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### Article

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## **Parent's experiences of their child's withdrawal syndrome: a driver for reciprocal nurse-parent partnership in withdrawal syndrome.**

### **Abstract**

Withdrawal assessment in critically ill children is complicated by the reliance on non-specific behaviours and compounded when the child's typical behaviours are unknown. The existing approach to withdrawal assessment assumes that nurses elicit the parents' view of the child's behaviours.

**Objective and research methodology:** This qualitative study explored parents' perspectives of their child's withdrawal and preferences for involvement and participation in withdrawal assessment. Parents of eleven children were interviewed after their child had completed sedation weaning during recovery from critical illness. Data were analysed using thematic analysis.

**Setting:** A large children's hospital in the Northwest of England.

**Findings:** Parents experienced varying degrees of partnership in the context of withdrawal assessment and identified information deficits which contributed to their distress of parenting a child with withdrawal syndrome. Most parents were eager to participate in withdrawal assessment and reported instances where their knowledge enabled a personalised interpretation of their child's behaviours. Reflecting on the reciprocal nature of the information deficits resulted in the development of a model for nurse-parent collaboration in withdrawal assessment.

**Conclusion:** Facilitating nurse-parent collaboration in withdrawal assessment may have reciprocal benefits by moderating parental stress and aiding the assessment and management of withdrawal syndrome.

## **Key words**

Critical care, Decision-making, Family-centred care, Iatrogenic withdrawal syndrome, PICU

## **Implications for clinical practice**

Parents need to be better informed about the potential for withdrawal syndrome.

Parents contribute a unique perspective to clinical assessments of withdrawal.

Nurse-parent partnerships may have reciprocal benefits.

Nurse-parent collaboration should be more consistent during withdrawal assessment

## **Introduction**

Withdrawal presents as a group of symptoms, of variable clustering and severity, on absolute or relative withdrawal of a psychoactive substance after persistent use of that substance (World Health Organisation, 2016). In the PICU, withdrawal may occur during weaning of sedative and analgesic infusions. Whilst diagnostic criteria do not exist for this population, this state has been termed Iatrogenic Withdrawal Syndrome (IWS) (Franck et al 2012; Best et al 2015) to reflect how the conditions for withdrawal in PICU are a consequence of clinically prescribed care. Prevalence of withdrawal ranges from 22% to 77% (Madden et al 2017), varying across settings due to differences in the drugs prescribed, peak doses administered and speed of drug weaning.

Validated assessment tools - the WAT-1 (Franck et al 2008) and SOS (Ista et al 2009) - focus on signs of withdrawal and demonstrate superior sensitivity over nurses' judgement (Franck et al 2008, Ista et al 2013). Assessing whether a child is displaying clinically significant withdrawal

remains a challenge, due to confounders such as the concurrent tapering of more than one sedative or analgesic drug, the impact of the child's underlying condition on non-specific signs and symptoms of withdrawal, the nurses lack of familiarity with the child's typical behaviours (Craske et al 2017) and behavioural similarities with other differentials including delirium and adverse drug reactions (Madden et al 2017).

It is assumed that nurses routinely elicit the parents' view during the withdrawal assessment to address some of these challenges (Harris et al 2016; Ista et al 2013). This view reflects a partnership approach to decision-making, which as a defining principle of Family Centred Care (FCC) (Kuo 2012, Mikkelsen and Frederiksen 2011), often underpins the child's nursing care. However, eliciting parents' views is not an explicit part of the withdrawal assessment and appear to be inconsistently sought (Craske et al 2017). Furthermore, parents' views of their child's withdrawal and their preferences for involvement and participation in withdrawal assessment have not been established. This paper is the first to report parents' views of their child's withdrawal and parents' preferences in terms of involvement and participation in the assessment and management of withdrawal.

## **Method**

### **Research objective**

To illuminate parents' perspectives of withdrawal and their experiences of partnership and to identify future preferences for participation.

## **Design**

The data presented in this paper were obtained from part of a larger mixed methods study, which used chart reviews, questionnaires and interviews to illuminate parents' perspectives of withdrawal. This qualitative study is grounded in the pragmatic underpinnings of mixed methods research. A pragmatic approach does not commit to one philosophical view of reality, instead focusing on solution to problems (Creswell 2013, Morgan 2007). Contrary to the objective view of reality that typically underpins tool evaluation studies, pragmatism embraces the principle that multiple perspectives enhance and enrich a single perspective (Bryman 2008). This principle reflects the researcher's position that collaboration between parent and the nurse, interpreting non-specific withdrawal signs in light of the child's usual behaviour and underlying condition, augments the single perspective of the nurse. This study draws on the theories of decision-making and family-centred care to develop conceptual descriptions of nurse-parent collaboration in withdrawal assessment.

The tool in use within the study setting was the Sedation Withdrawal Score (SWS) (Cunliffe et al 2004); a checklist of 12 behavioural and physiological signs of withdrawal scored by nurses every 6 hours during weaning of opioid and sedative drugs. The SWS has not been formally validated but shares similar content and format with WAT-1 (Franck et al 2008) and SOS (Ista et al 2009).

## **Ethics approval**

Ethics approval was granted by the Liverpool East NHS Ethics committee (12/NW/0681). The lead researcher is a member of the clinical team overseeing sedation weaning in patients after discharge from PICU. As such, she may have been known to some parents but when

undertaking the study was no longer involved in the care of their child. Parents were not approached to participate in the study until sedation weaning had been completed. The initial approach was not made by the lead researcher but by either the nursing shift co-ordinator or a member of the Pain and Sedation Service who was unknown to the family. Written consent was gained by the lead researcher from parents who agreed to participate.

## **Participants**

Participants were selected from parents who had completed a questionnaire (Phase 1 of the study) to elicit recall of withdrawal signs during their child's sedation weaning and who had ticked a box to show their willingness to discuss their experiences further. A purposive sample frame then screened parents according to two characteristics that related directly to the research question; the nature of the circumstances of the PICU admission (planned or emergency) and previous experience of PICU, to maximise variation of parent experience. Therefore, the sample purposively comprised of four groups typically admitted to PICU and who therefore had different experience; elective admissions, with and without previous experience of PICU; and emergency admissions, with and without previous experience of PICU. It was anticipated that these characteristics might impact on parents' views of their child's withdrawal behaviours and their willingness to participate in withdrawal assessment.

Inclusion criteria were parents of children aged birth to five years who had completed sedation weaning as an inpatient in the study setting and had at least one documented episode where SWS scores were indicative of withdrawal. This age group was selected as it represents 80% of the PICU population (Schieveld et al 2016) and comprises children whose parents would be expected to act as proxies, in order to meet the study aims of examining the parental perspective. The exclusion criterion was that neither parent was sufficiently proficient in English to participate in the interview.

The study was conducted in a large children's hospital in the Northwest of England.

### **Data collection**

Patient data (age, gender, underlying condition/s, the reason for and duration of PICU admission and the date and time of the highest SWS score) was collected in Phase 1 of the mixed methods study.

Semi-structured, audio-recorded interviews were conducted by the lead researcher. After initial questions asking about the current progress of the child and summarising their PICU admission, the interview focussed on parents' recall of and feelings evoked by behaviours displayed by their child during weaning of sedation, their participation in withdrawal assessments and their views on including the parental perspective in future assessments. An interview guide was developed to ensure all parents were asked the same major questions, whilst allowing new issues to be considered and opportunity to explore responses in depth and at their own pace.

Interviews took place at the child's bedside or in a quiet room adjacent to the ward, according to the parents' preference soon after weaning was completed in order to minimise recall bias.

Interviews were performed between December 2012 and December 2014. The study continued until at least two participants from each group of the sampling frame had been interviewed and no new themes were emerging. Recruitment was restricted by lead researcher availability in the limited time frame between completion of sedation weaning and discharge home.

## **Data analysis**

The interviews were professionally transcribed, anonymised and checked by the researcher for accuracy and completeness. Data were subjected to thematic analysis, an approach which whilst not tied to a particular theoretical position, complemented the study aims of examining the perspectives of different participants to generate insights and highlight similarities and differences (Braun and Clarke 2006). The steps taken in analysing the data were modelled on the phases of thematic analysis described by Braun and Clarke (2006). All transcripts were read several times and preliminary notes were made of initial impressions. Significant statements related to the lived experience of parenting a child who was withdrawing were identified from each transcript. Potential themes and shared meanings emerged from the significant statements and ongoing analysis across all cases before a final synthesis was developed. A thematic map was presented to a team of clinical psychologists who support children and their families in PICU, and who verified the emerging themes as resonant with the concerns typical of parents with a child in PICU. Aligned with the continual interaction between the research question and stages of the research process described by Johnson (2014), analysis and interpretation continued until emerging causal relationships between major themes had been refined. A model was developed to demonstrate the interaction between the themes and will be presented in the findings.

Quotes from individual interview transcripts are identified by the codes P1 through to P11; with 'M' and 'F' referring to mothers and fathers.

## **Rigor of the study**

A range of strategies were employed to enhance the rigor of this study; particular attention was paid to Lincoln and Guba's (1985) four criteria (credibility, transferability, dependability and confirmability) (Creswell 2003) and these are briefly mentioned now (further details can



be requested from the lead author). Rigor was considered throughout all elements of the study from conception, design, data generation and analysis, discussion as well as the presentation and reporting. Transferability was considered, for example, when ensuring that the sample size was adequate, and the rationale underpinning purposive sampling was described clearly. The use of thick-description supports transferability (Creswell 2003) and the way in which the findings of the study are critically contextualised within the existing literature provides reassurance about the credibility of the study. The clear description of the study and the rationale for decisions made supports the dependability of the study.

Researcher reflexivity was fundamental to ensuring the confirmability of the study. Adopting a reflexive approach throughout the study encouraged the researcher to consider factors including assumptions and theoretical or other predispositions (Schwandt 2015). As an expert clinical nurse with years of experience of engaging with parents of children recovering from critical illness, it was essential for the researcher to continually question any assumptions and positions and to present the reader with sufficient detail to allow them to understand the context in which the study was undertaken. Peer review of the preliminary themes (Morse 2015, Creswell 2002) by clinical psychologists with expertise in supporting the parents of children in PICU was used to challenge and reduce any unconscious biases or gaps in analytical thinking.

## **Findings**

Eleven interviews lasting between 23-68 minutes were conducted; nine with one parent (6 mothers and 3 fathers) and two with both parents. For five families this was the first time the child had been admitted to PICU; two were planned and three were emergency admissions. Of the six families with previous experience of PICU, four were planned and two were emergency

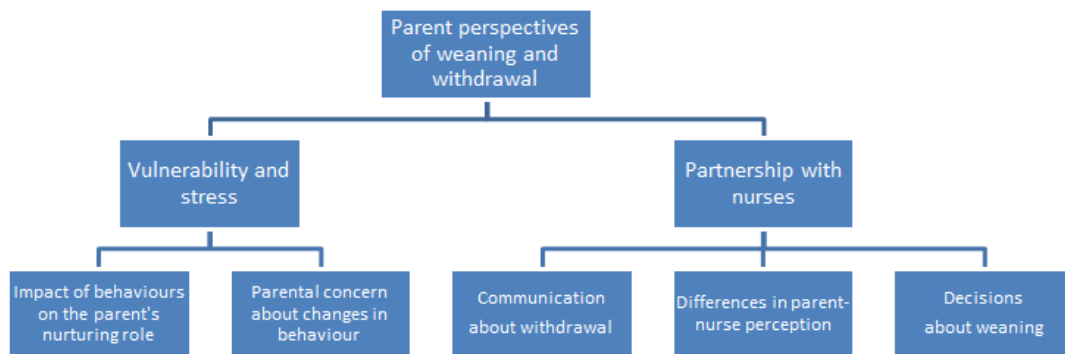
admissions (Table 1). The highest SWS score demonstrated that all patients scored for withdrawal (SWS $\geq$ 4) during weaning of their sedation.

**Table 1 Patient demographics including highest SWS score**

Study no.	Parent interviewed	Child demographics					
		Plan/ Emergency 1 <sup>st</sup> / previous	Age	Gender	Reason for PICU admission and underlying condition	Number of days on PICU	Highest SWS score, day (D), location
1	Mother	Planned 1st	3 years	Female	Cardiac surgery	31	9 D30 PICU
2	Both parents	Planned Previous	1 year	Male	Cardiac surgery VACTERL Association	19	8 D3 ward
3	Mother	Planned Previous	9 months	Male	Cardiac surgery	28	10 D5 HDU
4	Father	Planned Previous	5 months	Male	General surgery Neurodevelopmental delay	19	10 D16 PICU
5	Father	Emergency 1st	5 months	Male	Bronchiolitis Ex premature 34/40	6	10 D2 ward
6	Mother	Emergency Previous	9 weeks	Male	Respiratory collapse Cardiac patient	20	9 D20 PICU
7	Mother	Emergency 1st	4 months	Female	Bronchiolitis, Trisomy 21, AVSD <u>Tracheobronchomalacia,</u>	12	10 D8 PICU
8	Both parents	Planned Previous	5 months	Male	Cardiac surgery Williams syndrome	6	8 D0 ward
9	Father	Emergency 1st	2 years	Female	Adenovirus Kabukisyndrome	20	10 D3 HDU
10	Mother	Planned 1st	27 days	Male	Cardiac surgery	38	7 D27 PICU
11	Mother	Emergency Previous	3 years	Male	Sepsis Cerebral Palsy, TPN dependent, Developmental Delay, <u>Tracheomalacia</u>	13	8 D11 PICU

M=male, F= female TPN =Total parenteral nutrition AVSD= atrial ventricular septal defect

Two major themes were identified that reflected the main theme of parent perspectives of weaning and withdrawal. The theme ‘vulnerability and stress’ had two sub-themes; parental concern about changes in behaviour and impact of behaviours on the parents nurturing role. The theme ‘partnership with nurses’ had three sub-themes; communication about withdrawal, differences in parent-nurse perception and decisions about weaning.



**Figure 1 main themes and subthemes**

The themes and sub-themes are presented, followed by parent preferences for participation in withdrawal assessment and the model derived from the themes and sub-themes.

### **Vulnerability and stress**

Parents revealed that the overall experience of parenting a child with withdrawal syndrome was stressful and differed from other challenges presented by their child’s critical illness. These differences were reflected in the sub-themes, namely parental concern about changes in behaviour and the impact of behaviours on the parents’ nurturing role.

Parents described withdrawal as a distinct source of stress during their child’s critical illness *“It’s like a separate issue, like being sick again”* (P5F); while a mother described it as *“a horrendous 24 - 48 hours”* (P6M). Another mother talked of distress being associated with the fact that withdrawal was *“an unexpected part”* of his journey and that withdrawal had *“probably been one of the most distressing bits”* (P2M). A similar sentiment was expressed by a father who said *“you don’t realise it can be quite an ordeal and that it brings a different set of problems”* (P9F). Withdrawal was talked of in terms of how stressful it was in relation to

previous experiences. One mother summed up the feeling that was typical of the other parents when explaining that although it was distressing, this was “*not in the same way as the operations and the bad news*” (P1M). Another mother declared “*withdrawal was nothing really*” compared to being told her son might die and that “*at least he’s alive, but on a day to day basis it’s everything*” (P3M).

### ***Parental concern about changes in behaviour***

Parents noticed changes in their child’s behaviours during sedation weaning which added to parental stress and vulnerability. One mother explained that insomnia was, “*as stressful as seeing them do stuff on PICU*” (P8M). One father described how the reality of his child’s suffering evoked a different response to the anguish of not knowing if his child would survive, which possibly explains the paradox;

*“When they’re on a ventilator they look very peaceful... if you look deeper they’re very poorly. When they wake, you see their distress and they’re struggling to breathe, you see withdrawal and pain – it’s a different kind of emotion.” (P9F)*

In some cases, seeing their child undergo withdrawal ranked very highly in terms of stressful events during their child’s critical illness as one father whose son had had multiple PICU admissions explained;

*“The thing I dread every time is withdrawal..... I dread it every time.....It’s just a nightmare as a parent to see your child go through that..... it’s heart-breaking, it’s absolutely awful” (P4F).*

Parents found some withdrawal behaviours more distressing than others. One father differentiated between distressing signs where “*you can see there is something wrong with*

him" (P5F) and others that were not distressing, because they were "*just side effects*" (P5F). A mother described the basis upon which she perceived signs as distressing or not, as "*I understand why these sort of things happen, so they are less scary*" (P2M). In some cases, the child's underlying condition dictated which signs were more distressing because "*we knew some were more serious than others*" (P9F). Parents expressed concern that some signs might compromise the child's recovery, and, as one mother explained;

*"Restlessness and irritability I don't like to watch, especially when you've got a child with a heart problem, you are worrying that they're going to get tired."*

(P2M).

Other behaviours evoked distress because they were not typical of their child, so parents were concerned about what these might mean, as one mother explained "*it's just not his normal behaviour and so it's upsetting, you just don't know what's going on*" (P11M). Communication disturbances ranked highly amongst these atypical signs as one mother explained, "*Not recognising me was the most upsetting really, because they didn't know if there was something wrong with his brain*" (P11M). This was a rational concern, because, as one mother explained, "*it could be a sign of neurological problems, which is a part of what we signed on the consent [form before heart surgery as a risk of the operation]*" (P2M). Despite attempts by staff to reassure parents about the temporary nature of withdrawal signs, one mother worried that "*it could be that it's never going to go away.*" The possible irreversible damage suggested by communication disturbances was more distressing than signs such as "*insomnia, because hopefully that can be reversed*" (P2M).

The spectre of neurological damage was pervasive and "*probably more upsetting than anything else really*" (P11M). One mother explained her "*major concerns*" about whether she would "*get the same child back*" (P1M). Another mother described how living with the

uncertainty of neurological damage was *“like waiting for heart surgery, it’s a massive albatross round your neck”* (P3M).

### ***The impact of behaviours on the parents’ nurturing role***

Parents described the negative impact of withdrawal on their usual comforting or nurturing role. Some described feeling bereft in the absence of their child’s usual interaction. One mother described about wanting *“your child to know who you are, that’s all you want back when they’ve been so poorly, and then you wait ages for them to realise that ‘mummy’s here’”* (P11M). Another mother of a 3 year old girl described how;

*“You’d speak to her and she’d just look right through you..... It was like there was nothing there; there was no light, there was no sparkle and that upset me”*  
(P1M).

The sense of ineffectiveness of parental nurturing was also shared by fathers and one father summed up a sense of helplessness that was common;

*“You can’t control it, there’s no control over it, all you can do is sit there and be with them, and watch them go through it. But there’s no comforting him, no matter what you do”* (P4F).

In addition to the sense of helplessness, not being able to comfort their child caused frustration, *“you can’t do anything for him, can’t understand what he wants”* (P5F), and stress; *“why can’t he sleep?”*, and *“why can’t I get him to sleep?”* (P8M). One mother, whose son had been ventilated from birth, reflected that she felt like a *“useless mother”* because she was *“obviously wasn’t good enough yet at comforting him”* (P6M). This sense of despair was also shared by a more experienced mother whose baby was a few months old and had previous

PICU experience, who described her inability to comfort her baby as what *“upset me the most”* (P8M).

### **Partnership with nurses**

The extent to which nurses engaged in a partnership approach with parents varied considerably. Three sub-themes describe the main components of partnership, or the absence felt by a lack of partnership; communication about withdrawal, differences in parent-nurse perceptions and decisions about weaning. Parents reported receiving very little communication about withdrawal which may have contributed to their sense of vulnerability and stress about the behaviour changes they noticed in their children.

### ***Communication about withdrawal***

There appeared to be an inconsistent approach to involving parents in the withdrawal assessment. Parents' awareness of the nurses' clinical withdrawal assessments was mainly predicated on parental enquiry rather than nurses volunteering information. One father explained *“you'd hear the discussions and so naturally ask what's going on”* (P5F). When parents were informed about the purpose of the withdrawal assessment they reported feeling *“more comfortable”* (P10M) and *“more relaxed”* (P2M) as they were reassured that this was expected behaviour and *“what other children do”* (P2M). One father explained how he found *“it was interesting as a parent to look down the list and keep an eye out for things.”* (P9F).

However, some parents were not informed and felt *“left in the dark”* (P4F) or had to be *“nosey”* (P8M). Not knowing added to the parents' burden and sense of powerlessness as *“it's a scary time for parents”* (P4F) and they would have preferred to have known about the *“score... or what the next stage is going to be.”* (P4F)

### ***Differences in parent-nurse perceptions***

Parents acknowledged that their constant presence at the bedside gave them a different insight to the nurses into their child's behaviour. This was manifested by reporting behaviour the nurse might not have seen; *"you missed this bit where she was happy and singing"* (P1M) or by recognising subtle changes in behaviour because *"they've [nurses] got nothing to compare to, there's no consistency, people can't work 24/7"* (P9F). One mother noticed how her daughter's behaviour altered during the nursing assessment and this might lead to an inflated score;

*"They were saying she was really agitated and he [father] disagreed. I think because nurses are in uniform, she thinks 'what are they going to do?' She would only really become agitated when they were approaching her"* (P1M).

Higher scores, suggestive of withdrawal, may have slowed or stopped the rate of weaning. Conflicting opinions about withdrawal scores were highlighted by some parents who felt the nurse score was higher than their own view. Despite parents feeling the child had had a *"really good day"* (P8M), lack of familiarity with the patient meant the nurse scored behaviours on face value, despite the mother explaining *"he does that anyway, it's just how he is"* (P8M).

### ***Decisions about weaning***

Parents reported their occasional unsolicited participation in decisions about weaning. At times, a partnership approach was described by parents, with evidence of nurses empowering parents regarding decisions to omit sedative drugs. One mother described how the nurse involved her in the decision-making;

*"They started telling me what he [child] was scoring. One night they said 'we're onto '6' and they said 'should we ride it out, should we not?' Whether they*



*were really involving me or not, I felt like they were and I felt like I was part of the decision” (P10M).*

In another example, the parent appeared to instigate the discussion and described the exchange using language suggestive of negotiation and partnership;

*“Last night we [nurse and mother] managed to hold off. She said ‘He’s doing really well, he’s not distressed and he’s asleep.’ So I said ‘If he’s asleep when it’s due and not upset, can we skip that dose and see how he goes?’ The nurse said ‘Yes, that’s great.’ And we managed to do it” (P8M).*

Disagreement about the withdrawal score and subsequent treatment was also reported, due to differences in parent-nurse interpretation of behaviours. When one couple’s daughter was scored higher than they perceived, the mother described how they voiced their opinion *“she’s not a ‘6’ and we want that turning down tonight.” (P1M)*

There was also evidence that parents acted as gatekeepers to stop too many reductions occurring simultaneously. One mother described how she *“started waiting by his bed ready to pounce on anyone if they wanted to change 2 or 3 things” (P10M)*, after her son experienced a *“very bad”* withdrawal and was *“just in a mess really”* after a number of concurrent treatment changes to medication, sedation and respiratory support had made it difficult to determine the cause of his distress. Another mother described the staff as being *“trigger happy”* as she knew *“it takes ages to get out of your system”* and that the frequent reductions which resulted in her son being in *“a right state” (P11M)* were in contradiction to the weaning plan suggested by the pharmacist.

## Parent preferences for participation in withdrawal assessment

The majority of parents (n=10/11, 91%) were receptive to the idea of participating in the withdrawal assessment, qualifying that this might not suit all parents, but *“if parents want to be involved they should be”* (P11M). The parent who did not like the idea of participating felt that being asked about the presence or absence of specific behaviours might *“cause worry to a parent unnecessarily”* (P7M). Other parents felt involvement would help them feel *“competent”* (P1M) and *“comfortable with what’s going on”* (P4F) or *“reassured”* (P6M). One father recognised his involvement might mean *“you can help a lot more”* by contributing to the assessment, but that *“you can’t learn until somebody tells you what’s going on.”* (P4F)

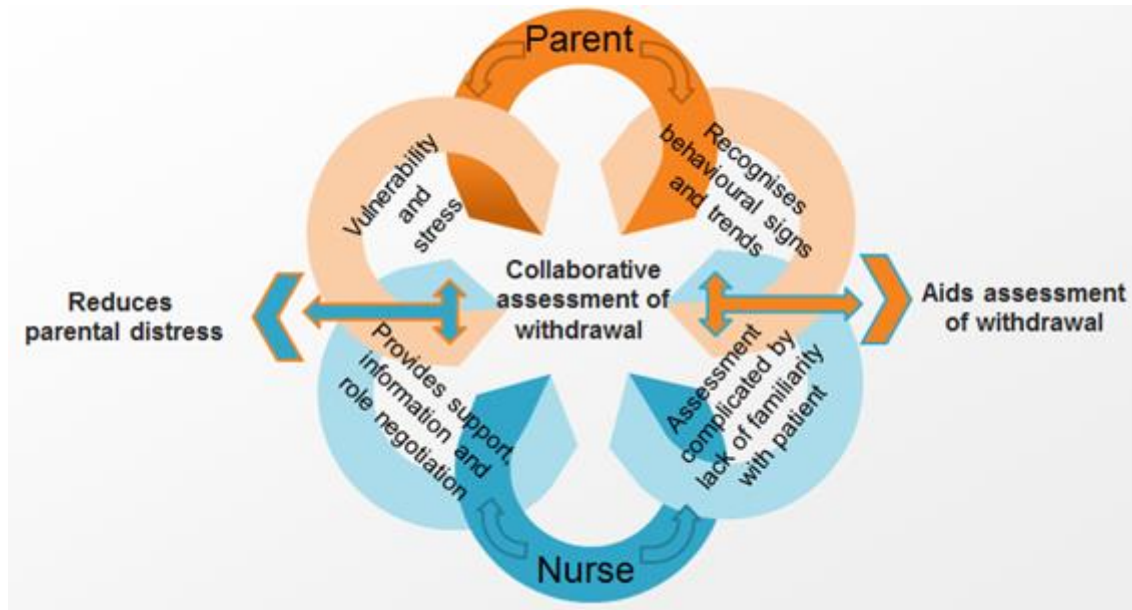
One mother endorsed the value of parental participation succinctly *“I’m not an expert on sedation, but I am on my son [know my son] and that’s the same for every parent, isn’t it?”* (P11M). Parents felt their participation could assist the clinical assessment by establishing *“the norm”* (P8) and assist nurses if they were vigilant and kept *“an eye out”* (P3M) for signs. However, one mother felt the responsibility of participation, expressing concern about the impact of the accuracy of her assessment;

*“I wouldn’t want to score him too high and have someone put something back up that actually we are trying to get him off, or I wouldn’t want to miss something that would mean he should actually have it taken back up.”* (P10M)

Although one parent felt the nurse’s objective view *“is probably better”* (P5F) and another parent recognised that they may have a *“differing opinion”* (P9F) to the nurse, overall a partnership approach was endorsed.

## A model for nurse-parent participation in withdrawal assessment

The finding that most parents were eager to participate in withdrawal assessment prompted further consideration to how the themes and sub-themes might interact to support parents' participation and improve their experiences (Figure 2).



**Figure 2 Proposed reciprocal benefits of nurse-parent collaboration in withdrawal syndrome.**

The model proposes that collaborative assessment of withdrawal should reduce parental distress and promote assessment of withdrawal. This can be achieved if participation and partnership were consistently offered, with nurses providing support and information to relieve parental concerns about behaviours and negotiating a preferred role with parents. Parents may then be empowered to reciprocate with their insights into their child's behavioural signs to enhance the nursing assessment and aid the assessment of withdrawal. This role may also offer an alternative channel for parents to maintain their nurturing role during their child's recovery from critical illness.

## Discussion

This is the first study to describe the parents' perspective of their child's withdrawal syndrome, illuminating the emic perspective, which is "silent in healthcare literature" (Spiers 2000, p126) and revealing the reciprocal benefits of nurse-parent collaboration. While this study aimed to identify a role for parents in sharing their unique knowledge of their child to benefit withdrawal assessments, this contrasted sharply with the dearth of communication that parents received about withdrawal. Parents did not feel adequately prepared for the signs of withdrawal their child might develop, despite studies over the last two decades showing that parents on PICU value being kept up to date with their child's condition, having explanations for the behavioural changes they see in their child (Seideman et al 1997), being reassured of the normalcy of their child's behaviour (Ames et al 2011) and being prepared for what to expect as the child's condition progresses (Shudy et al 2006).

Parents recognised behaviour changes in their children and were eager to contribute their unique and informed perspective to the withdrawal assessment. However, parents' experiences of involvement and participation were generally passive with unspoken and consequently unmet information needs; a deficiency which is described as "one of the most significant barriers" (Joseph-Williams et al 2014, p303) to participation in shared decision-making. Sharing information and making decisions with parents are two principles of FCC, along with hearing parental voices, individualising communication and negotiating roles (Richards et al 2017). Participation and partnership were not consistent features of the parent experience. Although parents felt confident to give an opinion about their child's behaviour, this information was not routinely elicited by nurses. That these principles were not consistently evident in the parents' accounts is contrary to the established clinical perspective

that nurses elicit parent views during withdrawal assessment (Harris et al 2016, Ista et al 2013).

One limiting factor may be the interplay in communication styles between different nurses and parents. Nurses may not realise the extent to which their communication style regulates parent participation (Mikkelsen et al 2011, Corlett and Twycross 2006). In this study parental participation appeared to occur when parents were assertive communicators: the enabling onus appeared to be on the parent rather than the nurse. Parents with a passive communication style are effectively waiting for permission, or a cue, from the nurse to participate (Joseph-Williams et al 2014), whereas nurses may inadvertently assume they do not have questions or do not want to participate. Highlighting this potential power imbalance emphasises the nurses' role in empowering parents by proactively providing information, listening to parents and respecting their concerns; a process which promotes parent participation in decision-making (Eldh et al 2006, Peek et al 2009).

Another factor in suboptimal communication may be the differing extent to which nurses recognise and value parents as an important source of information about the child (Mikkelsen et al 2011). In the nurse-parent relationship, recognition of the other's expertise is the foundation for a partnership and collaborative approach (Lundqvist and Nilstun 2007). The nurses' expertise in assessing critically ill children contrasts with the parents' expertise about their child, which may be viewed as nurses "knowing children" and parents "knowing their child".

Contrary to the view that parents in PICU are too overwhelmed to participate in their child's care (Campbell-Yeo et al 2008), this study demonstrated that, in addition to being willing participants, parents offer a unique perspective to complement the clinical assessment of withdrawal. Although parental participation in care is widely advocated, in practice this ranges

from a passive role (Glasper 2015, Franck and Callery 2004, Simons et al 2001) in which they resume aspects of their usual parenting role (Ames et al 2011, Latour et al 2005, Seideman et al 1997) through to participation in clinical assessments (Carter et al 2002), decision-making (Lipstein et al 2012) and clinical rounds (Muethling et al 2007, McPherson et al 2011). This study shows that parental participation may enhance the clinical assessment of withdrawal due to the consistent and consoling nature of parental presence and also due to their unique knowledge of the child. Parents recalled how their reassuring presence at the bedside contrasted with the nurses' intermittent assessments which induced apprehension or unease in some children. Accordingly, nurses were more likely to observe behavioural distress, which if perceived as withdrawal may have delayed weaning of sedation unnecessarily. Similarly, the parent perspective contributed reassurance when behaviours represented an improving trend thereby also prompting continuation of weaning and reduced the risk of unnecessary delays.

As some parents noted, partnership may not suit all parents and parents' preferences for participation in care may vary during the course of their child's PICU admission depending on both personal and situational factors. In keeping with the philosophy of FCC and the mutual benefits of reciprocal communication, it is imperative that nurses establish and review a level of participation that meets the expectations of parents (October et al 2014).

Even though this is the first study to examine parents' perspectives, there are a number of limitations to acknowledge. This was a small exploratory study in a single institution. There is a risk of bias as parents self-selected for interviews, which may have resulted in parents who were more distressed with withdrawal and other aspects of the PICU experience, agreeing to take part. The researcher may have been known to the parents, which may have biased parents' responses, although the study did not relate to aspects of care overseen by the

researcher. However, a strength of this study is that interviews were undertaken as soon as weaning was completed, to minimise the parents' recall bias.

## **Conclusions**

Illuminating the parents' perspectives has shown that withdrawal signs are a source of distress for parents due to uncertainty about the meaning of the signs and their impact on both their child's immediate and long-term recovery. Participation in withdrawal assessments was viewed as a positive potential role by most parents. Enabling parental participation in withdrawal assessments may prompt a two-way flow of information epitomising family centred care; providing a timely flow of information and reassurance to parents and aiding nurses understanding of the child's behaviours and increasing confidence to continue weaning. More research is needed to understand factors limiting nurse-parent collaboration.

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