify areas requiring further education and research. The first part of this study, a survey describing current respiratory physiotherapy practice, is published elsewhere [8]. The aim of the current report was to understand physiotherapists’ decision-making regarding delivery of respiratory physiotherapy in UK PICUs.

Methods

Study design

This was a qualitative study, involving virtual semi-structured interviews and focus groups with PICU physiotherapists. The study has been reported in line with the COREQ checklist (Supplementary material 1).

Sample and recruitment

Physiotherapists from nine pre-selected UK PICUs were invited to participate. Units were selected based on size of unit, geographical region, and regional and sub-regional services/specialities offered, to ensure they were representative of all 27 UK NHS PICUs. Study invitations and participant information sheets were emailed to the lead physiotherapist at each site, for dissemination to physiotherapists who met inclusion criteria (Table 1).

Data collection

Virtual semi-structured interviews were completed by the lead researcher (ES) using a piloted topic guide (Supplementary material 2). This was developed with the research team (HS, JW) and based on the research questions and findings from the previous study [8]. The questions focused on participants’ experience, variability in practice, experiences of decision-making and perceived levels of autonomy.

Two virtual focus groups were completed, one involving senior physiotherapists (agenda for change band

Table 1 Study inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Full- or part-time, static or rotational qualified physiotherapists working in a UK NHS PICU.	Physiotherapists who only work in paediatric intensive care as part of on-call/emergency overnight or weekend shifts.

7/8) and one junior physiotherapists (band 5/6). These were moderated by an academic cardiorespiratory physiotherapist (SR), external to the research team. The lead researcher (ES) was present as an observer and to manage the technology but did not interact. A topic guide was developed with the research team, based on the research questions, and findings from both the previously published survey [8] and interviews (Supplementary material 3). The focus group included a vignette involving the assessment and treatment of a mechanically ventilated child with physiological instability. This included a video of a simulated patient assessment and treatment.

Demographic data for each participant were collected. Interviews and focus groups were audio-recorded, transcribed verbatim and stored securely. All identifiable data were removed during transcription.

Researcher-participant relationship

The lead researcher (ES) was a PhD student and physiotherapist working in a UK PICU. She explicitly introduced and presented herself in the role of researcher rather than clinician. However, her clinical background enabled understanding of the clinical context and presentations. Open questions were used and linked to the survey [8] results to prevent association with personal opinions or experience. The researcher completed reflective field notes during data collection.

Data analysis

Ritchie's and Spencer's (1994) Framework method, involving five interconnected stages, was used for data analysis [15, 16]. The lead researcher (ES) completed the familiarisation process by listening to the audio-recordings and repeatedly reading transcripts. Preliminary frameworks were created using the initial themes and topics documented during familiarisation. Transcripts were then indexed. Transcripts and preliminary frameworks were explored and discussed with one member of the research team (JW) to ensure transparency and minimise bias [17]. NVivo was used to complete the charting process. Case summaries were generated for each framework and illustrative quotes highlighted. Frameworks went through several iterations as analysis stages were repeated and themes refined. During the final stage the range of responses were mapped, including similarities and differences, and themes interpreted. The research team (HS, JW) were provided with a de-identified interview and focus group transcript and the frameworks. They were asked to follow the data from its raw form to the final themes, checking transparency and credibility. The focus group frameworks were also verified by the moderator (SR), to ensure data validity.

Results

Sixteen physiotherapists from eight of the pre-selected PICUs were recruited for the interviews. Seven of these were also recruited to the focus groups. No physiotherapists from the ninth PICU responded to the invitation email or reminder. Participant demographics are displayed in Tables 2 and 3. Interviews ranged from 33 to 55 min, and focus groups ran for 67 and 69 min. The researcher (ES) had previously met six of the physiotherapists due to her clinical role, specific strategies related to the researcher-participant relationship have been outlined in the methods section.

Final interview analysis included five frameworks with 16 themes, and the focus group analysis four frameworks with 12 themes (Supplementary material 4). One framework from the interviews and one from the focus groups which address the research question are included in this report. Illustrative quotes are provided in the text, identified by interview participant (PI) or focus group (FG) number. Additional numbered quotes are displayed in Table 4.

Interview findings

Five themes were developed within the framework 'Factors influencing decision-making' (See Supplementary material 5 for complete framework):

1. Physiotherapist knowledge.
2. The physiotherapist.
3. Consideration of family.
4. Other health care professionals.
5. External influences.

Most physiotherapists discussed that clinical knowledge and understanding were key factors in decision-making. Physiotherapists described completing a thorough assessment to enable them to use clinical reasoning to identify clear indications for treatment:

"And, it's almost coming back to the very basics of what we're taught in physio of actually is there something either on X-Ray, auscultation, ultrasound, clinical examination, is there something the patient can benefit from me intervening. Not just, 'let's give it a go and let's see what comes up'" (PI16).

Additionally, physiotherapists talked about how previous knowledge of, and exposure to, the patient aided decision-making. They aimed to ensure continuity of care, seeing the same patient throughout their PICU stay and sometimes beyond (Quotation 1).

The second theme 'The physiotherapist' related to experience. Physiotherapists reported making decisions by drawing on experience gained through patient contact,

Table 2 Summary of interview participant characteristics

Demographic	Categories	Number of physiotherapists n (%)
Sex	Female	13 (81)
	Male	3 (19)
Ethnicity	White British	16 (100)
Size of PICU	Large	7 (44)
	Medium	5 (31)
	Small	4 (25)
Agenda for change band	Band 8	2 (13)
	Band 7	9 (56)
	Band 6	4 (25)
	Band 5	1 (6)
Geographical region	East Anglia, South East and Greater London	1 (6)
	Midlands	6 (38)
	Scotland, Northern Ireland, and North East	4 (25)
	North West, Yorkshire and The Humber	1 (6)
	Wales and South West	4 (25)

(Band 5/6 – junior physiotherapists, Band 7/8 – senior physiotherapists)

Table 3 Summary of focus group participant characteristics

Demographic	Categories	Number of physiotherapists	
		Focus group 1 Band 7/8 (n=4)	Focus group 2 Band 5/6 (n=3)
Sex	Female	3	3
	Male	1	0
Size of PICU	Large	1	2
	Medium	1	0
	Small	2	1
Geographical region	East Anglia, South East and Greater London	0	0
	Midlands	1	0
	Scotland, Northern Ireland, and North East	1	2
	North West, Yorkshire and The Humber	0	0
	Wales and South West	2	1
Years of PICU experience	Range	1 year– 26 years	6 months– 3 years

(Band 5/6 – junior physiotherapists, Band 7/8 – senior physiotherapists)

and the opportunity to make mistakes, reflect and learn from them (Quotation 2). Physiotherapists associated increased experience with greater confidence to deal with clinical situations. The quote below illustrates how a lack of experience and confidence made the management of a patient challenging:

“Obviously, it came to PICU, so she was probably a really difficult one for me to, sort of, manage. Number one, because we don’t see that type of patient very often and then knowing, or having the confidence to, sort of, provide the best possible care to her.”(PI10).

Physiotherapists suggested that previous experience allowed them to base decision-making on instinct:

“Yes, and sometimes it’s just you get, like, a bit of a gut feeling, don’t you? That I think, ‘Yes, I think this is going to work for this one,’ and you, sort of, go with that, really.” (PI14).

The personality of the physiotherapist was also highlighted as influencing decision-making. One individual mentioned how differing risk behaviours can impact decisions (Quotation 3). Most physiotherapists felt that other demands on their time influenced practice and decision-making. More senior physiotherapists reported numerous non-clinical responsibilities, including supervision and teaching, and the complex process of balancing these with patient care (Quotations 4 & 5).

Within the third theme ‘Consideration of family’, the role of the family in decision-making was frequently acknowledged, however differing experiences were discussed. Several physiotherapists referred to the parent/family as being the expert and utilising their knowledge and skills to facilitate decision-making:

“So, we quite often ask parents if it’s a patient that’s been in hospital a lot but not necessarily with us, we do tend to ask them, you know, what’s worked in the past? Or have you tried this before and what happened?” (PI14).

One individual highlighted this as a challenge, with the expert care parents provide becoming more difficult to deliver in the PICU environment:

“Some of the parents become really, really skilled at looking after their children but almost-, their children become such a skill to look after that unless you are their parent, you actually can’t replicate it.” (PI12).

Despite these differences all physiotherapists agreed that decisions needed to be made collaboratively with the family/carers. Physiotherapists talked about managing expectations, allowing them control over certain decisions, and negotiating (Quotation 6). Several physiotherapists commented that communicating with parents/families was a strength of physiotherapists, *“for us, that feels like a bread-and-butter conversation” (PI11)*. However, building effective relationships was seen as a double-edged sword, with decision-making more difficult (Quotation 7). Feeling under additional pressure from the family/carers was also discussed by the band 6 physiotherapists. They talked about having to actively work on, and develop, communication skills with family/carers.

Theme four was ‘Other healthcare professionals’ and referred to the influence they had on decision-making. Positive relationships were described by several physiotherapists, who felt able to make joint decisions with consultants. Physiotherapists occasionally reported feeling pressured by consultants to provide treatment which they deemed inappropriate or use treatments based on the consultant’s preference (Quotations 8 and 9). Physiotherapists across all experience levels reported using other physiotherapists for guidance with decision-making.

The final theme was ‘External influences’. Physiotherapists reported that, although limited, they did use evidence to inform decision-making. Linked closely to the use of peer support, physiotherapists from both small and large PICUs reported liaising with other units for guidance (Quotation 10). The impact of COVID19 on decision-making was mentioned by several physiotherapists. This included practical changes to treatments, which restricted treatment options. An experienced physiotherapist discussed how decision-making had been challenging with this unknown patient group:

“I’ve now got that experience of one, but I feel that would be something to help me and I could give that example because that’s, like you say, I didn’t have that wealth of knowledge like I do with many other conditions, so, yes that was a challenge for me.” (PI01).

Table 4 Additional numbered quotes illustrating the interview findings

Theme		Quotation	
Physiotherapist knowledge	<i>Specific knowledge of the patient</i>	1	<i>"I think, again, it's just come with experience, so I've been working with this patient for, like, the last six weeks, she's a long stay patient, but I think if it was a new patient, maybe not. Because I know her background inside and out, I know what's normal for her, what's abnormal for her, I was able to make those clear decisions, but, I think, for a new patient I probably would have, maybe, doubted myself a bit more and maybe just probably push towards what do the doctors want, what do the doctors want. Where, in this situation, because I knew her, I knew, kind of, what she needs from a cardiac point of view, what she's like from a chest point of view and what she's like weaned off sedation, I was able to have those confident discussions with the doctors and help, like, inform the nursing staff on what to do." (PI06)</i>
The physiotherapist	<i>Learning from exposure</i>	2	<i>"Making mistakes. Experience. The more you see, the more mistakes you make and there's nothing worse than having a buzzer pull and not having any idea why it's happened. Because you feel like a complete idiot. And so I think it's, yes, the more you're up there. For me, I had to learn through doing." (PI04)</i>
	<i>Differing risk behaviours</i>	3	<i>"That does play a part in it. I will use an example, myself and another physio... we are very different in personality and very different in that risk adversity, but that isn't to say either of us are wrong or right but it is just interesting that we would go about it in a different way I guess, with situations like that." (PI05)</i>
	<i>Other demands on time</i>	4	<i>"you try and do some joint treatments as an education role as well but, you know, when it gets super busy you just have to divvy up and treat." (PI01)</i>
		5	<i>"So to be honest, it's very stressful, but it's not necessarily the volume of patients, that tends to be quite steady. It's the extra crap that goes with everything, that's the thing that really gives me the biggest stress. It's the expectations of the staff on ICU and then the expectations of the medical team leaders across the other areas where they think they have full control over what physio they get, how many physios are around, wherever they are." (PI11)</i>
Family	<i>Negotiating</i>	6	<i>"I mean, there are going to be parents who are difficult. But I suppose, again, it's just about that explanation and talking to them about what we would like to do and maybe giving them some options so they feel like they've got an element of control. So, this is what we want to achieve, this is how it could happen, I would choose this one. Are you happy for me to do it? I suppose if they're more informed and they understand and they feel like they've had a choice or been involved in the decision making then that makes that compliance a little bit easier." (PI07)</i>
	<i>Challenges of good rapport</i>	7	<i>"It's really difficult when you know the families as well. You know, we've known that patient's mum for four years now and she knows you as well because you've had loads of chats at the bedside. You get to know each other more than what one person who's come in and gone back out again would get to know them. So, then, I don't know, things just sometimes-, they don't get a wee bit woolly, but you've obviously got pressures from the parent who's saying, 'Well, what are we going to do? How are we going to fix this?'" (PI12)</i>
Other health care professionals	<i>Pressure from consultant</i>	8	<i>"If I would've said, 'No, we're not treating that child,' then she would've done it anyway. My perception in that situation, and this could be, I don't think it's arrogance, but it's just value of my profession. I think that if anyone is going to do that to that baby, then we're the best people to do that because we're the ones that are most likely to be, (a) effective, if the effectiveness is required, or (b) know when to stop pushing." (PI03)</i>
		9	<i>"I had just kept this patient on my caseload because the doctors had wanted it, but for three days didn't do anything. Went in, made sure Mum and Dad were happy, made sure that he was still getting up into his chair, made sure he was getting regular nebulisers just to keep everything loose. Okay, great, and then I was leaving, do you know, so I could have discharged him on that day, but just because the doctor is like, 'No, I would quite like the physio to still go. We're worried about his chest,' we kept him on." (PI09)</i>
External Factors	<i>Guidance from other units</i>	10	<i>"I, sort of, do benchmarking or I have our chats with you guys and I've spoken to (person) at (place) quite a bit lately about a patient that I was, sort of, stuck with-, because that's what I struggle with. Because we're so small, it's that if I'm struggling with a patient, who do I go to?" (PI10)</i>

Focus group findings

Three themes were developed within the framework ‘Clinical decision making’ (Supplementary material 6):

1. Information gathering.
2. Listening to the patient.
3. Learning from experience.

Participants in both focus groups discussed the importance of gathering as much information about the patient as possible, including history, clinical presentation, and handling. They aimed to develop a detailed picture of the patient. Focus group 1 talked about detailed questioning of nursing staff, and that superficial knowledge was insufficient. This process also allowed them to determine clear indications for treatment:

“I always think I put my detective hat on and try and find out as much as I can about the patient. What are the secretions like, if they’re just loose, and white, and they’re clearing, then why would we want to get involved? If it’s just a bit of patchy lobar collapse that you get in bronchiolitis, then again you might just want to leave, but if that has then progressed to a whole lung collapse, and the CRP’s gone up.” (FG1).

The second theme was ‘Listening to the patient.’ This referred to decision-making and information processing at the bedside during treatment. Participants in both groups commented on taking cues from the patient and including this information and interpretation in the clinical reasoning process:

“So, I felt he was, kind of, multitasking when the patient was not really liking things and the patient didn’t like the first suction, but he then went ahead and did more treatment when I think the patient was trying to say that, ‘Actually I don’t like this, I want to be left alone for a bit.’” (FG2).

Both groups discussed how increased experience facilitates decision-making, being able to reflect and use this knowledge for future decisions. Focus group 1 identified that this was highlighted by COVID19, a new disease. A physiotherapist described the challenges of being unable to rely on previous experience:

“Yes, I think it’s a lot like PI08 was saying, from your previous experiences, that you draw from, and that’s why for me it was tricky with this baby with COVID that was so young, because I didn’t really have much experience to draw from, and I found that really unusual, because I’ve been doing PICU for about

20-odd years. So, normally I’ve got quite a lot to draw from. So, that felt different.” (FG1).

Focus group 2, involving the junior physiotherapists, discussed how experience and exposure also led to increased confidence.

Data synthesis

Key findings from the interviews and focus groups were merged and are summarised in Fig. 1. This conceptual model depicts physiotherapists’ decision-making as complex, iterative and collaborative, with experience and expertise important factors. It includes multiple, interacting components, and numerous challenges to decision-making. The inner circle of the model focuses on the individual patient and physiotherapist involved in the process. The surrounding influencers incorporate other stakeholders, together with external, wider factors.

Discussion

Physiotherapists described decision-making as a complex, iterative process, which evolves over time and includes a combination of linked influencing factors. Physiotherapists’ knowledge and experience, relationships with family/carers and multidisciplinary team collaboration were important factors.

The multifaceted nature of decision-making, as described in this study, has been widely documented in both intensive care and physiotherapy [10, 12, 18]. Several decision-making models are discussed in the healthcare literature, offering theoretical bases for these complex interactions. Historically, individually defined models were proposed, the hypo-deductive and intuitive-humanist [19, 20]. However, several authors have described physiotherapy decision-making as involving a combination of these models [12, 20]. This resonates with the current findings, where experience, knowledge and intuition were used, in combination with information gathering and processing.

Despite the value decision-making models have in understanding behaviours and informing education, they focus on the individual. Collaborative decision-making with families and MDT was a common theme in this study. Shared decision-making is advocated in PICU and involves incorporating family values and preferences into the process [21]. It has been described as an essential component of family-centred care, which is recognised as best practice [22, 23]. Family/carers face significant challenges in the unfamiliar and threatening environment of the PICU, including communication barriers and lack of control [23]. The physiotherapists in the current study demonstrated good awareness of these issues and shared decision-making appeared to be inherent within their practice.

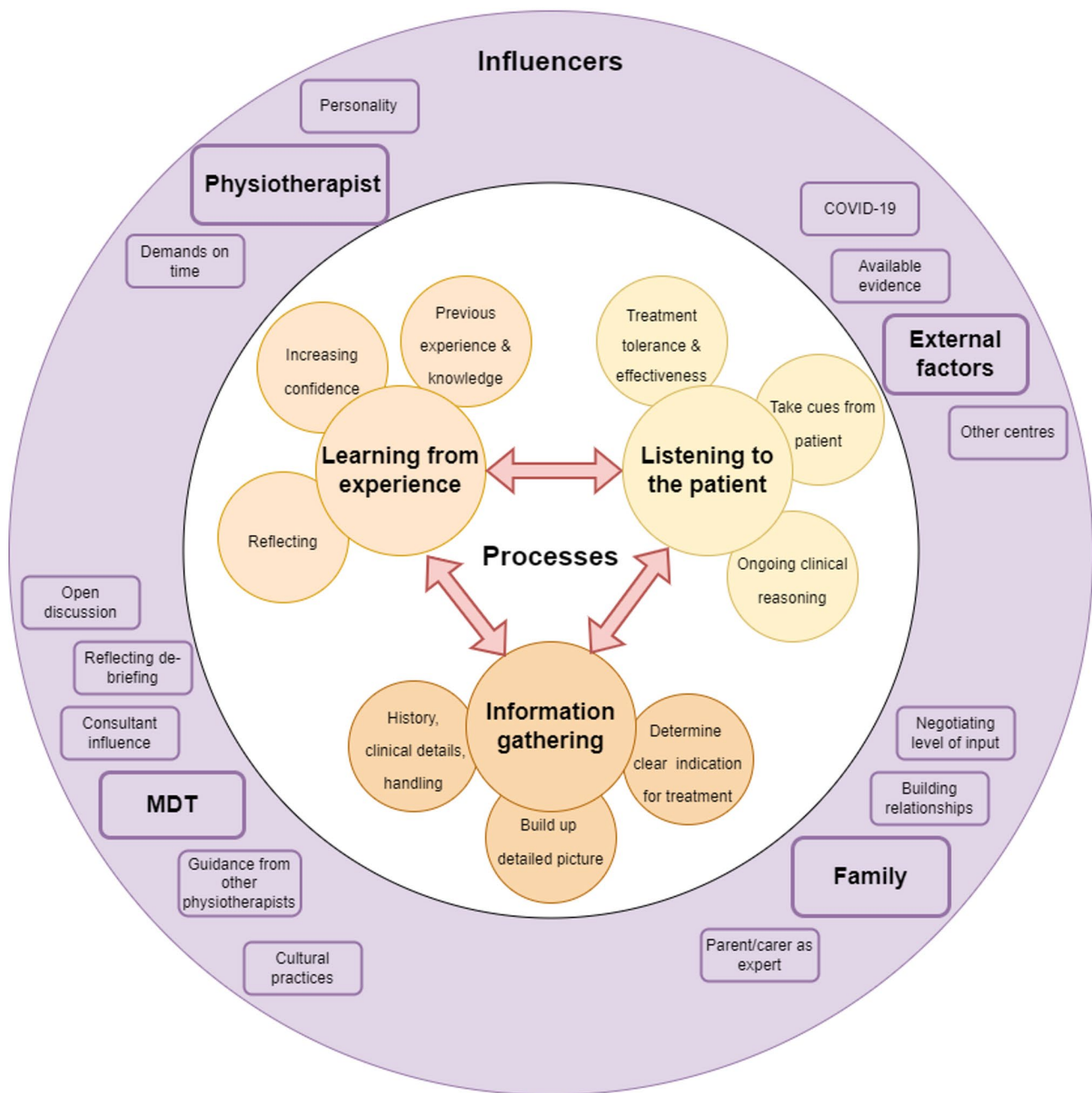


Fig. 1 Summary of physiotherapists' clinical decision making - processes and influencing factors (MDT – Multidisciplinary Team)

Components of shared decision-making include describing treatment options, tailoring information, and creating choice [24]. Physiotherapists in this study highlighted the importance of educating, allowing control and engaging families in decisions. Therapists working in paediatric rehabilitation have described similar approaches to support informed choices [25]. Other studies have highlighted the importance of open communication and ensuring parents are fully informed to facilitate shared decision-making [21, 26]. This was also reflected in the findings of the current study, where

building relationships and developing effective communication skills with families were frequently discussed.

Alongside shared decision-making with families, the physiotherapists reported that other healthcare professionals influenced decision-making. Similar findings have been reported by Smith, Higgs et al. [27] who described physiotherapists' decision making as a social and collaborative process. Care models that prioritise MDT collaboration and involvement in decision-making have been linked to better safety and quality of care [28, 29]. MDT models of care are widely endorsed, and UK standards

stipulate that PICUs should have pharmacy, psychology, dietetic, physiotherapy, occupational therapy and speech and language therapy [30, 31]. Despite this, several physiotherapists in this study described a culture of professional hierarchy which negatively impacted their decision-making. The persistence of traditional hierarchies in PICU has been reported to limit nursing and allied health input into decision-making and increase moral distress [32, 33]. These power dynamics were not experienced by all physiotherapists, which may indicate a changing culture within PICUs. Given the increasing complexity of patients on PICU, the knowledge and skills of the MDT should be utilised in decision-making to ensure best practice.

Level of experience accounted for some differences in decision-making approaches in this study. Experience has been reported as a key component of physiotherapists' decision-making in adult ICU and other healthcare settings [10, 34, 35]. It is important to consider the increased support required by less experienced physiotherapists and the impact on workforce planning, supervision models and education strategies.

Implications for practice and future research

The results of this study have highlighted several areas that require consideration from a clinical perspective. The increased support and supervision required by junior physiotherapists was discussed. Joint treatment sessions and opportunity for reflection should be part of day-to-day practice. However, this has an additional impact on workforce planning and the increased demands on senior physiotherapists need to be accommodated. All physiotherapists described learning through experience. Developing the role of simulation-based learning should be considered. Currently simulation education specifically for PICU physiotherapists is available in a limited number of UK centres. Greater access and research into appropriate training programmes would be beneficial.

The challenges of communicating and negotiating with families were raised in this study. Formal training and opportunities to develop these skills are limited. Hence, greater emphasis should be placed in this area, both at an undergraduate level as well as within the workplace. To promote effective MDT collaboration on PICU it is recommended that education related to the role of the physiotherapist is routinely included in training for new starters of any profession on PICU.

Limitations

Sampling bias is a risk in this study, with only one ethnic group represented. Whilst this may be representative of the wider UK physiotherapy workforce [36], the exclusion of the experiences and opinions of physiotherapists from

ethnic minority backgrounds needs acknowledging. The focus group participants were recruited from the same pool of physiotherapists interviewed. This ensured data and themes were linked. However, this may have limited the richness of data. Self-selection bias also needs consideration, physiotherapists with less confidence or negative experiences may not have volunteered. However, a wide spectrum of experiences, both positive and negative, were shared. The results of the study would have been further strengthened via member checking of the transcripts and themes, however due to time constraints this was not feasible.

Conclusions

This is the first study to explore physiotherapists' decision-making on PICU. A conceptual model has been developed which depicts physiotherapists' decision-making on PICU as complex, iterative and collaborative, with experience and expertise important factors. The findings from this study have highlighted several areas that require consideration from a workforce and education perspective.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1007/s44253-025-00078-1>.

Supplementary Material 1.
Supplementary Material 2.
Supplementary Material 3.
Supplementary Material 4.
Supplementary Material 5.
Supplementary Material 6.

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Authors' contributions

ES, HS and JW conceived the project. ES led the project. ES and SR were involved in data collection. ES and JW were involved in data analysis. ES wrote the first draft of the manuscript. All authors contributed to refining the final draft of the paper and gave approval of the final draft to be submitted.

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Data availability

The anonymised transcripts underpinning the findings of this paper are available from the corresponding author upon reasonable request.

Code availability

Not applicable.

Declarations

Ethics approval and consent to participate

The study was approved by the Health Research Authority (278215) and UCL Research Ethics Committee (16837/001). All participants provided written consent prior to the interview and focus groups.

Consent for publication

All participants provided written consent for publication of the results and the use of anonymised quotations.

Competing interests

Not applicable.

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