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## Tacit knowledge in medical consultations for patients with profound intellectual and multiple disabilities: An exploratory qualitative study

Ilse Harmina Zaal-Schuller <sup>a,b,c</sup>, K. Kruithof<sup>a</sup>, M. Hoogsteyns<sup>a</sup>, A.M. Nieuwenhuijse<sup>a</sup>, D.L. Willems<sup>a</sup> and S.A. Huisman<sup>a,b,c</sup>

<sup>a</sup>Department of Ethics, Law & Humanities, Amsterdam UMC, Amsterdam, The Netherlands; <sup>b</sup>Department of Pediatrics, Amsterdam UMC, Emma Children's Hospital, Amsterdam, The Netherlands; <sup>c</sup>Prinsenvestiging, behandelcentrum Zodiak, Purmerend, The Netherlands

### ABSTRACT

**Background:** Patients with profound intellectual and multiple disabilities (PIMD) cannot clearly express themselves. Therefore, tacit knowledge (TK) is crucial in caring for individuals with PIMD, while it possibly also plays a significant role in medical consultations.

**Method:** A qualitative inductive, thematic analysis was performed of 14 audio-taped consultations with intellectual disability physicians for patients with PIMD to explore how TK is represented and considered between parents and physicians.

**Results:** Parents conveyed their TK by sensing and perceptions of changes of their child's behaviour. Our findings demonstrate that parents of individuals with PIMD primarily shared TK concerning pain, sleeping issues, and epilepsy. Physicians recognised and incorporated parents' TK, highlighting its significance in patient care.

**Conclusion:** This study underscores the important role of TK in consultations for patients with PIMD. Parents' TK help to shape medical-decisions, urging physicians to validate parents' TK while relating this TK to other types of medical knowledge.

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### KEYWORDS

Tacit knowledge; parents; intellectual disability physician; interdisciplinary consultation; medical care; PIMD

Understanding and meeting health needs is most challenging for physicians when codified knowledge cannot be used because patients cannot express themselves through writing, speech, or signs. One group of patients who cannot clearly express themselves are people with profound intellectual and multiple disabilities (PIMD). Patients with PIMD have an estimated IQ of less than 25, sensory impairments and severe motor disabilities manifesting in the inability to move independently (Nakken & Vlaskamp, 2007). They are also compromised by both complex and life-limiting conditions from birth (Flink et al., 2021; Tyrer et al., 2007; Zaal-Schuller, de Vos, et al., 2016). They express pleasure, pain, and discomfort through idiosyncratic facial expressions, vocal sounds, body language, and behaviour (Davies & Evans, 2001; Olsson, 2004). Communication with them is intricate, necessitating customised approaches tailored to their unique abilities and needs (Doukas et al., 2017). For example, Dhondt et al. (2023) explored the early expressive communication behaviours of individuals with PIMD, highlighting the subtle cues and gestures they utilise to express themselves. This means that people with PIMD fully

depend on others to interpret their unique signs and reactions and to understand their wishes or needs (Hostyn & Maes, 2013; Reinders, 2010). As a result, caregivers' tacit knowledge (TK) about persons with PIMD plays an important role in understanding and interpreting their wishes and needs (Hoogsteyns et al., 2023).

TK refers to the unwritten, unspoken, and hidden reservoir of knowledge held by individuals, often derived from personal experience and context rather than formal education (Polanyi, 2010). Polanyi emphasised that "we know more than we can tell". According to Reinders (2010), a significant amount of what individuals learn about others comes from their intent to be in tune and connected with them. This type of knowledge often remains uncoded and is not easily conveyed through language and is often contrasted with codified or explicit knowledge.

Previous research has shown that parents consider themselves experts in relation to the health and well-being of their children with PIMD (Kruithof et al., 2020; Zaal-Schuller, de Vos, et al., 2016). They function as the "translators" of the expressions of complaints and

**CONTACT** Ilse Harmina Zaal-Schuller  i.h.schuller@amsterdamumc.nl  Department of Ethics, Law & Humanities, Academic Medical Centre, University of Amsterdam, P.O. Box 22700, Amsterdam 1100 DE, The Netherlands

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needs of their children during medical consultations (Stringer et al., 2018). This demonstrates the significance of their roles and underlines their specialised knowledge and deep understanding of the patient's behavioural patterns. They have a personal, embodied kind of knowing that is difficult to explicate or pass on to others (Kruithof et al., 2020; Kruithof et al., 2024; Reinders, 2010). Parents and professional caregivers refer to this specific skill as “reading” or “hearing” a person”, or “sensing” their needs (Nieuwenhuijse et al., 2022; Zaal-Schuller, Willems, et al., 2016). Parents build up TK through a long-standing relationship of connection and attunement, which is developed in caregiving dyads during the long-term care for a patient with PIMD, characterised by repeated intimate interactions between caregiver and recipient (Hoogsteyns et al., 2023; Kruithof et al., 2020; Kruithof et al., 2022; Reinders, 2010; Watson et al., 2017).

TK may have significant implications for the medical care of patients with PIMD, particularly in situations where a physician finds medical knowledge lacking or when a parent feels that their understanding of the situation does not align with conclusions based on medical knowledge. In the Netherlands, intellectual disability physicians, a recognised medical specialisation by the Dutch Ministry of Health, provide dedicated medical care to people with PIMD based on a growing body of evidence-based knowledge and prevailing guidelines (Huisman et al., 2024). An Intellectual disability physician has completed a three-year postgraduate training course focusing on healthcare specifically related to intellectual disability; however, this training focusses on the codified knowledge regarding the care for patients with PIMD. Parents of children PIMD indeed make use of codified knowledge during consultations with intellectual disability physicians. Codified knowledge in the care of patients with PIMD encompasses a wide range of practical experience, strategies, and information acquired throughout the duration of the child's life, such as daily care routines, preferences, and reactions to certain types of stimuli. This codified knowledge equips parents to engage in consultations with physicians, providing the necessary tools and information to offer comprehensive care for their children and advocate for their needs during medical consultations. However, we expect that parents additionally use their tacit knowledge (TK) during these consultations.

The use and diagnostic value of TK have been explored in various healthcare settings, such as nursing (Carlsson et al., 2002; Carroll, 1988; Hams, 2000; King & Appleton, 1997; Turnbull, 1999) and general medical practice (Donker et al., 2016; Stolper et al., 2009; Stolper et al., 2009; Stolper et al., 2011). The use of TK in general

medical practice has proven beneficial in diagnosing disease (Stolper et al., 2011), such as diagnosing early-stage cancer (Donker et al., 2016). Several studies have demonstrated the enhanced utility of TK in critical medical scenarios, such as decision-making during cardiopulmonary resuscitation (Brummell et al., 2016) and evaluating the severity of infections in pediatric cases (Van den Bruel et al., 2012). While these findings highlight the importance of integrating TK into medical practices, our aim was to investigate the specific role that TK plays in the medical care of patients with PIMD. This is an important topic as it seems plausible that TK holds even greater relevance in such a setting, as persons with PIMD cannot express themselves verbally (Hoogsteyns et al., 2023). Therefore, in this study we investigated the interactions during consultations between parents and intellectual disability physicians to explore how TK is represented, reflected and employed (Iedema et al., 2009) during such consultations. In so doing, we explored (1) its content; (2) its form (presentation and expression); and (3) its function.

## Method

### *Study design and participants*

In this study, we conducted a qualitative investigation utilising thematic analysis of audio-recorded “first visits” or follow-up consultations between intellectual disability physicians and parents of patients with PIMD, and, in certain instances, professional caregivers. The consultations took place at an intellectual disability outpatient clinic of a regional care centre and at an academic expertise centre for adult patients with PIMD or with genetic syndromes. There were no exclusion criteria for this study; all consultations from November 2021 to February 2022 of intellectual disability physicians with parents of patients with PIMD were eligible for this study.

We disseminated comprehensive information about the study via email to intellectual disability physicians who possess experience or a special interest in patients with PIMD working in the North-Holland, South-Holland, and Utrecht regions. The email communication outlined the request for these physicians to record all consultations involving patients with PIMD where parents were present over a period of four months. Two weeks after the dissemination of information a designated researcher (IZ or SH) initiated contact with the intellectual disability physicians via telephone. The primary purpose of this communication was to address any remaining inquiries they might have had and to request their oral consent for their active participation

in the study. By recruiting intellectual disability physicians from different clinical settings and geographical areas researchers strived to capture a sample, as varied as possible, of parents and patients with PIMD regarding age, gender, aetiological diagnosis, co-morbidity, ethnic background, and length of physician-family relationship.

Parents of patients with PIMD with a planned appointment for a consultation with participating intellectual disability physicians received an information letter and consent form directly at their consultation appointment or via the outpatient clinic. Parents who wished to participate in the study were asked to fill in the consent form. The hospital's Research Ethics Committee approved the protocol of this study (W21\_435 # 21.484).

### **Data collection and analysis**

We transcribed the tape-recorded consultations verbatim and conducted thematic analysis (Braun & Clarke, 2014; Braun & Clarke, 2019) using MaxQDA (VERBI GmbH, Berlin, Germany). Since we aimed to explore how TK is used in practice during consultations between parents of a child with PIMD and intellectual disability physicians, we have conducted a content analysis of such consultations. We analysed transcripts related to two conceptualisations of TK (Ambrosini, 2001; Gourlay, 2006): (1) parental intuition and (2) the parental interpretation of subtle signs that may be challenging to articulate verbally. In the subsequent phase, we employed specific sensitising concepts to analyse the conversations. These concepts included words that referred to parents' intuition, such as "having a feeling" or "suspecting," where parents indicated that they found it challenging to explain why they had such feelings or thoughts. Another sensitising concept was when parents referred to certain very subtle signals that they expected could potentially be missed or misinterpreted by other caregivers. Subsequently, these TK segments were categorised based on who raised them in conversation: parents, physicians, or both. Further, segments were categorised into three major themes: the content of TK, the way TK was discussed, and the function of TK during the consultation. Additionally, a fourth category was added inductively: the type of worry/complaint TK concerned.

The two main researchers (IZ/SH) independently conducted the coding and categorisation of all transcripts, except their own consultations. Discrepancies between codes were discussed until a consensus was reached. Following this, two other researchers (KK, MH) independently coded six transcripts to validate

the established codes and coding dictionary, resulting in some minor adjustments. The number of six transcripts was chosen to ensure a robust sample and to prevent missing relevant themes. In the last phase of analysis, four researchers (KK, MH, DW, MN) extensively discussed all categorisations and the overarching patterns. The coding process continued until all transcripts were analysed, even though data saturation was achieved after coding approximately two-thirds of all transcripts.

### **Data evaluation**

Of the six participating physicians, two were the main authors of this article. They both have extensive experience in treating patients with PIMD. This kind of participatory research can have both advantages and disadvantages. For example, involving physicians as authors allows for insider perspectives and enhances the relevance and applicability of the research findings. However, it may also introduce biases or conflicts of interest. To mitigate such potential limitations, we regularly held meetings with the entire research team during the data analysis phase. These sessions provided opportunities for comprehensive discussions on the data analysis process. This collaborative approach ensured transparency and rigour in our research process, thereby enhancing the credibility of our findings.

Additionally, to enhance the reliability of the data analysis, the consultations conducted by these physicians were part of the sample of six consultations, which were independently coded by other researchers, ensuring consistency and accuracy in the interpretation of the data. No discernible differences were observed in the quantity, content, presentation, or function of TK during consultations between intellectual disability physicians directly engaged in data collection and those who were not.

## **Results**

### **Characteristics of participants**

Six intellectual disability physicians consented to participate in this study including two authors of this article (IZ, SH). These intellectual disability physicians audio-taped 14 consultations of patients with PIMD. In two of these consultations, both parents were present. However, there were two consultations where parents could not attend the appointment at the last minute and were substituted by professional caregivers. One parent consulted the intellectual disability physicians for both his son and his daughter, representing two discrete dyads, in the context of this study. The characteristics of the

parents are shown in Table 1, of the patients with PIMD in Table 2, and of the physicians in Table 3.

### Themes

To provide a comprehensive overview of the various themes discussed in the results, we have included a thematic map (Figure 1). In designing this, we drew inspiration from the work of Byrne (2022).

- (1) What TK is brought forward during consultations of intellectual disability physicians for patients with PIMD?

The prevailing issue that parents disclosed through their TK was pain; frequently mentioned in eight consultations as the main health problem. Throughout these consultations, parents believed that their child was experiencing pain, yet they were uncertain about the underlying cause of this pain. Parents could provide detailed descriptions of their child's pain threshold or pain experience, even when the child was unable to express it themselves. Additionally, parents identified specific noticeable behaviours as indicative of pain. This included behaviour that might not be immediately associated with pain by an outsider but parents interpreted these signals unquestionably as expressions of pain.

#### Mother and Father 1:

**Father:** Once on a weekend, it was late in the evening, we didn't know what to do. It was so elusive, and then we decided to call the GP. Well, the GP came and he was observing him from a distance. And then he said: "It is really pain?"

**Mother:** And I said: "I'm sure of it."

**Father:** The GP questioned: "What do you see on him? What is he trying to show?" And I answered: "That he is having a lot of pain." The GP replied: "Yes, yes, but why do you think that?" And I said: "Because he is standing!"

**Mother:** Normally, when there is something wrong, he can hit himself. Or he crawls to me to hit me. But right now, he was standing!

Another frequently cited concern in which parents shared their TK was sleeping, particularly regarding reasons for poor sleep. In several consultations, parents shared TK about epilepsy. One mother described how

**Table 1.** Characteristics of the parents ( $n = 14$ ).

Characteristics	<i>N</i>
Parental role	
Mother	9
Father	5
Age	
40–49	1
50–59	6
60–69	6
70–70	1
Religious affiliation	
Presbyterian	1
Orthodox Christian	1
Islamic	1

she cared for her daughter with severe epilepsy. She monitored her daughter's seizures by measurements of heart rate and saturation. She described how she often perceived her daughter's seizures more accurately than professionals did. Notably, the mother's unique ability extends beyond recognising seizures; she intuitively senses the severity of each episode.

#### Mother 13:

In retrospect, we should have seen this derailment [of epilepsy] coming. That's why I actually immediately ... once that happened ... I knew ... I could hear it through the baby monitor.

This mother described how both she and the father could "feel" their child's epileptic seizure and referred to a situation where they were convinced that their child had an epileptic seizure even though this was not noticed by others.

#### Mother 13:

During the initial hospitalisation and shortly after, I felt her head. It felt like you (could) feel some kind of vibration, an electrical charge or something. Yes, I do feel that and [name of father] feels that too. But if I would ask you: "Do you feel this?" Then I wonder if you would be able to do that? We have never been able to do an EEG at those times, but to me that is indeed a sign of a severe epileptic activity.

Another topic parents mentioned was TK about whether their child's general condition was improving or declining.

#### Mother 8:

He's getting older. I really think that you can see in the last year, or half a year, that he has really aged. It's also a feeling, you see it. It is difficult to describe in words what you see, but you just see changes.

Besides medical issues, parents shared TK about the meaning of the behaviour of their child. In most cases this concerned negative changes in behaviour, only a

**Table 2.** Characteristics of the patients with PIMD ( $n = 14$ ).

Characteristics	<i>N</i>
Gender	
M	10
F	4
Age (yrs.)	
10–19	2
20–29	7
30–39	3
40–49	2
Primary diagnostic category	
Cerebral palsy	1
Genetic condition	8
Periventricular leukomalacia	1
Other neurological condition	1
Unknown	3
Living situation	
At home	9
Residential care	5
Treatment relationship (yrs.)	
First consultation	5
≤2	5
≤5	2
≤7	1
≤10	1

**Table 3.** Characteristics of the physicians ( $n = 6$ ).

Characteristics		<i>N</i>
Gender	M	2
	F	4
Age (yrs.)	30–39	2
	40–49	0
	50–59	1
	60–69	3
Religious affiliation	No affiliation	6

minority of parents discussed positive changes in behaviour. For example, in one-third of the consultations, parents mentioned a change in behaviour, which they experienced as burdensome for themselves or the patient such as agitation, screaming or self-injurious behaviour. A father and mother described how their son was hitting himself. They were convinced that he did this because of pain. Intuitively, they sensed that it was intense pain. Several healthcare providers questioned this, they considered his behaviour as an expression of psychological issues, but parents never doubted their conviction. Six months after this discussion it was discovered that the patient had oesophageal cancer, providing credibility to the initial TK assessment of the parents.

In six consultations, parents introduced TK which was contradictory to medical information provided by the intellectual disability physician. One mother mentioned that she was convinced her daughter had an epileptic seizure when she showed certain behavioural patterns, while on the EEG there was no epileptic activity. Another mother described that “as a mother looking at her son” she was convinced that her son had good vision, although according to the medical file he was blind.

## (2) How is TK presented?

Parents talked about their TK as information they had about their child that was difficult to put into words. They used words like “knowing,” “sensing,” or having a certain belief about what was happening. Additionally, parents presented their TK as an interpretation of their own perception of (changes in) behaviour. These changes were sometimes obvious. For example, according to one father, his son was crawling over the floor and hitting himself, something he never did before, as an expression of severe pain. More often, these changes were very subtle and could be easily missed by outsiders. For example, one mother described that her son was fiddling with his trousers when he was feeling bored. Another mother shared how her son, who had severe epilepsy, used to be visibly agitated or even screamed before a seizure. This made it very clear to those around

him when they needed to be vigilant for a new episode. However, over the years, this has changed significantly. Now, it was a subtle change in the way her son looked that the mother interpreted as an absence seizure. It had never been investigated whether this was indeed accurate, but the mother was convinced of her own intuition about it.

### **Mother 8:**

He also has that during those absence seizures. Because you can see something. But it's not possible to say: “Look! This is it!” You can see a change in his eyes. It makes you think you look at me, but you don't see me.

In nearly half of the consultations, parents described TK that had been developed through pattern recognition based on their extensive years-long experiences with their children. In such instances, parents elucidated how they interpreted specific signs by drawing upon their past experiences.

### **Mother 13:**

I have 20 years' experience with caring for F. Still, I'm not medically trained, so healthcare providers don't need to follow my reasoning exactly. But they should grasp the sense of it: this is not normal. I can precisely point out: there, can you see that? That is different.

## (3) What function does TK have during these conversations?

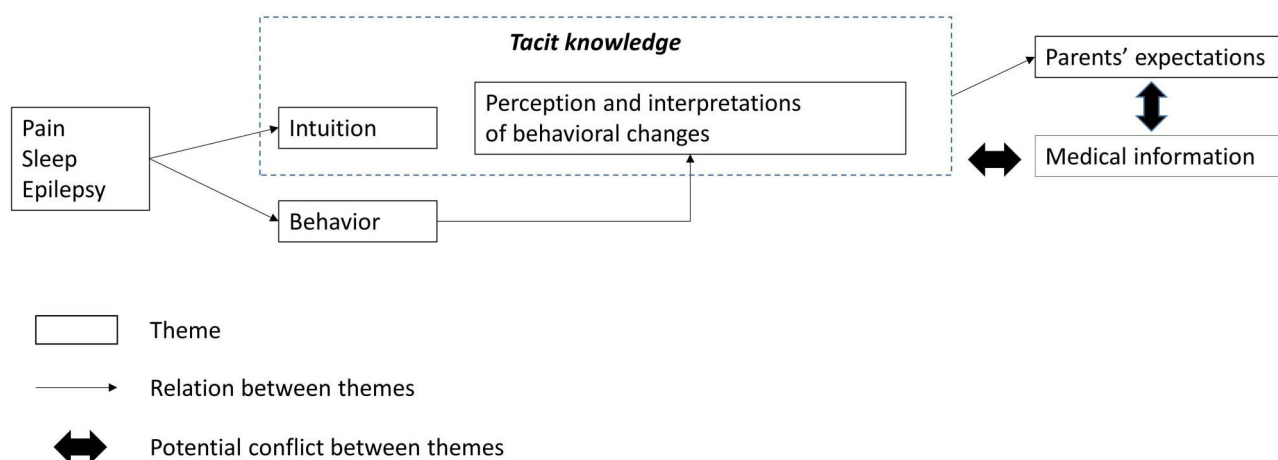
It was noticeable that some parents referred to a situation from the past in which their TK had played a significant role. In these situations, parents held a firm conviction about the nature of the situation solely based on TK. At that time, parents presented their TK as a significant observation and held the expectation that the physician would corroborate their findings. A mother was recalling a situation that occurred in the hospital when her daughter was admitted for epilepsy. Her daughter's condition was deteriorating. The neurologist made every effort to treat the epilepsy effectively, but the mother was convinced that there was something more going on and insisted for further investigation.

### **Mother 13:**

She was admitted to the neurology department. I said to the neurologist: “I can see that something is wrong” Everyone on the ward found it very difficult to understand that. So, I kept repeating to them: “Listen to me, this is not normal.” I could accurately indicate, “this and this is why I think she is not well” I saw my child, her heart rate remained high, and she was lethargic, all those strange signals . . .

Then I requested: “I want you to measure her hemoglobin.” The neurologist found me troublesome, also because I interfered with everything concerning her care.

The neurologist replied: “I'm neurologist, I do not know much about this. But if you want it, we will check it.” And it was found out that her haemoglobin was decreased significantly.



**Figure 1.** Thematic map of conceptualisation of tacit knowledge in this study.

During all actual consultations, the intellectual disability physician acknowledged the presence of TK shared by parents and proceeded to delve deeper into its implications. Parents proactively presented their TK as a means to elucidate certain concerns and shed light on the situation at hand. Subsequently, physicians proactively engaged in addressing queries to gain further clarity on these concerns. The information gleaned from these exchanges was then considered during collaborative discussions between parents and intellectual disability physicians to determine the most appropriate course of action. This was a process that could unfold throughout an entire consultation. During this, parents shared their TK about what was going on, which the intellectual disability physician reflected on, and then parents shared new TK in response.

In one consultation, parents shared their concerns about a change of behaviour of their daughter. She could, from one moment when she was appearing comfortable, suddenly change and begin screaming. Parents interpreted this as their daughter was having auditory hallucinations. This particular intellectual disability physician had a longstanding treatment relationship with this patient and she recalled that the patient had occasionally exhibited similar behaviour in the past when she felt frustrated. She openly discussed her doubts about the parents' belief that their daughter was experiencing psychotic symptoms. Parents acknowledged that their daughter had previously screamed out of nowhere, but they indicated that during this episode there were subtle changes compared to episodes before. The actual behaviour was more intense, although the patient seemed less frustrated. Additionally, there was a specific difference in the way she screamed, which parents could not easily put in

words. This was leading parents to the conviction that their daughter was hearing voices that were not there.

Through the act of sharing their TK, parents were able to contribute valuable insights that influenced the direction of medical care. By engaging in this process, TK exerted an impact on decision-making pertaining to medical care. There was a consultation where the doctor deemed it appropriate to taper off the antipsychotic medication that a patient was using because of potential long-term side effects. The mother opposed this decision as she was convinced it would make her son psychologically unstable. She expressed that she felt he would not want that. Based on the mother's TK, a decision was made not to change anything in the situation. There was another mother who determined the use of laxatives as not desirable for her son. Various healthcare providers involved with her son believed it was necessary for him to use laxatives. She had specific reasons why it was not necessary, based on her intuition about how her son was feeling when he had a bowel movement. A decision was made to follow the mother's conviction that it would be better for her son not to use laxatives.

**Mother 11:**

They say he should get something for bowel movements. I disagree. He is always restless when he needs to have a bowel movement, but his stool is not thick. They want him to receive something for it, but I prevent that. He experiences a sense of restlessness when he needs to have a bowel movement. I sense his restlessness; you cannot resolve that with laxatives.

## Discussion

In this qualitative study, we investigated TK during consultations with intellectual disability physicians for people with PIMD. Parents and caregivers tended to

share their TK about current and previous health situations, specifically when intellectual disability physicians asked about these situations. The most frequently mentioned issues in which parents shared their TK were pain, sleeping problems and epilepsy. Parents presented their TK as an intuitive sense of “knowing” and their interpretation of changes in their child’s behaviour. In some cases, by sharing their TK, parents gave direction to their child’s medical care.

People with PIMD frequently suffer from complex medical problems (Chaney & Eyman, 2000; Oeseburg et al., 2011; van Schrojenstein Lantman-de Valk et al., 1997), and parents must face multiple healthcare encounters during the lifetime of their child. The role of TK in medical consultations has been researched before (Brummell et al., 2016; Donker et al., 2016; Stolper et al., 2011; Van den Bruel et al., 2012), but as far as we know this is the first study to research TK during consultations with intellectual disability physicians.

Owing to its personal and embodied nature that often remains implicit, TK is difficult to explicate or pass-on to others (Kruithof et al., 2020; Reinders, 2010). However, during medical encounters, parents may feel the need to make their TK explicit to assess and defend the interests of their child (Carter et al., 2017). Parents acquire their TK through an extensive history of caring for their child with PIMD. During medical encounters, parents share their TK based on their assumptions, skills, and background information with physicians, who might not possess this specific knowledge. By observing these interactions, TK of parents may become explicit (Iedema et al., 2009).

Health problems such as pain, sleeping problems, and epilepsy, have a high life-time prevalence for people with PIMD (van der Heide et al., 2009). This high prevalence gives parents and professional caregivers ample opportunity to develop and refine TK concerning the identification and determination of these health problems. This means that TK concerning these specific health problems within this specific clinical population may be particularly well developed, which is confirmed by two other studies in which the role of TK in assessing pain for people with PIMD is investigated (Carter et al., 2017; Davies & Evans, 2001). Based on the findings of this study, and those of others (Carter et al., 2017; Kruithof et al., 2024) it can be hypothesised that parents’ TK can play a pivotal role in the timely detection, or perhaps even prevention, of these health problems with a great impact on quality of life. This means that health care professionals should be sensitive and value this TK until proven otherwise (Olsman et al., 2021).

In our study, most parents shared TK about behavioural changes, especially when they were seen as burdensome for the patient or his/ her caregivers. Other studies confirm that the first clues of discomfort are often behavioural changes (Poppes et al., 2016). Previous studies have also emphasised the significance of TK in caregiving practices for individuals with PIMD, particularly in recognising psychological issues such as overstimulation, (Reinders, 2010), interest (Hostyn et al., 2011), boredom or pleasure (Olsson, 2004). Intellectual disability physicians are not specifically trained in identifying and treating psychological problems that may cause behavioural changes in patients with PIMD. As it is important in these situations to differentiate between pain and distress, a behavioural assessment by a behavioural specialist is essential to balance medical diagnostic and timely interventions to address the root of behavioural changes. Therefore, this finding underlines the importance of a multidisciplinary consultation, together with behavioural scientists such as psychologists, when behavioural changes of patients with PIMD are the main reason for concern.

Previous research among physicians of different specialties illustrates the role of TK in medical encounters (Brummell et al., 2016; Donker et al., 2016; Stolper et al., 2009; Van den Bruel et al., 2012). However, in our study we found little evidence of TK of intellectual disability physicians. An explanation for this can be that in most consultations, the treatment relationship was relatively short. Given the assumption that the development of TK requires a longer period to build up (Kruithof et al., 2020; Reinders, 2010; Watson et al., 2017), it is possible that the involved intellectual disability physicians will not have had ample TK concerning these specific patients due to insufficient time for its acquisition or development. TK of physicians can also be expressed in care routines and practical know-how (Palese et al., 2018; Pope et al., 2003). Therefore, another explanation for the lack of TK of intellectual disability physicians in our data could be that the TK of the intellectual disability physicians involved were especially reflected by their routines; for example, during physical examination. As research methods for this study were limited to audio recording of consultations, it was not possible to assess the potential TK being used during routines or other non-verbal interactions.

A complicating factor when assessing the validity of the TK of parents with children with PIMD, is that this TK can never be verified with the person with PIMD. Furthermore, the situation and needs of patients with PIMD may change over time as they grow, learn and develop. Therefore, parents’ TK about their child may be outdated or may become less accurate



(Hoogsteyns et al., 2023; Kruithof et al., 2020; Phelvin, 2013). This underlines the importance of the ongoing need for reflection and adaptation of parental TK and the need of intellectual disability physicians to explore whether TK is relevant or outdated. Nonetheless, parents are typically the first ones to notice any changes or issues concerning their child with PIMD, often relying on their TK to do so. This is particularly important because their child itself is unable to indicate pain or other discomfort. This implicates that parents need to be taken seriously in their concerns and convictions. It is extremely frustrating for parents when this does not happen (Carter et al., 2017; MacGregor, 2022).

For physicians, medical-decision-making can pose challenges as they must strike a balance between respecting parents' concerns, acknowledging their TK, while also being mindful that not all TK may be entirely accurate. Physicians play a crucial role in navigating these scenarios with openness and sensitivity. Encouraging parents to articulate their TK, physicians should seize the opportunity to validate its accuracy through active listening and continued questioning. While fostering an empathetic environment, they should also uphold a critical mindset, assessing the appropriateness and necessity of additional medical examinations (Olsman et al., 2021).

We acknowledge that this study has several limitations. First, by exploring TK using audio-taped consultations intellectual disability physicians, we have not been able to question parents about the TK they raised during consultations and discussions. Subsequent future research could involve conducting post-consultation interviews with both parents and physicians to delve deeper into the TK shared and to validate whether the TK identified by researchers genuinely aligns with the concept as defined by Gourlay (2006). This approach could provide richer insights into the nature of TK in the context of medical consultations, enhancing our understanding and contributing to the ongoing discourse on TK in healthcare settings. Nevertheless, all the TK identified by the researchers bears significant similarities, as it encompasses instances where parents expressed intuitive feelings that were difficult to articulate or their interpretations of subtle signs exhibited by their child with PIMD. Our use of audio-taped consults is simultaneously a strength of this study, as it enabled us to explore how parents and physicians actually use their TK in practice. Another limitation is that we made no video-tapes of the consultations, which would have enabled us to identify TK existing of care routines. Furthermore, this study included a sample of consultations with intellectual disability physicians, which is a specialism that only exists in the Netherlands.

Therefore, the findings described may not be reflective of practices of medical specialists in other countries. It is plausible that intellectual disability physicians, given their specialised experience with patients with limited capacities to articulate their complaints and symptoms, are particularly equipped to value, to help to explicate and make use of parents' TK in medical practice. Nevertheless, the insights gleaned from this article regarding the TK shared by parents during interactions with intellectual disability physicians are relevant for medical consultations involving patients with PIMD in general. The findings of the study underscore the significance of extending the awareness regarding the importance of TK during medical consultations to all healthcare professionals attending to patients with PIMD. Moreover, the basis for selecting six interviews to achieve robustness may be another limitation of this study. Although this number was chosen to provide a robust sample and to minimise the risk of missing relevant themes, it may not fully align with statistical research on intercoder reliability, which typically requires a larger sample size to confidently assess the reliability of the data. As a result, there is a possibility that the findings may not be as robust as desired. Lastly, the first and last author of this study also participated in this study and audio-taped their own consultations. Their involvement could be seen as a limitation of the study, as they may have directed the consultation (sub-)consciously towards parents' TK. However, our thematic analysis, which involved working with four independent coders, did not show a difference between the (amount of) TK brought forward during these consultations compared to others.

Further research is needed to investigate the importance of TK in complex medical-decision-making for patients with PIMD. Furthermore, the findings of this research should be extended, especially by investigating TK during consultations with medical specialists other than intellectual disability specialists. Steps should be taken, in cooperation with support groups for parents with children with PIMD, to develop practical recommendations on how to improve the use of TK during medical consultations for patients with PIMD.

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## ORCID

Ilse Harmina Zaal-Schuller  <http://orcid.org/0000-0001-8640-5292>

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