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Title: Mental healthcare for children with chronic conditions: a qualitative study

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Abstract:

Objective: To explore parent perspectives on accessing mental healthcare for children with a chronic physical health condition.

Design: Qualitative research using semi-structured interviews and Framework Analysis. Rankings were used to select attributes for a Discrete Choice Experiment(DCE).

Setting: Four speciality outpatient clinics (diabetes, epilepsy, bronchiectasis unrelated to cystic fibrosis and epidermolysis bullosa) at an Australian tertiary paediatric hospital.

Participants: Eighteen parents of children with a chronic physical health condition.

Results: Most parents identified the child's general practitioner and/or hospital team as an initial pathway to seek help if they were worried about their child's mental health. Parents see mental healthcare as part of care for the whole child and want the outpatient clinics to proactively discuss child and family mental health, as well as refer to appropriate services as needed. The hospital being a familiar, child-friendly environment was identified as a key reason the hospital might be a desired place to access mental healthcare, as previous research has found. Six attributes of mental health services were identified as important and will be included in an upcoming DCE: travel time, cost, wait time, available hours, knowledge of physical health condition, and recommendation.

Conclusions: This study highlights the opportunity presented in specialist outpatient clinics to address the often unmet mental healthcare needs of children with chronic physical health conditions. Parents identified practical ways for outpatient clinics to better facilitate access to mental healthcare. These will be further explored through a quantitative study of parent preferences.

INTRODUCTION:

Children with a chronic physical health condition (e.g. diabetes or epilepsy) have 32% increased odds of developing a mental health problem compared to their peers.[1, 2] These mental health problems, commonly internalising problems (anxiety and depression), can adversely impact their physical health condition, general and family wellbeing.[1, 3, 4] In Australia, most children with a chronic condition receive care in a publicly funded specialty paediatric clinic, with no out-of-pocket cost for families. Families can see paediatricians in private practice. Private healthcare providers often have an out-of-pocket cost (also called 'bulk-billing'), charging a fee above the federal government rebate that is not covered by private health insurance. In a public Australian paediatric speciality service, discussion of mental health was found to occur in only 30% of consultations.[5, 6] Previous research has identified barriers from clinicians (not enough time, lack of training), families (not identifying it as relevant, not wanting to discuss it), and services (clinics not resourced to provide mental healthcare, lack referral pathways).[5, 7] Barriers in the Australian system have been explored qualitatively with clinicians but not families.[7] Understanding the family perspective is vital to design family-centred care.

To improve the mental health of children with a chronic physical health condition, we need to better understand how to help their carers access appropriate services for them. Families of children without chronic conditions are well studied. They report cost, wait time, unclear pathways, feeling dismissed, recognising problems, and family circumstance (e.g. rurality and language spoken at home) as key barriers.[8] There is little information from the perspectives of families where the child has a chronic physical health condition. A United States (US) study in an adolescent outpatient rheumatology clinic identified barriers (stigma, fear, uncertainty, parental emotional burden, minimisation by doctors, cost, and time burden) and enablers (strong clinician-family relationships, clinician proactivity, and family mental health literacy).[9] It is not known whether these are similar in younger children, different conditions, and different healthcare systems. We do know these families would like their child's mental healthcare addressed at the outpatient clinic they attend, but

not why.[5, 10] This study aimed to understand, in a sample of parents whose child attends a public specialist paediatric outpatient clinic: (1) awareness of pathways for mental healthcare for their child; (2) why they would like mental healthcare addressed at the outpatient clinic; (3) how such clinics can better facilitate access to mental healthcare, and; (4) factors important to families when accessing mental healthcare. This will inform the design of better pathways to mental healthcare for children with a chronic condition attending specialist outpatient clinics.

METHODS:

This qualitative study was stage one of a Discrete Choice Experiment (DCE) examining parent preferences for accessing mental healthcare for children with chronic physical health conditions.[11, 12] Stage one of the DCE identifies what factors are important to parents to construct the choices offered in stage two.[11]

The study used a semi-structured qualitative interview methodology, and was informed by a conceptual framework of patient-centred access to healthcare in which access (reaching and obtaining healthcare) occurs at the interface between people's ability to access and service accessibility.[13] Study methods and findings are reported in accordance with the COnsolidated criteria for REporting Qualitative research (COREQ).[14]

Recruitment

A purposive sampling strategy was used. Clinicians recruited caregivers of children attending four outpatient clinics at a tertiary paediatric hospital, The Royal Children's Hospital (RCH) in Melbourne, Australia: diabetes, epilepsy, bronchiectasis unrelated to cystic fibrosis and epidermolysis bullosa clinics.[15] Sampling continued until saturation was reached. Participants were offered a \$20 supermarket gift voucher for their time. Interviews occurred between March and June 2020.

Procedures

RJ and JR conducted 18 semi-structured phone interviews lasting approximately 30 minutes, following the interview guide (see supplementary materials). Interviewers first defined mental health and checked this aligned with participants' understanding. Participants were asked to discuss pathways to seek mental healthcare for their child; why parents might identify the hospital as a desired place to access mental healthcare for their child; their expectations of the hospital regarding mental healthcare; what factors are important to them when accessing mental healthcare for their child; and to rank all factors (from most to least important). An initial list of factors was obtained from discussion with five experts and literature review.[11, 16] Participants were asked to identify all factors important to them, before going on to explore those they did not mention.[11] We discussed their views on four reasons we hypothesised might contribute to the hospital being a desired place to access mental healthcare: hospital seen as usual care provider; Australian public outpatient clinics have no out-of-pocket costs; seeing hospital clinicians as experts; or convenience of co-location. The interview guide was adapted iteratively based on issues highlighted in participant responses (e.g. the hospital being a desired place because it is child-friendly). Field notes were maintained. Interviews were audio-recorded and transcribed. Transcripts were checked for accuracy and identifying information removed. Transcripts were coded using NVivo 12.0.[17]

The study was approved by The Royal Children's Hospital Human Research Ethics Committee (HREC 58713).

Analysis

A qualitative framework analysis approach was used to identify themes from the coding, with initial deductive coding from the interview guide and conceptual framework and inductive coding of additional categories as they appeared.[18] An analytical framework was developed by the primary analyst (RJ), a research assistant with a Master of Public Health, with the principal investigator (JR), a health economist with a background in clinical medicine. The final version of the framework was

applied to all transcripts. Three transcripts were read and coded independently by RJ and JR to ensure consensus. To monitor processes and findings, a reflective journal was maintained.

Important factors were translated into attributes of a mental health service and in accordance with the Good Research Practices for Conjoint Analysis Task Force recommendations, the selection of final attributes for the DCE was primarily based on mean rankings.[19] If rankings were similar, we reviewed qualitative data to decide on importance. Additionally, attributes were required to be feasible for inclusion in a choice scenario.[11, 16] The description of attributes was informed by qualitative findings. Attribute levels were chosen to represent feasible options covering the range of services available, with levels of cost and wait time informed by a recent Australian study.[20]

RESULTS:

Table 1 summarises participant characteristics.

Interview data

Themes identified from the transcripts are presented below with representative quotes. Where necessary, quotes have been truncated (represented by an ellipsis). All quotes are pseudonymised.

Aim 1: Understand parent awareness of pathways to mental healthcare for children with a chronic physical health condition. (Table 2)

Pathways to help: Most parents identified an initial pathway to seek help if they were worried about their child's mental health. The child's general practitioner (GP) and/or hospital team were the most common pathways nominated. School, searching online, and mental health support organisations were also identified.

Barriers to reaching acceptable and affordable services: Despite knowing pathways to seek care, some parents experienced barriers that prevented them reaching services. Some found their

child did not meet criteria to access a service, or were not confident they would receive acceptable help.

Aim 2: Understand why families of children with a physical health condition would like their child's mental healthcare addressed at the outpatient clinic they attend. (Table 3)

Many parents identified that the hospital being a **familiar, child-friendly environment** might explain why it is a desired place to access mental healthcare. They noted it was preferred to a doctor's office because of the fun activities available. Parents also identified **clinician communication, expertise, trust, and lack of out-of-pocket costs**. However, some parents noted a **negative association with the hospital** might mean they would not like their child's mental healthcare delivered at the hospital.

Aim 3: Understand how specialist paediatric outpatient clinics can better facilitate access to mental healthcare. (Table 4)

Proactivity: Parents would like outpatient clinic staff to regularly discuss mental health with them and be vigilant for signs of mental health issues.

Referrals: Parents would like clinics to assist them in accessing mental healthcare, including having a list of potential services. Parents felt hospital staff were well-placed to detect mental health concerns, possibly better than GPs, and that hospital clinicians should refer families to appropriate mental health services.

Holistic care: Parents expect mental healthcare as part of care for the whole child. They identified the importance of the wider family's mental health, not just the child's. They noted that poor parent mental health can impact the child's health and vice versa.

Aim 4: Understand factors that are important to these families when accessing mental healthcare.

Determining initial list of factors

Review of the literature identified seven key factors: travel time, cost, service hours, administrative systems, wait time, recommendation of a service, and type of service and therapeutic approach (e.g. evidence-based practice).[8, 21-24] Discussion with experts identified a further six factors: upfront information about service, knowledge about physical health condition, experience with children's mental health, continuity of care, choice of provider, and access to child's medical history. No additional factors were derived from the qualitative interviews.

Understanding importance of factors

Parent perceptions of **factors** are described below grouped into *themes*. A full list of themes, factors (attributes), rankings, and representative quotes are presented in Table 5.

Practicalities: Parents preferred shorter **travel time**, and flexible **service hours** to avoid taking children out of school. **Wait time** was very important to parents because once a mental health concern is identified they want it addressed quickly. Parents were frustrated by cumbersome **administrative systems and service thresholds**, but most parents noted this would not stop them accessing a service. Many parents expressed they would be willing to pay any **cost** to improve their child's mental wellbeing, although they had differing ideas on what this might entail, and desired clarity on cost up front. Parents were willing to trade off practicalities for a 'better' service in terms of other factors.

Expertise: Expertise was desired because it was perceived to increase the likelihood their child would build rapport with the practitioner and get a better outcome from the service. **Knowledge about physical health condition** allowed mental health practitioners to understand the impacts of the child's condition on their daily life and mental health. **Expertise with children's mental health** was valued more than years of experience.

*Finding out about services: **Recommendation of a service*** - from the hospital, GP, or family or friends who had used the service - was somewhat important to parents. Most wanted **upfront knowledge about service**, particularly how to get there and out-of-pocket costs. Some also wanted information on the type of approach the practitioner used.

*Service type: **Continuity*** of service provider was important to all parents to allow progression of a relationship over time. Some parents wanted **choice of provider** as they felt they knew who their child would connect with. When asked if the **type of service and approach** was important, parents noted a whole family approach would be a bonus. Some discussed the difficulty to know up front if an approach will work. The mental health practitioner having **access to child's medical history** was not important to most parents.

Defining final attributes and attribute levels for the DCE

Factors were translated to attributes of accessing a mental health service to inform the construction of choices in stage two of the DCE. Interview data and ranking (lower mean ranking reflecting higher importance) revealed the following six attributes that were important to parents: (1) travel time, (2) cost, (3) first available appointment (previously called wait time), (4) available hours, (5) knowledge of physical health condition, and (6) recommendation. Continuity, expertise in child mental health, and choice of provider were ranked highly by participants but were not included as final attributes because they were not feasible in the DCE choice scenario: provider continuity is common in most services, and the DCE scenario is about choosing between specific child mental health services/providers. Upfront knowledge about service was also important to participants but created unfeasible combinations with other attributes (e.g. having no upfront knowledge about cost but the cost also listed as a specific amount). Other attributes were not included based on ranking and discussion. The description of attributes and attribute levels was informed by qualitative findings with key quotes presented in Supplementary Table 1.

Discussion:

This study brings the parent perspective into discussions around how to improve pathways to mental healthcare for children with chronic physical health conditions, a group at high risk of mental health problems. These parents want mental health addressed in specialist hospital-based physical healthcare, but would welcome being connected with appropriate community-based mental health services for ongoing management, closer to their home. Rather than seeing mental healthcare as the role of the GP, parents expect clinics to address mental health as part of holistic management of the child's physical health condition.

Parents identified practical ways for hospital outpatient clinics to facilitate access to mental healthcare, including proactively discussing child and family mental health and referring to mental healthcare services. While parents felt hospital staff were well-placed to screen and refer to appropriate mental health services, Australian clinicians (including paediatricians) report a lack of training in mental health.[7] Travel time, cost, wait time, available hours, knowledge of physical health condition, and service recommendation were important attributes of mental health services and will be explored quantitatively in the forthcoming DCE. Continuity, expertise in child mental health, choice of provider, and upfront knowledge about service were also important to parents. There was consistency in parent perspectives across physical disease groups. Our results show that the hospital being a familiar, child-friendly environment could explain why previous studies have found the hospital to be a desired place to access mental healthcare for these children.[5, 10] Making community mental healthcare services similarly child-oriented could increase uptake and improve the experience of these families.

In a recent study, Australian clinicians identified similar barriers to parents in this study and from the general population: cost, wait time, and travel time.[7, 8] The consistent importance of these factors across stakeholder groups suggests they should be a priority for health service re-design.

For children with a physical health condition, mental health practitioners' familiarity with the impact of physical health conditions was important, and could be promoted through training offered by specialist services. For children who already miss school for medical reasons, flexible hours may be particularly important.

This study presents the views of parents, who may not understand the feasibility of implementing their suggestions. However, the parent perspective is often missing from health service design and is vital to ensure care is patient- and family-centred. We did not explore perspectives of older children, which can differ to those of their parents. Interviewees were largely well-educated and English speaking, which could mean we have missed factors relevant to culturally and linguistically diverse or less well-resourced families.[8] There may be perspectives we have missed from the broader pool of clinic attendees or other chronic conditions.

The findings of this study highlight the opportunity presented in specialist outpatient clinics to address the unmet mental healthcare needs of children with chronic physical health conditions. Presenting families' views in their own words offers those designing children's health services a richer understanding of the issues relevant to improving access to mental healthcare.

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Contributors: All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. R.J. collected the data, carried out analysis, drafted the initial manuscript, and reviewed and revised the manuscript. J.R. and H.H. conceived of the presented idea. J.R. collected the data, carried out analysis, and reviewed and revised the manuscript. H.H., K.K., J.F. and D.W. verified the analytical methods and supervised the findings and interpretation of results of this work. All authors discussed the results and contributed to the final manuscript.

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What is already known on this topic?

- Children with chronic physical health conditions experience high levels of mental health problems that are often unmet in current health service models.
- Clinicians report not enough time, a lack of training, clinics not being resourced to provide mental healthcare and lack of referral pathways as barriers.
- Families of children without chronic conditions report cost, wait time, unclear pathways, feeling dismissed, recognising problems, and family circumstance as barriers.

What this study adds?

- Rich, in-depth data on parent perspectives on accessing mental healthcare for their child with a chronic physical condition.
- Parents identified practical ways outpatient clinics can facilitate access to mental healthcare for these children: proactivity in discussing mental health and referrals as needed.
- Parents identified important policy relevant attributes of mental health services: travel time, cost, wait time, available hours, knowledge of physical health condition, and service recommendation.

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Table 1 Participant Characteristics

Characteristic	Number
Outpatient clinic	
Diabetes	11
Epilepsy	5
Bronchiectasis unrelated to cystic fibrosis	1
Epidermolysis bullosa	1
Total	18
Parent age	
18-35 years	2
>35 years	15
Total	17*
Parent highest education	
High School/Certificate or less	4
Undergraduate degree or higher	12
Total	16*

*Some participants declined to provide demographic information.

Table 2 Quotes linked to parent awareness of pathways to seek and reach mental healthcare for children

Theme	Representative quote(s)
Pathways to help	<p><i>"First of all, because CHILD is under care at the Royal Children's Hospital, I would probably start there. Then depending on what I thought the problem was, I would also contact his school and the counselling team at the school for their advice...I would probably then go to his GP, and then depending on what I thought the issue was, I guess I would use my own research in terms of accessing particular groups, like Beyond Blue and those sorts of organizations."</i> (Freya, parent of child with diabetes)</p> <p><i>"I would go to my local doctor and I guess I would talk to them... I usually just do a bit of research on the internet."</i> (Leah, parent of child with epidermolysis bullosa)</p>
Barriers to reaching acceptable and affordable services	<p><i>"I've looked for help for the last 14 years, but because CHILD doesn't tick the right boxes... he's fallen through the cracks."</i> (Chloe, parent of child with diabetes)</p> <p><i>"I'm actually going through it at the moment, going through an assessment here, so yeah it's easy to find out what to do, it's hard to actually do it though. There's a lot of requirements that you need to do and also it's very expensive as well"</i> (Mia, parent of child with diabetes)</p> <p><i>"No, mainly because I would not feel confident that the person I was speaking to would be able to understand how an autistic person struggles with mental health."</i> (Jane, parent of child with epilepsy)</p>

Table 3 Quotes linked to why families of children with a physical health problem would like their child's mental healthcare addressed within the context of outpatient clinic

Theme	Representative quote(s)
Child-friendly and familiar	<i>"I think it's to me, that familiarity with the place itself...because the child needs to be there for their usual check-ups and appointments. And it's not</i>

	<p><i>going to be scary in the appointment that they have to go to.” (Lauren, parent of child with diabetes)</i></p> <p><i>“it feels safe... There’s a culture there that is obviously geared towards children. Children are at the centre of the care model. It’s in the name and it’s obvious that it’s going to be, but you can tell culturally. I think once people feel that safety, especially when you’re talking about mental health.” (Jack, parent of child with bronchiectasis unrelated to cystic fibrosis)</i></p> <p><i>“I think when you go to a doctor’s office, there’s all these sick people and they’re all different illnesses, and they sit around, and you go in and see the doctor and you leave. So the Royal Children’s Hospital is amazing, like my children love going there. It’s bright and it’s beautiful, and there’s a fish tank and there’s the big bat, and it’s got games and activities and playgrounds, and I’d go every week to the Royal Children’s Hospital over a doctor’s office.” (Leah, parent of child with epidermolysis bullosa)</i></p>
Clinician communication, expertise, trust and no out-of-pocket costs	<p><i>“everything’s in one so, maybe the communication aspect with everyone being under the one umbrella” (Ali, parent of child with epilepsy)</i></p> <p><i>“Yeah, I would think absolutely people might look at cost and go, “Well, if it can be included ...” if it’s covered by this public health system, then yes, that might be a factor.” (Jack, parent of child with bronchiectasis unrelated to cystic fibrosis)</i></p> <p><i>“my assumption would be it’s a combination of co-location, convenience, all the records in one place, the bulk billing, and the assumption... I would assume that they would assume that everybody there was more than competent.” (Natalia, parent of child with epilepsy)</i></p>
Negative association with the hospital	<p><i>“I’d be more than happy to access the people via the hospital, so you’ve got that holistic team approach. Yet, the physical location for that for me, would have to be away from the hospital. Because the hospital is what brings up some negative vibes in CHILD ’s mind.” (Sam, parent of child with diabetes)</i></p>

Table 4 Quotes linked to how families would like tertiary paediatric outpatient clinics to facilitate access to mental healthcare

Theme	Representative quote(s)
Proactivity	<p><i>“I’m happy to bring it up, but I think as well, I think doctors need to bring it up as well and specialists need to bring it up” (Leah, parent of child with epidermolysis bullosa)</i></p> <p><i>“I think when our child was diagnosed, we got a lot of support and we got told about social workers and stuff like that. And then we went back a few days later and we had a review with them, but I think they need to maybe touch base, I understand they’re busy, but maybe touch base throughout, maybe at least the first year of the diagnosis.” (Sue, parent of child with diabetes)</i></p>
Referrals	<p><i>“Having those specific resources available and saying, “Hey Liane, this is the person that we deal with or this person that we talk to.” Instead of having to have to go out and do it myself. Because when you’re in an emotional state is usually when you need the help. Trying to find something in that emotional state is hard. I don’t know what I’m looking for. I don’t know what qualifications. I can Google a</i></p>

	<p><i>psychologist and have a look at 10,000 things, but it will say on their behavioural, "specialist" and then you call them up and they say, "Oh no, no, no, but not for six year old children." (Liane, parent of child with diabetes)</i></p> <p><i>"I would hope the doctor would start that conversation. And then if there was a concern from the doctor or from the parent, that there would be an immediate reaction of, "Okay. Well, this is who we can provide for you," or, "this is what we could do for you." So being given a list of people that you could go see." (Leah, parent of child with epidermolysis bullosa)</i></p> <p><i>"I think particularly a specialist because they see so many children with the same physical conditions I always feel like they would be better at picking up the mental health impacts of those physical conditions. The GP's are good because you'll go in, you'll talk about specific mental health condition. But, they don't have the background of how potentially... They haven't seen children, for example, with my daughter it was epilepsy.." (Mary, parent of child with epilepsy)</i></p>
Holistic care	<p><i>"Well, just like their physical health. I want them to be totally involved, because if their physical health isn't good, then their mental health isn't good. So it should be all combined. If I said to the doctor, "Okay, I need to speak to somebody about CHILD 's behaviour." They should be able to put me on at behavioural specialist within the hospital." (Beth, parent of child with epilepsy)</i></p> <p><i>"I think it's pretty naive to have a hospital diagnose your child and then send them off thinking, 'they're going to be fine, it's not going to affect them.' I don't know any child that has not been affected with their mental health flow once they've been diagnosed with something." (Mia, parent of child with diabetes)</i></p> <p><i>"Not so much as the patient but as well as the parents and the siblings because ... it's a life adjustment, a chronic condition and it doesn't just affect that person, it affects every person who they come in contact with in a close way...." (Jen, parent of child with diabetes)</i></p> <p><i>"It also involves the rest of the family and if there are other siblings, it impacts on them 100% because they're not getting the attention that they did need because of that child that needed it desperately. So it's got to be ... It's like a whole package that's not there, holistic for the whole family." (Beth, parent of child with epilepsy)</i></p>

Table 5 List of themes, factors and corresponding quotes

Theme	Factor	Initial source	Representative quotes from qualitative data	Mean ranking	Final inclusion	Justification for final inclusion
Practicalities	Travel Time	Literature [8, 22]	<i>“Probably within my local community would be the most accessible... somewhere that is 10, 15 minutes from home would be more viable and accessible for us.”</i> (Jen, parent of child with diabetes)	8.65	Yes	Ranking
	Cost	Literature [8, 21]	<i>“Only from the perspective of wanting to know what it [cost] was.... Anything that’s going to improve their quality of life, you just go, ‘Yeah okay, we’ll do that.’”</i> (Jack, parent of child with bronchiectasis unrelated to cystic fibrosis) <i>“It [cost] probably influences the regularity.”</i> (Mary, parent of child with epilepsy)	7.94	Yes	Ranking
	Service hours	Literature [8, 21]	<i>“I don’t like to pull her out of school, I would if I had to because we attend several medical appointments so you’re lenient, but there gets a point where you don’t want to have them out of school too often.”</i> (Ali, parent of child with epilepsy)	8.63	Yes	Ranking
	Cumbersome administrative systems and service thresholds	Literature [8, 21, 22]	<i>“It would never be a barrier, no, it could be an inconvenience. It could be so cumbersome. But it would never be a barrier.”</i> (Jack, parent of child with bronchiectasis unrelated to cystic fibrosis) <i>“Anytime any process adds onto that life admin that I already have to do for her, it just gets put on the back burner...”</i> (Jane, parent of child with epilepsy)	10.07	No	Ranking
	Wait time	Literature [8, 21, 23]	<i>“You know, because when you talk about mental health you want to get things straight away, you don’t want to be waiting around...I think anything more than a month on any list is too long.”</i> (Jane, parent of child with epilepsy) <i>“We’re actually going, I’m going privately for my son, that’s because I can’t wait on the waiting list any longer”</i> (Mia, parent of child with diabetes)	4.33	Yes	Ranking

Expertise	Knowledge of child's physical condition	<i>Expert opinion</i>	<p>"I don't think they need know the ins and outs of a disease but, or a health condition, but just to know how that disease can affect a daily lifestyle. What sort of impacts it can have, so that they can understand how the child's feeling and stuff like that." (Sue, parent of child with diabetes)</p> <p>"So if [they] didn't understand the disease...I don't know how well you would be able to create a bond or an understanding with them." (Jen, parent of child with diabetes)</p>	5.19	Yes	Ranking
	Expertise with children's mental health	<i>Expert opinion</i>	<p>"Yeah, it would be important, because obviously you don't want somebody who hasn't worked with children necessarily. I think there's a special skill that comes to working with children. It takes a type of person who knows how to build a rapport and build a relationship with a child... Length of time, like experience from how long have you been doing something I think is often less important" (Jack, parent of child with bronchiectasis unrelated to cystic fibrosis)</p>	4.2	No	Did not meet DCE criteria
Finding out about services	Recommendation of a service	<i>Literature [24]</i>	<p>"Certainly if it was an existing specialist or medical professional that we have a relationship with, and knows our case, and knows CHLD. If they were to make a recommendation, then that would be very much influential.." (Jack, parent of child with non-cystic fibrosis bronchiectasis)</p> <p>"But if a friend was in a similar situation and had success, then I would look at that." (Jen, parent of child with diabetes)</p>	7.65	Yes	Ranking
	Upfront knowledge about service	<i>Expert opinion</i>	<p>"So I want to know how much is it going to cost, when would this generally take place, where you park, how will you pay, are there any rebates? Do they do... This is a big one; if you can get a Medicare rebate, will they do that for you?" (Kate, parent of child with diabetes)</p>	6.88	No	Did not meet DCE criteria
Service type	Continuity of care	<i>Expert opinion</i>	<p>"Extremely important because you get a rapport with your mental health worker and if you're seeing a different person, you have to then explain to them every single time what your child's condition is or where they're at and that's not beneficial for your child." (Sue, parent of child with diabetes)</p>	3.33	No	Did not meet DCE criteria

Choice of provider	<i>Expert opinion</i>	<p><i>"I think that, that would be extremely important because I know that my son, when we were actually looking, he was telling me which lady or which man from their photos he would feel comfortable talking to. So for him to want to connect to a person first, visually, and then talk to them, I think that having a choice would be pivotal."</i> (Liane, parent of child with diabetes)</p> <p><i>"I find you often don't have choice because you're referred to someone and they're a recommended person."</i> (Mary, parent of child with epilepsy)</p>	7.79	No	Did not meet DCE criteria	
Type of service or approach	<i>Literature [23]</i>	<p><i>"I think that there would have to be the options or it would have to be... I do understand that they'd need to talk to CHILD first and deal with my child first. But then I would expect that they would bring the whole family and so as we could all learn together"</i> (Liane, parent of child with diabetes)</p> <p><i>"I'm open to everything as long as it has a proper basis for it."</i> (Natalia, parent of child with epilepsy)</p>	9.2	No	Ranking	
Access to child's medical history	<i>Expert opinion</i>	<p><i>"I don't mind if they do... I don't know how much benefit."</i> (Lucy, parent of child with diabetes)</p> <p><i>"Access to the child's medical history would be nice, but it's not a, I wouldn't say, determining factor."</i> (Mary, parent of child with epilepsy)</p>	8.71	No	Ranking	