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Dunay Schmulian & Christopher Lind

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ORIGINAL ARTICLE



Parental experiences of the diagnosis of permanent childhood hearing loss: a phenomenological study

Dunay Schmulian^a  and Christopher Lind^b

^aDivision of Audiology, School of Health and Rehabilitative Sciences, The University of Queensland, Brisbane, Australia; ^bCollege of Nursing and Health Sciences, Flinders University, Adelaide, Australia

ABSTRACT

Objective: The objective of the study was to discover the nature of parental lived experiences of the diagnostic process of Permanent Childhood Hearing Loss (PCHL) and to construct an emotional life-world of parent experience around PCHL.

Design: Through an Interpretive Phenomenological Analytical (IPA) framework and subsequent purposive sampling, parents were invited to semi-structured interviews.

Sample: Ten parents of children who were identified with PCHL as one or the only permanent childhood disability diagnosed during early childhood were interviewed.

Results: Five themes emerged; (a) a received disability, (b) casualties, (c) acceptance in real-time, (d) the unique signature of family life, and (e) audiologists are essential and appreciated guides. The emotional landscape chronicled two concurrent, non-linear affective groupings: the spiral of disorientation, and protective states of righting.

Conclusion: Parents require a level of emotional support that exceeds frameworks of counselling. We propose the Dual Process Model as an intermediary model of emotional literacy to address both grieving and coping during the passage from diagnosis to early management. We believe it provides an effortless articulation with the principles of Family-Centred Care philosophies (top down) and behaviours (bottom up) by providing a taxonomy of grieving, coping and parents' movement between the two orientations.

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Interpretative phenomenological analysis; early identification; permanent childhood hearing loss; Dual Process Model

Introduction

Both the protocols for and pace of the diagnosis of permanent childhood hearing loss (PCHL) have improved considerably in the past two decades (Cowan, Edwards, and Ching 2018; Fitzpatrick, Whittingham, and Durieux-Smith 2014). The availability of objective, automated technology, capable of differentiating children at risk for hearing loss from those with negligible risk (Olusanya, Wirz, and Luxon 2008), now allows for: (a) every newborn's hearing to be screened before 1 month of age (preferably before discharge and typically within the first week of life), (b) each hearing loss to be confirmed by 3 months of age, and (c) all families requiring services subsequent to the diagnosis of hearing loss to be offered habilitation services before 6 months of age.

This 1-3-6 paradigm allows for the prediction and likely achievement of educational, social and communicative outcomes commensurate with normally hearing peers (Kurtzer-White and Luterman 2001; Yoshinaga-Itano 2003). While the clinical outcomes imply a responsibility on audiologists to adhere to their stringent timelines, the clinical pressures these timelines imply may do so at the expense of time spent attending to the significant emotional impact of newborn diagnosis on the children's families. Contemporary service delivery sees well-intentioned clinicians delivering complex and often devastating news to unsuspecting parents at a time of great vulnerability, while having too little time and too few skills to address these matters effectively (English et al. 2007).

In a qualitative analysis of questionnaire data reflecting the perceptions of 82 parents' experiences of early detection of hearing loss in Victoria, Australia (Russ et al. 2002) parents reported wanting greater personal/emotional support from audiologists during diagnostic testing and when dealing with their child's diagnosis. Specifically, parents reported that audiologists' communication was perceived as lacking in sensitivity towards the impact of the diagnosis on individual family circumstances. Gilbey (2010) reported on the shock and upset parents felt at the time of confirmation of the diagnosis and their dissatisfaction with the manner in which the news of their child's PCHL was delivered. Audiologists' focus on the delivery of information often comprised highly technical language and in doing so, were perceived as blunt and non-empathic. Nearly a decade later, Scarinci et al. (2018) suggested that parental perspectives remain unchanged. Again, audiologists were described as secretive and showing lack of empathy during initial hearing loss diagnosis. Together, these suggest that increased education be offered for clinicians in the communication of findings to parents, to address the complex emotions present at such a critical time.

These results arise against the backdrop of increased awareness and implementation of more empathic and affectively oriented counselling to parents at diagnosis of their children's PCHL. Improving parental experiences during an emotionally tumultuous time of adjustment is a clinical imperative and we sought to discover, in parents' own words, the nature of parent

experiences of the diagnostic process of PCHL. To this end, the authors formulated two research aims: (a) to capture the lived experience of the diagnosis of PCHL by parents, (b) to construct an emotional life-world of parent experience around PCHL to further inform and identify potential clinical implications when counselling families during the diagnostic process.

To address the questions and aims, the project employed an interpretive phenomenological analytical (IPA) framework to achieve rich descriptions of the participant experience couched in the terms parents used to describe their experiences. IPA offers insights into how a given person, in a given context, makes sense of a certain life condition. It brings to light the details of a person's lived experience and offers an insider perspective (Smith 2010). The selection of IPA was aimed at adding to the growing understanding of the personal, interpersonal and emotional consequences of children's diagnosis of permanent hearing loss towards an increasingly clear clinical model for audiologists by which to address these matters with their clients.

Method

Ethical clearance was obtained from WA Health Research Human Ethics Committee (Ethics approval number 2015065 EP).

Participants

Through purposive sampling, comprising both critical case sampling (seeking the widest array of cases), and typical case sampling (seeking the more typical cases), ten (10) parents participated in semi-structured interviews based on their being parents of a child who was identified with permanent childhood hearing loss in early childhood

(see Table 1 for participant details). Participants were all sourced from the public Child and Adolescent Health Service in Western Australia, and in particular from the newborn hearing screening programme, and hearing implant programmes. Both programmes were managed from the Audiology Department within the Surgical Services Clinical Care Unit.

Materials

An emergent interview schedule was developed following an analysis of pertinent literature, from clinical experience and from

scrutinising other lived experience reports (see [Supplementary Appendix 1](#)). It was piloted with two potential participants (parents of a Deaf child, and parent of a child who uses listening and spoken language) to evaluate the clarity of the questions, whether the questions captured all they wanted to share, whether the questions were posed sensitively and did not cause any undue distress, and whether the interview duration allowed enough time to share their thoughts without disrupting their routines. The interviewees indicated minor changes to the structure of questions e.g. adding the clarification of what stands out in your mind. They felt that the questions were clear, sensitive and did not cause distress. They were satisfied with the time allocation. They also recommended issuing the interview schedule beforehand in order to parents to gather their thoughts. Reviewers checked the interviews to ensure that the material addressed was interpretable in light of the research questions.

Procedure

Prior to interview, the proposed interview schedule was e-mailed or distributed in hard copy to participants. Interviews were conducted in a quiet office environment, lasted between 35 and 70 min and were audio-recorded. The recording was supplemented with the interviewer's note-taking and memo-ing reflecting the interviewer's perceptions of significant content, attitude and affect, while taking the role as manager and clinician in a clinical setting. These notes later supported and informed the analysis.

Data analysis

Interviews were de-identified and organised into computer files. If two family members were interviewed together, recordings and transcripts were given separate codes. Interviews underwent orthographic transcription. Transcripts were read as a whole to get a holistic sense of the entire dataset. Each transcript was repeatedly read to immerse the researchers and to assist in the development of a Gestalt. From here, the coding loop (identifying, labelling, classifying and interpreting data) occurred, the analysis of interview data followed the phenomenological perspective of Smith (2010) in focussing on individual interviewees' stories as they reflected their perspectives on the impact on them of the diagnostic audiological process. The larger organising

Table 1. Description of research participants.

Participant number	Gender and marital status	Parental experience with deafness
1	Mother, Married, Australian, part-time employment, in her forties.	Daughter, second child, moderate SNHL and severe-profound SNHL, bimodal, additional disability
2	Mother; Married, permanent resident, full-time employment, speaker of language other than English at home, in her twenties,	Daughter, 3rd child, diagnosed with bilateral severe to profound (left) and profound (right) SNHL through UNHS, bilaterally implanted at 9 months chronological age Significant skull surgery at 12 months.
3	Mother; Married; Australian, sporadic volunteering work, with significant childhood hearing loss, in her forties	Daughter, 2nd child, diagnosed with bilateral severe-profound SNHL, bimodal, bicultural, Auslan first language
4	Mother; Married, Dual citizen, part-time employment, in her forties	Son, 5th child, diagnosed as bilateral profound hearing loss through follow up register at 6 months of age. Auslan user; one CI, implanted at 8 years of age.
5 a and b	Father (a) and Mother (b), full-time employment for both, mother dual citizen and in her twenties, father Australian in his thirties	Daughter, first child, diagnosed with profound bilateral SNHL and bilaterally implanted; bilingual approach; additional disability
6 a and b	Father (a) and Mother (b). Australian, full time employment for both parents, both parents in their twenties	Daughter, first child, diagnosed with moderate unilateral SNHL, aided.
7 a and b	Father (a) and Mother (b), father full-time employment, mother stays at home, permanent residents, language other than English spoken at home, both in their twenties	Son, first child, diagnosed with profound SNHL, aided; being evaluated for hearing implantation.

themes around this topic emerged and initial categories were developed through repeated reading and immersion. These categories, or *codes* (Creswell 2013) represented the heart of this particular analysis. Patterns and regularities appeared gradually, emerged as themes within individual accounts and across the interviews as well. Notable quotes were highlighted as they were seen to hold the central elements of the data's moral (Rubin and Babbie 2012).

Following the phenomenological framework, themes were hewn to meet the two aims of their lived experience (being in the parent's shoes) and their recollection of emotion (their emotional lifeworld) in the context of the phenomenon (early detection and diagnosis of hearing loss). Beyond the themes, the larger meaning of the data was interpreted and represented in text. Transitions in meaning were marked, and identified as meaning units. Meaning units were then transformed into expressions that were more directly related to the everyday experiences. These expressions evolved into the conceptual scaffolds used to clarify and interpret raw data.

Bracketing (after Creswell, 2013), defined as the process of setting aside the researcher's own opinions, feelings and insights, occurred by DS acknowledging her role as a clinician and manager within the audiological service and being known to the participants. She conducted all interviews in the study. CL is an experienced qualitative researcher and clinician, whose insights and opinions were honed clinically in adult rehabilitation and qualitatively in several qualitative methodologies.

Results

The data captured a complex landscape of lived experiences and emotional reminiscences in response to our questioning about what they had been through and what it felt like. On some occasions these responses reinforced, and on others opposed some of the commonly held beliefs of audiological counselling, allowing a sense of newness to infuse our current understanding of the parental perspective. Five themes emerged that reflected the lived experiences of the participants, specifically; (a) *a received disability*, (b) *casualties*, (c) *acceptance in real-time*, (d) *the unique signature of family life*, and (e) *audiologists are essential and appreciated guides despite a complicated relationship with emotions and information*. Much of the detail of the analysis was captured within the experiences reported by Participant 2, whose particularly content-rich interview embodied many of the themes that surfaced in this project. Participant 2's interview is used to scaffold the themes. The data from this interview are complemented by reference to comments from the other participants. The detail of each theme is set out below.

A received disability

Participants did not distinguish between audiology and the various other professional health or medical encounters they attended prior to the diagnostic appointment. While parents received an expert assessment of the presence of an impairment and its attendant disabling issues from their audiologists, the audiologists presented their diagnosis in the context of the health and medical system that preceded the involvement of the audiologist. Despite parents' reporting certain *focal* appointments within this system, the data suggest that *all* the events associated with the diagnosis were inextricably linked to the diagnosis recollection. Narratives commenced from the first sign of trouble.

For Participant 2 the first focal period was the newborn hearing screening experience and the first diagnostic appointment:

"...the one appointment that did stand out to me was that, the one where they actually diagnosed her and told me what was going on, I think that's the one appointment that we will always remember."

Participant 2 also noted the positive outcomes associated with early diagnosis and intervention on face value. The time-efficient adoption of intervention is unequivocally positive, but not without some negative consequences to the early attachment between infant and parent which were captured as casualties in Theme 2.

"And because [with] the hearing aids, we didn't really see any communication from her side. So we were talking and talking but nothing ever happened. And we thought: 'Oh, maybe this is how it's meant to be', but her responses with the cochlear implants were so significant that we could see: 'oh okay, it's working now.'" Participant 2

Because I didn't know. All I knew was every time I went to the one appointment they said, "Your next follow up appointment is in X." ... Yeah so I like I didn't ... You were, felt like you were going from one appointment to the next- ... So that would be really nice if you go, "Okay. Well this is the path, you know, you have your newborn hearing screening. Two weeks later you get that. Four weeks later you get your jack hammer in the ear." Participant 5a

Participant 2 and others indicated that they most readily recalled the initial diagnosis and then were presented with only localised portions of information pertinent to their child's assessment and diagnosis during appointments in the absence of a broader context. Critical moments of insight into their child's journey were spontaneous and powerful but in some cases occurred outside the matrix of appointments they attended. As a result, early in this process they were unable to gather any perspective of the pertinence, prominence or priorities within the provided information.

Casualties

Parents suffer losses as a consequence of their child's diagnosis and we labelled the events, life casualties. Participant 2's life casualties included the adverse impact of diagnosis on her bonding with her infant, her enjoyment of having a new addition to the family and her spontaneity during interactions with her infant. She recalls getting acquainted with her infant through a filter of worry.

"I think the only thing they might, they can do is just to give you a couple of days just to get the connection, just be happy. And then because it hits you so hard and then you forget about your whole experience with having a baby".

"Looking back, looking back I think that I should have enjoyed my time with [child's name] when she was little. When she was about a month or so I didn't because I was worried about everything that was still going to happen ... it was the unknown ..."

The diagnosis hampered happy, joyous parenting behaviours. Participant 2 recalls the advice to continue talking to her infant as normal by the early intervention team and its impact on her view of the interaction with her newborn child as "work":

"I know she can't hear you, but keep talking to her because she feels your emotion. So yeah I had to really think about it, it was work. Even just talking to her and getting myself to get out of bed and talk to her."

Other participants echoed these sentiments concerning the impact on their socialising with their newborn as a result of the clinical advice they were given. In the absence of a fully developed overview of the process in which they had been so

suddenly recruited. Parents also described feeling unprepared for the responsibility of having a dual role of advocate and of parent.

"...when there's so many things to [child] that she's got going on. You know, it does cloud your relationship with the child. A little bit. Because you're always assessing what's happening with them, what's going on with them? Are they getting what they need? Whether you're doing the right thing. Whether somebody is else is doing the right thing. You don't just, things aren't as fun." Participant 1.

"You've got so much to try and process. Apart from the fact that the baby is still new, so you've got all that going on." Participant 4

Acceptance occurs in real time

Acceptance of the diagnosis occurred during or immediately following the initial diagnostic appointment, at least to the degree that allowed initial management (referrals and follow up assessments) to occur. The acceptance and subsequent mobilisation came at a cost. Participant 2 described herself as behaving "... like a zombie ..." until a new routine established itself. It is perhaps testament to her resilience that she was able to see the positives shortly after trying the activities recommended to her by professional staff.

"... on the third day of her birth, we had appointments lined up all the way."

"So just being through it, just being like a zombie, doing what you need to do. And it takes you a while to get used to everything. But once you're used to it, it's great."

Participant 2 describes how several important issues arose in the months that followed her child's diagnosis. Of prime importance in her recounting, her husband's full time work commitments resulted in her having to tell him of the news of their infant's diagnosis and then of the expected need for and potential benefit from bilateral cochlear implantation. These events occurred during the early months while she was still making sense of it herself. Her honest disclosure about her grief, alongside her acceptance of life with a child with bilateral implantation is particularly poignant. She follows on:

All the information sessions and appointments are made to the mum. And so mum goes home and tells dad whatever happens today, but he's not part of the experience and how emotional that actually is for the mum. But also I think it's very, very important for the dad to be there when the cochlear implants are switched on. Um. It just gives them a better background to it and it just opens their eyes because he didn't just... he just got a shock the day her cochlears were turned it just shocked him, it just sunk it. So after seven months of maybe, I think it was disbelief and on seven month switch on he was like, "oh, okay. I got it [that she has a hearing loss] now"

"I think about it every day. I think about it every single day. Sometime I wish I can just put her back and protect her in there. Take back what happened."

Unlocking the unique signature of family life

The recollection of important events, their sequences, timelines and themes had a rhythm that could be uniquely associated with each member of the broader family unit. Participant 2 offered how the family unit coped with the implications:

"Luckily we have a family that just goes on. Yeah, so everyone just said: lucky she wasn't born without legs. So all of them were like that. For me and [husband], it took us a while. I had to deal with it by myself and [husband] had to deal with it by himself as well."

But both of them, [sibling] and [sibling], always have their eye on her They are very protective with her. When they go to school and people ask what's going on, [sibling] with tell them "she's got four ears, two's not working, but two is"

Other participants offered their views on the impact of the diagnosis and the changes visited on family life. The family signature is dynamic and unpredictable and, at times, positive. For Participants 5a and 5b, the diagnosis and early management of permanent hearing loss in their infant did not trigger big emotions due to the presence of other, more ambiguous and life-threatening conditions for the child. The mother (5a) and father (5b) report:

"You know, the hearing loss to me is now just a natural part of [child]... because of the medical problems that she had, the hearing to us wasn't as huge but I do know from talking to other moms that some of them are really suffering from grief." Participant 5b

"Well a lot of other parents I think are more focussed on curing and whether it is hearing aids or cochlears or whatever they're more interested in curing that the child can live normally, rather than coping with it." Participant 5a.

For others the presence of life-threatening conditions resulted in struggle and exhaustion throughout her child's early years.

"We've found it all through her life. It's a battle and I've found that as soon as you put a word, disability, into anything. You've got to fight everything. There's nothing easy." Participant 1

Audiologists are essential and appreciated guides through a complicated relationship between emotions and information

Participants reported positive experiences in response to the services provided by the audiologist. They were most appreciative when the clinician was responsive to and well versed in the emotional vocabulary and could discuss the diagnostic and habilitative process in the context of the family. The data suggest that families noted when the clinician's talk was pitched appropriately and sensitively and was adjusted to their talk over time. Participants perceived their needs as being met when clinicians: a) allowed parents to debrief other professional encounters, b) allowed fears and doubts created by other services to be dispelled or at least challenged and c) showed patience with parent's acceptance journey. Participant 2 appreciated kindness and patience:

"...I think the person that was most approachable out of all of this was [the audiologist].... I think he already knew, but he did it for me....so that I, that I can see this is what is actually going on and I can't just keep on hoping and I'm not just going on the doctor's word, I'm actually seeing the results for myself."

Participants most appreciated the honesty, matter-of-factness and unambiguous nature of their talk during and following the diagnostic experience.

"First of all it is the skill. I remember [the audiologist] showed me what they look for in the graph and explain to us, so we can believe." Participant 7

"Since meeting [implant audiologist], I always had someone to fall back on. And [audiologist] had been great in emailing me back." Participant 2

"The audiologist's way of talking to me was...like I am not an idiot but you just don't know. So he explains it in a very nice way so you don't get overwhelmed and not a lot of people do that and if they do, they're acting like there not there for your child, but just there because they need to be there. They don't take the time." Participant 2.

Constructing an emotional life world

Participants' emotional life-worlds were investigated by questions 3.5.7 and 8 of the interview schedule. Parents were articulate and enthusiastic in naming and elaborating on their feelings. The emotional landscape of participants chronicled feeling states that reflected sudden changes between emotions. Indeed, many of the recalled emotions were opposing and present simultaneously. The two concurrent, non-linear affective groupings we framed as a *spiral of disorientation*, and *protective states of righting*. Disorientation was described as confusion, limbic reactivity manifesting as shock and disbelief, fear manifesting as worry, and lowered affect manifesting as despondency. Simultaneously, in the chronicles provided by the participants, this spiralling effect was pierced and disrupted (righted) through determination manifesting as grit and resilience manifesting as gentle humour.

1. *Confusion*, which we define as uncertainty about what is happening, or what is required *was identified* by all participants as one of the initial emotions they experienced. Participant 7a states that, at the diagnosis of profound bilateral hearing loss and when complex anatomical anomalies were identified during the early management process:

"We got confused... until now we [were] still confused... less confused in terms of information, but more confused in term of what we should do next." Participant 7a

"It was confusing, so it was very confusing to know what to do, so it was all the ins and outs, I didn't know what to do." Participant 6b

2. *Disbelief/Shock*, which we define as the emotion-based inability to accept what is apparent via observation or received information, emerged from the interviews particularly in response to (questions/interaction), ranging from birth-related ear canal debris preventing a clear screening result, equipment failure during screening, to self-assessment after discharge from the hospital. In the presence of familial hearing loss, disbelief was evident:

"There is no chance we could produce a deaf child, ... my husband is due to meningitis and I thought I become deaf by immunisations. So this was always, you know, why I thought I became deaf so there was no way I could produce or we could make a deaf child, you know." Participant 3 (Deaf parents)

"The way I found out is that one [audiologist] said to the other, knowing I was standing right there holding him, "Oh, this little kid isn't going to hear a thing, he's seriously as deaf as anything." Which was quite a shock to hear." Participant 4.

3. *Fear and worry* permeated the routine, quiet times of early family bonding. Often, it was fear and worry that prompted parents to seek further contact with a professional to discuss early management.

"We don't ask much, like we just want to, like, if we really lost, and we just want something to hold. Sometimes we worry when we wait." Participant 7a

"All I could think of was she is going to be trapped in the deaf world again, like I was. Not actually thinking, well, what will it be, because I never had those opportunities, but I just felt more sorry for her because I struggled, I struggled growing up, being in a hearing world. But if I was going to turn my clock back 30 years ago, and was involved in the Deaf community like my husband was, it would probably be a totally different story." Participant 3

4. *Despondency*, which we define as being in low spirits from loss of courage, reflected the dejection during routine nurturing activities and the well-meaning but often insensitive comments from family and friends:

"It was crazy. I spent most of my night crying. It was awful. (laughs)" Participant 6a

"It hits you so hard... yeah and I remember breast-feeding her and just crying the whole time, Uh, I don't want to breast feed anymore, this isn't fun." Participant 2

"One thing we found was hard was people were like, she is only deaf, it's not cancer, she is not dying..." Participant 6a

The righting effect of grit and humour on the lived experience of the diagnosis yielded a more positive perspective on the emotional landscape of participants. *Grit*, which we define as a combination of courage and resolve.

"I've always said every door is open for her. Every door is open; no closed doors for you. Closed doors for me? Yeah, but all your doors are open, you can listen to music, you can use a phone, there is nothing going to stop you now." Participant 3

"We want the best for her." Participant 6b

"We want the best for him." Participant 7a

In some cases, *grit*, manifested through *humour* (which we define as trying to regain perspective by seeing the funny side of events, thoughts or feelings).

Like whether he making the surgery, I feel a pain in my head. (laughs). I tell my wife that... She say: "yeah, like, um, better than not feel anything." (laughs). Participant 7a

In summary, families report feeling buffeted by the diagnostic process with particular reference to the relatively localised advice they are given without reference to a broader perspective or a sensitivity to timing in relation to families' ability to digest and respond to the emotional impact and/or informational content.

Discussion

The study chronicled parents' lived experience and emotional life world during early diagnosis of their child's hearing loss. Methodologically, a phenomenological approach allowed us to transcend past knowledge (Merleau-Ponty and Bannan 1956) to not only understand parental experience and emotion at a deeper level, but also to foster lived experience distinct from their theoretical explanations (Creswell 2013). Data collected were abundant, analysis was challenging and stimulating and conclusions drawn have substantial implications for understanding parents' perspectives of the diagnostic and subsequent services related to their child's hearing loss. The data reflect the vivid nature of parent recollections, despite the progression of time since diagnosis.

Recollections did not follow a chronological order, but rather reflected the intensity of emotion recalled. Recollections were not always directly driven by the interviewer's questioning in as much as when asked about *helpful* behaviours, some participants first described *unhelpful* behaviours or when probed about helpful role-players, participants would first disclose unhelpful professional encounters with clinicians.

In response to questioning about lived experience (aim 1), participants all had a vivid recollection of that one appointment, that symbolised their initiation into the process (*"what I most remember"*). Equally and on a pragmatic level, there was an experience of being unmoored (*"from one appointment to the next"*) without an apparent plan or organisation. Parental uncertainty echoed the sentiment (*"is this how it is meant to be?"*). The high value and responsibility placed by family-centred care and early intervention exposed confessions of communication modifications that were hard to contemplate, with parents recalling how much they had to learn (*"it was work"*) about

communication with their child and that it wasn't a seamless experience. Despite some parents feeling that they "*had to fight for everything*", all were "*coping with it*". A positive, but most significantly, *unique* view on the child's future remained the goal ("*we want the best for her*").

The passage from screening to diagnosis created a view of audiologists based on prior contacts in the medical system, even in circumstances where they had no involvement. Clinicians were deemed effective when they acted as witnesses to the preceding events, and supported the processing of such encounters emotionally, as well as with practical, logistical support. However, the initial diagnostic appointment, where the presence of permanent hearing loss was unambiguously identified, provoked feelings of confusion, disbelief and shock.

Parents reported changes to their perspectives on parenting and their relationship with their child following pronouncements by clinicians around a child's hearing (whether during the screening process or during diagnosis). Parents' perceptions of attachment were at odds with professional advice on how to communicate which placed strain on their getting acquainted with their child. When probed about their emotional lifeworld (aim 2), it was unambiguously reported that the hearing habilitation process was an intensely emotional experience for parents. Persistent confusion, worry and despondency were chronicled during early management, while short bursts of anger and frustration were triggered when recalling logistical challenges of scheduling, or complexities in multidisciplinary case management. Parents longed for "*some time just to be happy*" and expressed regret for not "*enjoying the time with the baby*" following the diagnosis. The strength of family bonds permitted resilient traits to emerge from the emotional upheaval in order "*to just carry on*", to describe how siblings "*looked after each other*". Some parents "*cried every night*" and others had bigger health concerns to manage.

Our findings revealed a complex relationship between parental need for information, and clinician responsiveness to needs. Two focal areas emerged: the first is an *implicit* need for responsiveness to their confusion, shock and disbelief during the diagnosis and the second is an *explicit* attendance to family wellbeing through tailored informational counselling. Clinicians were overwhelmingly perceived as kind, helpful and sensitive to family's needs, and our findings oppose some of the reports in the literature of clinician bluntness and insensitivity, parental dissatisfaction with how the news was broken to them by professionals (Gilbey 2010); and emotional responses as being underestimated by audiologists, especially at the point of diagnosis (Bosteels, Van Hove, and Vandenbroeck 2012). It is apparent that both processes work in parallel.

Clinicians were praised for recognising and responding to parents' need for more emotional support during difficult periods. According to Crago and Gardner (2019), emotional support may be defined as *staying with or being there* for a parent that results in the parent perceiving the clinician as non-anxious and empathic during their interaction. The inherent individuality of the human coping response and the pressures introduced by an ambitious management timeline, suggest the need for a sophisticated level of emotional awareness on the part of parent and clinician.

During the early diagnostic period family and clinician emotions contribute significantly to the decision-making process, establishing productive relationships, the setting of boundaries and identifying hope amidst challenges and connection. Emotional literacy to support this awareness requires a

framework that can be contextualised to the family's life and interaction. Our findings form a possible basis for emotional literacy that encompasses the skill to work with expressions of shock, worry and disbelief, in a time-efficient manner, while, simultaneously capitalising on the good faith directed towards the profession, and the inherent grit and good humour of families. This response should also be based on the *professional's* natural emotional reactions to emotionally difficult situations (McLaren 2010).

A model with potential utility in at least supporting parent experiences of the diagnosis and management of hearing loss is the Dual Process Model (DPM) of coping with bereavement (Stroebe and Schut 2010). The model maintains that normal grief consists of an oscillation between attending to a loss (Loss Orientation), and then moving it to a tolerable distance to activate life-changes created by the loss (Restoration Orientation). It maintains that oscillation between loss and restoration should be considered a typical and expected during the adjustment to hearing habilitation.

The DPM's potential to accommodate individual signatures of grieving and coping could facilitate the timing of highly tailored emotional support during the paediatric diagnostic process. The potential utility of a model such as the DPM centres on the fluctuation in the emotional lifeworld (which we define as the subjective experience of the world) of parents which could be mitigated to some degree by tailored information at a time when families are in their most receptive state.

Our findings revealed a complex relationship between parental need for specifics and straight answers, while insisting on high levels of diplomacy and sensitivity. The need for straight answers and better curated information could be suggestive of a timing error: the clinician pacing information due to a presumption of being sensitive to the parents' grief response. Families may emerge from the initial exchanges in a restoration orientation, when clinicians provide 'straight answers'. However, parents may oscillate back to loss oriented perspective, as a completely normal process. The strength of using phenomenology was allowing these ambiguities and inconsistencies to co-exist and coalesce into a deeper level of understanding of the complexities of the collective and individual parental experience.

We acknowledge that Family-Centred Care (FCC) as a key philosophy supporting paediatric audiology practice. FCC provides a set of principles of clinical service delivery to accommodate the specific informational, and emotional needs of each family which includes informed choice, clinician-family partnerships, emotional support and equitable service delivery models (Harrison et al. 2016; Moeller et al. 2013). Sansoni et al. (2015) provide research-based guidance that marks the characteristics of the clinician's communication skills at the clinical interchange point and translates FCC as a philosophy into a framework of actions in paediatric audiology. DesGeorges (2010) identifies interpersonal aspects of the questioning process that promote appropriate "attitude" (p. 294). Despite these questioning strategies, negative reports on the nature of counselling persists in paediatric audiology (DesGeorges 2010). A dynamic model such as the DPM animates important principles of FCC (top down) while simultaneously contextualising clinician behaviours and attitudes (bottom up) by acknowledging both grieving and coping processes and movement between the two. Without the intermediate level of emotional literacy provided by the DPM, many endeavours translating FCC into behaviours will remain stabs in the dark.

Conclusion

The study yielded rich data which revealed experiences of day to day living and some key elements of parents' emotional responses as they came to terms with the hearing loss identified in their child. Issues in family dynamics and interaction were reported that seem critical for clinicians to respond to. At the same time, so deeply were clinicians trusted during the diagnosis, that families responded by adjusting their emotional, intellectual and relational resources to align with and act on clinician recommendations without delay.

Parents require a level of emotional support that exceeds frameworks of counselling. We introduce the DPM as an intermediary model of emotional literacy which has potential to address both grieving and coping during the passage from diagnosis to early management. We believe it provides an effortless articulation with the principles of Family-Centred Care philosophies and behaviours by providing a taxonomy of grieving, coping and parents' movement between the two orientations.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Dunay Schmulian  <http://orcid.org/0000-0003-1203-4032>

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