RESEARCH ARTICLE

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Between hope and disillusionment

ECMO seen through the lens of nurses working in a neonatal and paediatric intensive care unit

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Abstract

Background: Using extracorporeal membrane oxygenation (ECMO) in paediatric and neonatal intensive care units (PICU/NICU) creates ethical challenges and carries a high risk for moral distress, burn out and team conflicts.

Aim: The study aimed to gain a more comprehensive understanding of the underlying factors affecting moral distress when using ECMO for infants and children by examining the attitudes of ECMO nurses.

Methods: Four focus groups discussions were conducted with 21 critical care nurses working in a Swiss University Children's Hospital. Purposive sampling was adopted to identify research participants. The data were analysed using reflexive thematic analysis.

Results: Unlike "miracle machine" stories in online media reports, specialized nurses working in PICU/NICU expressed both their hopes and fears towards this technology. Their accounts also contained references to events and factors that triggered experiences of moral distress: the unspeakable nature of the death of a child or infant; the seemingly lack of honest and transparent communication with parents; the apparent loss of situational awareness among doctors; the perceived lack of recognition for the role of nurses and the variability in end-of-life decision-making; the length of time it takes doctors to take important treatment decisions; and the resource intensity of an ECMO treatment.

Conclusion: The creation of a multidisciplinary moral community with transparent information among all involved health care professionals and the definition of clear treatment goals as well as the implementation of paediatric palliative care for all

paediatric ECMO patients should become a priority if we want to alleviate situations of moral distress.

Relevance for Clinical Practice: The creation of a multidisciplinary moral community, clear treatment goals and the implementation of palliative care for all paediatric ECMO patients are crucial to alleviate situations of moral distress for nurses, and thus to improve provider well-being and the quality of patient care in PICU/NICU.

KEYWORDS

decision-making, ECMO, ethics, neonatology, nursing

1 | INTRODUCTION

Invasive treatments in paediatric and neonatal intensive care units (PICU/NICU) put a heavy burden on medical staff and evoke ethical discussions about resources, doing good and omitting harm.[1–3] This is particularly true for extracorporeal membrane oxygenation (ECMO),[4,5] a life-saving support tool, initially pioneered for neonates, but currently used to support patients of all ages.[6] It is most commonly used in the case of respiratory and cardiorespiratory failure and is provided in intensive care settings. Although ECMO takes over the job of the heart and the lungs, allowing them to rest and recover, ECMO cannot directly cure the underlying disease. This is why it has been called a bridge to recovery, to decision, to transplant or to long-standing cardiac support.[7–9]

2 | BACKGROUND

ECMO is used for an expanding number of conditions and indications, including severe forms of COVID-19.[6,10] Furthermore, important technological advances have considerably increased its safety and efficacy.[11] Despite these improvements, ECMO remains surrounded by outcome-related uncertainty given the challenging risk–benefit ratio. Its use is associated with high morbidity (e.g. major neurologic injury, neurodevelopmental and functional problems, seizures) and mortality rates both because of the underlying disease and the potential for severe complications (e.g. haemorrhage, thromboembolic events, infections) that might occur while being on ECMO.[12–15] Moreover, although ECMO is not meant to be a destination, but to provide transient support for recovery or transplantation, for some patients it becomes a "bridge to nowhere" (i.e. to no recovery), as has been testified by a case report on a 17-year-old boy with cystic fibrosis who was no longer eligible for a lung transplant and remained confined to the ICU without the possibility to recover.[16] Currently, there is a robust debate in the literature on whether it is always ethically appropriate to continue ECMO in a bridge to nowhere scenario.[17,18]

Because of the complicated nature of ECMO, a multidisciplinary team consisting of trained specialists (e.g. ECMO nurse, critical care physician, surgeon, perfusionist, respiratory therapist, cardiologist, etc.) is needed to guarantee safe care nand positive outcomes. The highly specialized staff, the 24/7 intensive bedside care, together with

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What is known about the topic

- Using ECMO in PICU/NICU creates ethical challenges and carries a high risk for moral distress, burn out and team conflict.

What this paper adds

- A. Important triggers of moral distress for ECMO nurses in PICU/NICU are:
- (1) Perceived unspeakable nature of death in infants and children.
- (2) Perceived injustice and credibility deficit of nurses' role at the bedside.
- (3) Perceived epistemic injustice towards parents.
- (4) Perceived lack of situational awareness.
- B. The creation of a multidisciplinary moral community and the establishment of clear treatment goals are needed to mitigate moral distress among ECMO nurses (and other health care professionals).

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frequent testing and treatment, make ECMO not only an invasive, but also a very resource-demanding procedure.[11,19] Also, being a scarce and expensive tool, ECMO leads to ongoing concerns about fair resource allocation decisions. Other pressing ethical challenges regard the initiation, duration and withdrawal of ECMO in addition to respect for patient autonomy, consideration of long-term quality of life and societal repercussions.[20,21]

Within the neonatal and paediatric context, many of these ethical dilemmas are further exacerbated as many key bioethical principles (e.g. autonomy, decision-making, informed consent) are more difficult to apply because of children's evolving capacities and their inability to provide voluntary informed consent for treatment. Paediatrics turns bioethics, as it were, on its head[22]: the traditional (dual) patient–physician relationship is mediated by a third party and decisions and treatment goals are re-evaluated in line with both parental and patient values and needs.[16,17] However, in the case of ECMO, research shows that providers primarily prefer physician-led decision-making as they consider ECMO a too complex, resource-intensive and scarce medical

therapy to let less knowledgeable patients or surrogates make decisions.[23] Parents, on the other hand, often seem to feel powerless in the decision-making process because although, theoretically speaking, they provide consent for ECMO, many feel as if they do not really have a choice as there is no time to consider other options.[24] Moreover, although shared decision-making is a guiding goal of critical care, there is a paucity of decision-making tools or guides for communicating with families on ECMO.[25,26]

Additionally, ECMO decisions are often taken under time constraints and high acuity, based upon uncertain prognostic factors and limited data regarding survivor outcomes and in the absence of clear clinical parameters that define criteria for a failed ECMO trial.[27–29] As a result, disagreement among providers and between parents and clinicians might arise about the initiation and timing of decannulation or withdrawal of ECMO.[28] These differences of opinion in turn might give rise to decisional regret among family members and moral distress for the health care team.[28] Moral distress may cause compassion fatigue, burnout and staff turnover and can thus severely affect provider well-being[*] and the quality of patient care in the intensive care setting.[31] Existing evidence on the moral distress among ECMO specialists is mostly limited to quantitative research measuring the level of moral distress and possible correlated drivers.[32,33]

Throughout the article, following Campbell and colleagues,[32] we understand moral distress in relationship to a situation that is perceived to be morally undesirable. Unlike the traditional view, moral distress is thus not restricted to situations in which one knows what is the morally correct thing to do, but is inhibited from doing so. We understand moral distress in a more open-ended sense; it can include any type of moral event, that is, cases of moral uncertainty as well as situations that are morally good, but considered sub-optimal.[†] A similar—broad—definition has recently been used by Morley et al.[33,35] to understand and respond to moral distress in nursing practice.

2.1 | Aims and objectives

This study aimed to gain a more comprehensive understanding of the underlying factors affecting moral distress, with a specific focus on the nursing profession as ECMO nurses report higher levels of moral distress compared with other health care providers.[33] In particular, we aimed (1) to explore nurses' attitudes (i.e. the way in which they think and feel about something) on the use and purpose of ECMO in PICU/NICU; (2) to identify and describe the ethically challenging situations they encounter; and (3) to explore key challenges in managing these situations from a nursing perspective.

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*When using well-being, we refer to the WHO definition as a state in which the individual realizes their own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to their community.[30]

†With morality/moral/morally correct, we mean to refer to what nurses hold up to be the basic ethical aims and values (i.e. respect for autonomy, beneficence, nonmaleficence, justice, keep promises, and veracity) of their role as a health care provider who cares for patients and their families. For the definition of moral event, we refer to the work of Morley[34]: «'Moral event' could be any/combination of the following: moral tension, moral conflict, moral dilemma, moral uncertainty or moral constraint».

3 | METHODS

3.1 | Research design and theoretical foundation

A descriptive qualitative study was developed to gain data on the nursing perspective on the use of ECMO in the PICU/NICU setting in Switzerland. We followed the qualitative philosophy of Braun and Clarke's reflexive thematic analysis (RTA), a six-phase interpretative, non-positivist approach to data analysis that rejects the idea that meaning is fixed in the data.[35] We further embraced a constructionist epistemology; this means that although recurrence was important for code and theme development, meaningfulness was considered more central in the coding process. We also took on an experiential orientation to data interpretation; analysis was inductive and codes predominantly semantic.[36]

3.1.1 | Research setting

The research took place in a Swiss University Children's Hospital. In Switzerland, ECMO centres with single-separate paediatric and single-separate neonatal ICU do not exist. Thus, only mixed NICU/PICU centres, with approximately half neonatal patients, provide ECMO.

3.1.2 | Participant selection and recruitment

Eligible participants were critical care nurses having at least 2 years of ECMO experience in a NICU/PICU centre. Purposive sampling was used to recruit the participants. As this is a qualitative study, no representative or randomly selected samples were pursued because those samples are neither necessary nor appropriate.

Nurses were approached by email by one of the researchers to participate in the focus groups. Nurses who expressed interest in participating received the participant information sheet from a member of the research team via email. They received it immediately after recruitment and then again (as a reminder) some days before the actual date of the focus group discussion to give them enough time to read over it.

3.1.3 | Data collection

The data for this manuscript come from four focus groups with ECMO nurses. Because of their interactive nature, focus groups enable access to data that might be less easily obtained through one-to-one interviews as some thoughts can only be probed within a group context.[37,38] Four group discussions is a number that is considered to be effective to capture about 90% of relevant themes.[39] The total number of participants for each discussion varied between four and six nurses. Given the focus on a specific topic and the experience of the research participants, this number is adequate to gain different perspectives, but at the same time give everybody enough space to

speak.[38] The focus groups took place between June and November 2015. Focus group discussions were conducted by a physician with a doctoral degree in bioethics and a medical student and took place at the Children's University hospital in Switzerland at a time agreed upon by all participants. Written informed consent was sought from all participants prior to the start of the focus group. At the beginning of the discussion, the moderator briefly restated the purpose of the overall project, their role in the project and allowed participants to ask questions.

Focus group discussions were unstructured and started with the open question "What do you think about the use of ECMO in PICU/NICU?" The moderator only stepped in to ask for clarification or to encourage participants to further elaborate on their viewpoint in order to answer the main research question. The list of follow-up questions (e.g. regarding ethical complications and multidisciplinary team collaboration) was built on data obtained from individual interviews with ECMO experts (on average 5 years), experiences of the research team, expert opinions and by reviewing the existing literature on the topic. One pilot focus group discussion was conducted to verify the adequacy of the follow-up questions. The four focus groups lasted between 20 and 48 min and took place in person at the hospital in a conference room, which was especially booked for the focus group discussions to avoid interruptions.

3.1.4 | Data analysis

To facilitate qualitative analysis, all the discussions were tape-recorded and transcribed verbatim in the language of the interview (German). The focus group transcripts were checked for accuracy by two researchers (JS and JJ) and transferred into the qualitative analysis software ATLAS.ti 2011 to support the analysis process. To analyse the data, we opted for reflexive thematic analysis.[35] To enhance data familiarization, we first read the transcripts several times. In the next step, three authors (JS, EDC and JJ) coded the data based on a close line-by-line analysis and examined the codes to identify potential themes. Afterwards, to complete comparative analyses of individual findings and to ensure credibility, the three team members refined their respective categories and provisional themes by discussing and checking them against the dataset.

Sub-themes were added and similar ones were combined whenever they shared the same organizing meaning. The last step of the analysis consisted in generating clear definitions and names for each theme. Finally, the last author reviewed the group-level thematic taxonomy from the perspective of each individual participant to see which themes represented and did not represent the individual's account to identify both differences and commonalities among participants.

3.1.5 | Rigour and quality criteria

Lincoln and Guba's trustworthiness criteria of credibility, transferability, dependability and confirmability were adopted to ensure rigour in

TABLE 1 Participant characteristics.

Participant	Gender	Age	Years of experience PICU/NICU
1	F	31	5
2	F	35	9
3	F	28	2
4	M	34	8
5	F	26	2
6	F	52	25
7	F	29	4
8	F	41	14
9	F	48	23
10	F	29	4
11	F	33	7
12	F	45	19
13	F	31	5
14	F	32	6
15	F	28	3
16	F	42	16
17	F	51	22
18	F	35	9
19	F	31	6
20	F	47	18
21	F	27	3
	Average	36.0	10.0

qualitative research.[40,41] Credibility was obtained by the moderators' familiarity with the research setting, the flexibility of the open-ended interview procedure, the investigators' skill in data collection and analysis and the multidisciplinary background of the authors (i.e. paediatrics, ethics, philosophy, emergency medicine). To ensure transferability, we achieved data saturation. Dependability was reached through researcher triangulation and thick description. Confirmability was obtained through reflective debriefing by the researchers during data collection and analysis.

3.2 | Ethics approval

The study was approved by the Ethics Review Board of the University of Zurich. Study participation was entirely voluntary, and participants could withdraw from the study prior to data anonymization. The privacy of research subjects was ensured by maintaining confidentiality of the answers collected from research participants and by anonymizing any identifying data they provided.

4 | FINDINGS

A total of 21 critical care nurses working in a Swiss Children's Hospital participated in the study. All participants had experience working with

TABLE 2 Participant quotes.

a) ECMO narratives: between solutionism and threat

a.i. Life-saving treatment

Nurse 1 (FG4): In many cases, I think it is helpful and vital, (...) it is a form of therapy that can save lives, and with which we have saved lives, (...) I just think you have to use it in a considerate way.

Nurse 5 (FG1): it is diagnosis-dependent, because we have very different experiences. So, with the cardiac patients we actually have very poor outcomes, with pulmonary ones relatively good outcomes, and in the case of sepsis even very good outcomes.

Nurse 2 (FG2): that's why we have less trouble with patients who get a lung ECMO, so with a meconium aspiration or with a sepsis, because they can go home again, cured, at least so in our imagination.

a.ii. Buying time

Nurse 1 (FG2): a toddler under resuscitation where you don't know at all what the current problem is (...) you just have to somehow bridge the time a bit to diagnose the underlying cause (...) or sometimes you do not want to take a difficult decision, and therefore quickly put the child on ECMO to save time, and then (...) especially with children who have meconium aspiration or who have fulminant sepsis, who also have a good outcome, it is comprehensible [to put them on ECMO] for us, absolutely, but (...) if the goal can't be defined then you can't stand behind it, I think.

Nurse 1 (FG1): so we really had that a few times that you actually know that ECMO won't bring much; just really do it to gain time or (...) you have to do it because there is just this technical possibility.

Nurse 1 (FG4): ... quickly on ECMO to gain time, I'm all for that, but then you have to think just as quickly about what diagnostics you still need, what to do next and so on, and not that (...) we are dragging ... that's what gives me a lack of orientation where I say, 'What do we actually want? Where do we want to go? Do we really have a chance?

a.iii. No clear tipping point

Nurse 3 (FG1): if the operation was long or something, and you say you will wait for another 3 days to see what happens and then you stop, for example, that is fine, but if you do it for 10 or 14 days, and even longer, (...) I find this problematic, the question is how far do you go and when do you reach the point where you say now we have done everything what is possible with this technique.

Nurse 2 (FG 4): so many disciplines are involved and then you are maybe at a point where the cardio surgeon says, "I can't do anything anymore, we have to stop"'; the senior physician in charge also thinks "well then we'll stop" and then someone else from cardiology comes and thinks, "I have a problem with that, we have to do something now". Then I think, for God's sake if the one who operated upon the child says they can't see a way, well he knows (...) how can someone who was on holiday for a week, come and think, "no, we can't [decannulation] we have to do something".

a.iv. A risky enterprise

Nurse 6 (FG 1): I think it [ECMO] is not the solution to the problem; we have so many problems with the child that maybe it helps to bridge something, but I have the feeling that it is often advertised as "yes, nothing helps anymore and this is then like the solution" but you later on you have more problems that come along with it.

Nurse 2 (FG 1): (...) holes are simply plugged, but then new ones open up again, or new ones are created by ECMO, which then leads to an infinite number of other problems. It's like a "rat's tail" that then continues to grow.

b) Moral residue at the bedside

b.i. Initiating ECMO: an ethical decision

Nurse 2 (FG3): basically it is a very good therapy, but it also brings problems with it, especially with regard to ethics.

b.ii. Important factors influencing ECMO decisions

Nurse 2 (FG3): what for me personally is problematic is that these children suffer, that they partly need enormously high analgesia and sedation (...) no movement or activity is possible for the child without that this would somehow impair the ECMO treatment and that for weeks, (...), you have the feeling that you can see the suffering of the children, which is increasing, (...).

Nurse 2 (FG2): which quality of life, well that's important for me (...) what kind of life does the child have then (...) That's the whole problem with very early premature babies, yes 1 out of 10 survives without any disorder, but which out of 10 and what about the 9 others? (...) who, in the end, takes care of the child (...) parents will always do everything for their child, always! (...) what am I doing, of course first and foremost to the child, what kind of life does it have but, also what am I doing to a whole family, how many families break up because of it? Of course they could also break up if you say, 'we'll stop now', but this, this horror without end, this endlessness, I think it's much worse (...) but good quality of life, not everyone understands that in the same way.

b.iii. A matter of justice

Nurse 2 (FG3): the other thing that I find ethically problematic is that ECMO patients require a lot of nursing and a lot of medical resources (...) I don't know if statistically the quality of treatment is worse but it's just that if you have an unstable ECMO on the ward, then it somehow eats up 60% or 70% of the resources which on the one hand reduces the places, which means that patients also have to be transferred externally (...) but also that one concentrates all one's efforts on a situation that has little to no chance.

Nurse 2 (FG4): I find it difficult when one has the impression that the other patients are done too short, so one, focuses on this EMCO (...) they have no chance or a small chance and still everything is focused on it.

b.iv. ECMO withdrawal

Nurse 1 (FG3): well, in my experience nurses are usually far ahead of time, we would always stop about a week before the actual stop (...) but then we are the ones who are still a week at the bedside for 8 hours, (...) the surgeons pass by quickly, look and run away again (...) the last week you have the feeling it no longer works, also the child looks worse and worse, it lies there and, sometimes, you don't know if it's almost a desacralization of death (...) partly you maybe then slowly give up hope in the last few days and then you just simply separate yourself to protect yourself, (...) just

(Continues)

TABLE 2   (Continued)

don't let it get to you because otherwise I think we wouldn't, I couldn't, do it like because I work 90% of the time, (…) sometimes I have the feeling that maybe an outsider might think: "oh, she's hard" but it is actually to protect yourself.

Nurse 6 (FG4): the last ECMOs that we had, were all very frustrating and with many days of ECMO, on average 21 days, and they all bled to death, and you also have to say that all the hours we stand at the bedside nursing, we suffer together with the parents and the child; the surgeons come afterwards to extract the cannula and that's it.

Nurse 2 (FG3): what should certainly not be disregarded is that we have experienced relatively many difficult situations on ECMO (…) that also plays a role every time, so past experiences and memories (…) I personally have trouble getting emotionally involved as deeply with the patients as I did 2 or 3 years ago.

b.v. A loss of situation awareness

Nurse 5 (FG 1): it turns out that actually those who are closest at the bedside can detach and separate themselves from the child and situation more easily than the, let's say, third parties such as cardiologists or cardio surgeons (…) for them it is a pure catastrophe if you consider to stop, and this is also a bit of a paradox in this whole story, because they are not actually at the bedside, I mean not 24 h a day.

Nurse 1 (FG2): We once had a child, it was clear to everyone, it was clear to the doctors that the child would be severely disabled, but they still didn't want to go off ECMO, despite the mother's wish to switch off the machine (…) I somehow have the feeling that (…) they don't see the child any more, they only look at the operational result, they have invested a lot.

Nurse 3 (FG2): For me, to simply address the ethical issue, it is important to ask what can I do first and foremost for the child, and secondly for the parents, (…) it sometimes seems to me as if the doctors need somehow to get a sense of achievement, for themselves, and they look at the situation from this perspective, instead of looking at it from the child's or the parental one.

b.vi. Difficulty of ECMO withdrawal in NICU/PICU

Nurse 2 (FG 1): As a doctor you basically decide about life and death, something that we as nurses don't do, we just share our opinion. It's kind of easy to say: "This does not make sense anymore" and "what are we actually doing here?" But if you have to take the final decision and give the command to stop the treatment, this is of an entirely different calibre.

Nurse 4 (FG1): someone once told me that death is definite, there is nothing afterwards, (…) I think for many it is (…) the fear of having missed something or of having not seen something diagnostically that could still be offered to this child (…) I think that's probably in the foreground for many physicians.

b.vii. Lack of transparency with parents

Nurse 2 (FG3): When in the interdisciplinary conversation it is actually clear between the lines (…) that there is a very low possibility [to save the child], but this impression is often not communicated to the parents so directly. This makes it difficult for me, when I personally know that the survival rate is in the range of 5% but the parents actually expect much higher chances (…) the parents are often given hope, whether that is somehow on purpose or simply results from the word choice in the conversations, parents have illusory hopes, for a very long time. (…) when you die on ECMO, then it doesn't usually look very nice, as far as complications are concerned, parents are often very poorly prepared, and (…) several times I have hear from parents that if they had known it meant and how it would look like, they wouldn't have done it.

Nurse 3 (FG 1): Just a short while ago, parents told me again: "we wish we would not have been offered [ECMO], because then it had been clear 3 weeks ago, and the child didn't need to bleed to death, we would have let them go 3 weeks ago as normal beautiful baby and not as a monster". This is pretty hard if parents are telling you things like this.

b.vii. cont.

Nurse 2 (FG2): we sometimes disagree with other disciplines, or with other specialists who say "well, they can't do competitive sports" (…) I can't do competitive sports either, but I think I have a different quality of life than a child with hypoplastic left heart syndrome (…) a comparison is drawn, where I then also think as a parent, "well, competitive sport, not everyone is able to, but otherwise everything is normal". That is for me then also an ethical issue that I give parents the feeling that everything is easy and, that's just not true.

Nurse 1 (FG2): Then you have to talk to the mother on clear terms, and not always have a nice conversation but a realistic one about what that means afterward to have severely disabled child at home.

(c) In search of a moral community

c.i. MDT affect communication with parents

Nurse 5 (FG3): I think the problem is often that there are different disciplines that are involved: there are the intensive care physicians, the cardiologists and the cardio-surgeons, and it is often the case that one of these three is not yet ready to stop or, and then one continues for another day or more (…) I think if they were come to an agreement in a case where one really knows that continuing does not make sense anymore, then there would be no dilemma (…) but often they are not in agreement, but you have to be in agreement before you can go to the parents and say how to proceed, you have to be in agreement in the team, otherwise it just doesn't work.

c.ii. MDT affects communication among health care professionals

Nurse 2 (FG2): we are perhaps not informed about what new surgical techniques are out there now (…) we are simply kept in the unknown, it [ECMO] is simply done and then of course we ask ourselves the question, "does it make any sense at all?"(…) when you say: "we have to sit down together ethically"; we don't dare to do that anymore, it costs an incredible amount of force because you know exactly what the person in front of you thinks, namely "they want to turn it off", but that's not what it's about for me, we are basically put off.

Nurse 3 (FG2): I have the feeling that ethical discussions, although it would actually be a super good thing, have gotten a negative meaning, not among us nurses, but among the doctors, and they also bring it across to us in a very negative way: "you can't cope and that's why you want to stop now" and it's actually about something completely different, you actually want to support the parents and the children.

Nurse 1 (FG 2): they have also said that we are too emotional, (…) to say "we're going to stop now", no one dares to do that and it's always us, (…) the ones who don't pull themselves together, who somehow are unable to take distance.

TABLE 2 (Continued)

Nurse 6 (FG4): it is sometimes said (…) "there is the angel of death again" (…) just because we ask "is there perhaps a palliative option for this patient to live a high quality life at home for maybe 5 years instead of bleed to death here after 21 days".

c.iii. The need for a shared mental model among healthcare professionals

Nurse 2 (FG2): "If one would do it earlier and ask "where do we want to go" and which way do we want to go" (…) but also "how far do we go" that would probably give everybody e a common goal, (…) they decide and then we do it, and that is it. We are not enough involved enough in the process, so I don't want to be involved in the decision-making, but I want to be involved in the process so that I understand what is actually planned and when I have understood that, then (…) I can also stand behind it much more, but if I am left out, (…) then I row against something and it stresses me (…) I do a big part of the work, so why am I not asked about what I think, I can perhaps contribute (…) I think we have to learn again to trust each other more in the team and not to play off against each other for whatever reason. We are a team and that strengthens us.
Nurse 1 (FG 2): I also think that if all the doctors would agree and then make a decision together "ok, we'll give the patient 10 days, depending on the complications, and then we'll stop. If it would be limited in time, that would be easier for us to work, but also for the parents.
Nurse 6 (FG4): if you make a timetable and really say "ok, we put everything in balance, what can we do?" If you communicate this clearly, as if you determine and say when everyone is present, "1 week or 10 days, depending on the situation, it is always individual, "let's try and then we stop", that would reduce this tension.

ECMO, with a professional experience ranging from 2 to 25 years (see Table 1).

Analysis of the focus groups resulted in three major themes: (1) ECMO narratives: between solutionism and threat; (2) moral residue at the bedside; and (3) in search of a moral community. Representative quotes were taken from the various focus groups (using numbering to identify the various participants and focus groups) to illustrate the reported results. All quotes were translated from German into English, and translations were checked for accuracy.

4.1 | ECMO narratives: between solutionism and threat

Most nurses considered ECMO to be a life-saving and meaningful treatment, but under certain conditions. For many of them, the type of disease, a favourable prognosis and a long-term functional outcome were essential in this regard. Overall, ECMO was considered more appropriate in patients with pulmonary conditions than in those with heart failure (see Table 2.a.i.).

> That is why we have less trouble with patients who get a lung ECMO, so with a meconium aspiration or with sepsis, because they can go home again, cured, at least so in our imagination
>
> (Nurse 2, FG2).

Another important way of describing ECMO was in reference to time. Several nurses highlighted that the treatment allows the medical staff to "buy time" and thus to prolong life. "We really had that a few times that you actually know that ECMO won't bring much; just really do it to gain time or (…) you have to do it because there is just this technical possibility" (Nurse 1, FG1). Participants' evaluation of this extra time, however, was goal dependent, that is, they considered this extra time to be positive if it enables the health care team to identify the underlying medical problem or to offer patients a bridge to a life-saving treatment; they perceived it more negatively whenever ECMO is used as a kind of last resort without clear purpose, or just because it is medically feasible (see Table 2.a.ii.).

Many nurses also raised the critical question of *how much* time is needed: « When you start ECMO, the problem often is that you don't find the exact time point at which to say: "now we stop"». (Nurse 4, FG3). The majority of participants expressed concern about this continuous postponement of decannulation and lamented the fact that at the last moment doctors often come up with new ideas to "save" the child and defer withdrawal (see Table 2.a.iii.).

The inherent risk of constant deferral to stop ECMO led to a more critical and even pessimistic perception of ECMO: instead of being life-saving, initiating ECMO is seen as deeply problematic and even a risky enterprise.

4.2 | Moral residue at the bedside

All ECMO nurses experienced moral uncertainty: they asked the question of whether initiating an ECMO run is always the ethically appropriate decision to make (see Table 2.b.i.): "It is a very good therapy, but it also brings problems with it, especially with regard to ethics" (Nurse 2, FG3).

Important factors for them to consider included survival rate, but especially quality of life. The participants focused on the child's current suffering (i.e. medication, immobility, etc.) and on the long-term outcome for the patient. In addition to the best interest of the child, they also took into account the profound impact of the child's health status (e.g. functional disabilities, neurological complications) on the well-being of parents and other siblings because of the high care burden. At the same time, they recognized that quality of life is difficult to define and might mean different things depending on the individual or family situation (see Table 2.b.ii.).

Some nurses also reflected on the broader implications for justice. They were worried that the resource intensity of ECMO treatments might negatively affect the quality of care of other patients on the ward. The complexity of care required by an ECMO patient, in fact,

reduces the time nurses can dedicate to other patients, with the result that they might not be able to fulfil all nursing care requirements and need to transfer these other patients to other hospitals (see Table 2. b.iii).

> I find it difficult when one has the impression that we fall short on caring for other patients. One, focuses on this EMCO patient (…) they have no chance or a small chance and still everything is focused on it
>
> (Nurse 2, FG4).

If the question whether or not to start ECMO was subject to moral uncertainty, many interviewees seemed to be more decisive about the question of when to stop ECMO. They reported that by being at the patient's bedside they gained a better understanding of the child's deteriorating health compared with the physicians who make the actual treatment decisions but just drop by once in a while. The nurses highlighted that in some cases decisions to withdraw ECMO are made too late, that is, when there is no doubt about the child's overall deteriorating health condition and there is no hope for recovery. They considered this to be deeply morally problematic and encountered an interior conflict: on the one hand, they were moved by the situation and felt the need to be the child's and parents' advocate; on the other hand, they perceived the necessity to take distance in order not to get emotionally overwhelmed. Witnessing the suffering of the child and the grief of the parents without the possibility to intervene made them feel powerless and emotionally drained. Some nurses also reported that high levels of moral engagement during previous bad ECMO runs had had an impact on their current attitudes towards treatment continuation and patient involvement and resulted in emotional distancing (see Table 2.b.iv.).

> The last ECMOs that we had, were all very frustrating and with many days of ECMO, on average 21 days, and they all bled to death, and you also have to say that all the hours we stand at the bedside nursing, we suffer together with the parents and the child; the surgeons come afterwards to extract the cannula and that's it
>
> (Nurse 6, FG4).

Some interviewees were very critical about doctors' inability to stop treatment, especially if they considered this hesitancy to be the result of a loss of situation awareness. They lamented that physicians are often blinded by a kind of tunnel vision: they focus on only one aspect of care, but disregard the family situation and the child as a whole. A few nurses were also concerned that specialists are sometimes more driven by their own personal interests and their inability to accept their own fallibility. They were afraid that doctors continued treatment in order not to face any personal defeat (see Table 2.b.v.): "It sometimes seems to me as if the doctors need somehow to get a sense of achievement, for themselves" (Nurse 3, FG2).

Some interviewees, however, recognized that although survival chances might be very low, it is not easy for physicians to be accountable for decision-making and that ECMO withdrawal remains controversial, especially in the case of infants and children. The fear of not having tried everything to save the child's life might be a haunting experience. It should not be forgotten, in fact, that unlike nurses, doctors actually decide about life and death because once ECMO is stopped there is no way back (see Table 2.b.vi.).

Despite acknowledging this difficulty when making decisions of withdrawal, several nurses believed it was morally problematic that the parents were not properly informed about the concrete survival chances of their child, or about the severe complications that might occur while being on ECMO. In their view, this false hope often misguided parental decision-making and afterwards had a severe negative impact on how parents' experienced their child's death (see Table 2.b. vii.): "parents told me again: we wish we would not have been offered [ECMO] (…) we would have let them go as normal beautiful baby and not as a monster" (Nurse 3, FG 1). But even in those cases when the ECMO is successful and the child survives, some participants believed that parents did not receive a realistic understanding of the child's future quality of life and its impact on family life. They found this lack of communication ethically troublesome (see Table 2 b.vii. cont.).

4.3 | In search of a moral community

According to some participants, the lack of communication with parents could be partly attributed to the multidisciplinary team approach (MDT) in the case of ECMO. Because of the involvement of different clinicians with different areas of specialization, disagreement is common and further complicates the possibility of transparent communication with parents. They highlighted the importance of coming to a medical consensus before approaching the parents (see Table 2.c.i.).

Many nurses emphasized that there were not only disagreements among the doctors, but also between the nurses and the physicians, especially then with regard to the contentious issue of when to stop ECMO. Some of them believed this divergence was because of the fact that nurses might not always understand the full picture and are not properly informed, but instead kept in the "unknown" about potential treatment options or new surgical interventions. Some of them, however, reported that physicians sometimes adopt a rather defensive and even hostile attitude towards the nursing staff. "There is the angel of death again" (…) just because we ask «is there perhaps a palliative option for this patient?» (Nurse 6, FG4). Nurses perceived an unwillingness of doctors to listen to them or engage in honest ethical discussions with them. Furthermore, a few of them felt unjustly accused for being too emotional, whereas in their view, they were merely being the family's advocate (see Table 2.c.ii.).

In order to release some of this tension, participants thought it to be important for doctors to use clear diagnostic criteria for ECMO initiation, to constantly re-evaluate these indications and to set transparent timetables for ECMO withdrawal so that everybody shares the

same mental model. Some nurses also wanted to be more involved in the decision-making process and to be listened too in order to re-build positive team relationships among the various professional figures (see Table 2.c.iii.): "I think we have to learn again to trust each other more in the team and not to play off against each other for whatever reason" (Nurse 2, FG2).

5 | DISCUSSION

Using an invasive and resource-intensive technology with uncertain outcomes like ECMO in PICU/NICU creates ethical challenges and carries a high risk for moral distress, burn out and team conflicts.[2,3] The present study offers an important contribution to the existing literature on ethical dilemmas and moral distress when using ECMO for infants and children by examining the attitudes of ECMO nurses.

Our study results highlight that unlike the "miracle machine" and "heroic rescue" stories in online media reports on ECMO,[42] specialized nurses offered much more nuanced accounts of ECMO: accounts that are not pervaded by an unfounded optimism, but take into account the different potential implications of this intervention. Although participants recognized ECMO's promising capacity to prolong life, provide time for diagnosis, and recovery or clarification of prognosis, they also acknowledged its limitations: they reported that the "gift of time" is often ambiguous and can even become harmful if treatment is protracted without any clear purpose or goal. Diagnosis, presumed prognosis and perceived potential future quality of life in combination with previous experiences with ECMO runs influenced nurses' assessment of ECMO initiation decisions. Overall, participants' accounts of ECMO became more pessimistic when discussing withdrawal in the case of an unsuccessful ECMO course.

Nurses' accounts of ECMO not only conveyed their hopes and fears towards this technology, but were also strongly intertwined with reports of events that triggered experiences of moral distress. An important—unavoidable—factor contributing to moral distress was the PICU/NICU setting itself. Participants, in fact, recognized the moral dilemma that physicians face when making decisions that limit life-sustaining treatment in the case of children and neonates. This finding is consistent with the existing literature on death and dying in paediatric and neonatal settings.[43] The death of a child or an infant betrays the natural order, and therefore, hope for cure remains the central principle in paediatric medical care, complicating discussions on death and dying.[43]

Still, nurses were concerned that this focus on hope compromised honest and transparent communication with parents about the risks of mortality and morbidity associated with ECMO. Although they recognized that quality of life is highly subjective and dependent on family context, their experience with previous ECMO runs made them wary of illusory hopes of full recovery. As already shown by the study of Morley et al.,[44] this kind of (perceived) epistemic injustice towards families can be an important trigger of moral distress.

Another closely connected factor generating moral distress was the perceived loss of situational awareness on the side of physicians.

Participants reported that physicians risk to lose track of the bigger picture (i.e. child's overall health, family situation) because of their tendency to focus on their own area of specialization or because they are unable to accept their fallibility. As confirmed by other studies,[45] the prospect of a child's death is perceived by many paediatricians as a kind of personal failure. In the literature, doctors' tunnel vision is also linked to the complexity of the health care context and the increased use of innovative medical technologies that risk distancing the physician from the real-life situation.[46] A promising life support system as ECMO is without a doubt exemplary here: it is an advanced technology that is used in high acute medical situations that are in a constant flux and might prevent doctors of gaining a more holistic view of the patient and the family's values and preferences.[27]

For many nurses, physicians' inability to comprehend the overall situation was ever the more frustrating and a source of moral distress when they had the impression that their experience at the bedside was not taken into consideration during decisions to start, but particularly to (dis)continue ECMO treatment. They viewed themselves as being misrepresented, overlooked and at times even silenced when physicians dismissed their concerns about patient suffering by telling them that they were too emotionally involved. Similar feelings of disrespect among nurses and the need for greater appreciation of their role in ECMO care have been reported by previous studies.[47,48] It has further been shown that such episodes of perceived injustice and credibility deficit might increase moral distress.[44]

The final factor contributing to experiences of moral distress was the perceived lack of team situational awareness. This lack was mainly attributed to communication difficulties among ECMO team members. Because of the high number of specialties involved, team collaboration and consensus among clinicians were said to be challenging. Nurses reported that decisions to discontinue ECMO were often arbitrary in the sense that they depended on which physician was on call in a given moment. This inconsistency in practice, or the so-called "roster lottery", has been described as deeply disconcerting for other team members.[44,49]

Participants were also concerned about the confusion it caused to parents if different doctors provide different recommendations. Roster lottery is believed to be more prevalent in cases when patient or family views and values regarding end-of-life decision-making are not well known and in situations where there is sincere uncertainty about the right course of action and standards of care are difficult to define.[49] The latter conditions are all fulfilled in the case of ECMO: the complexity of this technology presents an important barrier for parents to participate in shared decision-making as a full understanding of risks and benefits is rather rare; patient outcome and future quality of life are difficult to predict; and there is a lack of clear clinical parameters defining criteria for a failed ECMO trial.[4,27,28]

In line with Kirsch and Munson,[4] participants were in favour of transparent care plans that determine the goal (e.g. recovery, bridge to bridge, bridge to transplant) of ECMO for each individual patient and re-assess risks and benefits at set time intervals to better align different team members and families. The problem, however, is that nurses reported that they were often kept in the dark about treatment

plans and therefore were unable to comprehend and give meaning to clinical decisions to continue treatment. This often caused moral distress because, on the one hand, they felt the need to advocate on the patient's and family's behalf; on the other hand, they deemed it necessary to take distance from the situation in order not to get emotionally overwhelmed by what they predicted to be an unsuccessful ECMO course.

As suggested by others,[34,44,50,51] difficult moral decisions should not be the role of doctors alone but should rather be informed by the perspectives of a multidisciplinary team, including nurses. Involving nurses in decision-making processes allows them to better understand the care plan, and to improve their work motivation.

6 | LIMITATIONS

Our study has some important limitations. Because almost all participating nurses were female and worked in one single centre in Switzerland, our findings may not be applicable to other care providers, institutions or to other national and international contexts. Moreover, the fact that participants came from the same hospital might have resulted in taken-for granted "party-line" attitudes on ECMO. At the same time, this familiarity allowed participants to challenge the statements of other participants if they were not in line with the actual hospital practice. Also, by adopting Lincoln and Guba's trustworthiness criteria, we believe that some of our results can be useful for other settings with a PICU/NICU situation similar to the Swiss one.

7 | RECOMMENDATIONS OR IMPLICATIONS FOR PRACTICE AND FURTHER RESEARCH

Health care institutions should foster the creation of a moral community that offers a safe moral space for all team members to voice their opinion, a community in which the important role of nurses and other care providers is recognized and physicians can share the burden of responsibility over life and death with others. Furthermore, paediatric palliative care (PPC) should become a standard of care for all paediatric ECMO patients.[52] The involvement of the PPC team can support the ECMO team and the family with setting goals of care and help them to face ethically challenging decisions.[4,52] It would be extremely valuable to explore the viewpoints of other health care professionals in different cultural contexts and to study also the patient and/or family perspective.

8 | CONCLUSION

The study provides unique insight into the attitudes of nurses on the use and purpose of ECMO in PICU/NICU. Our findings show that unlike the "miracle machine" stories in online media reports,

specialized nurses working in PICU/NICU have a different understanding of the risks and benefits of ECMO. Their accounts on ECMO did not only convey their hopes and fears towards this technology, but also contained references to events and factors that triggered experiences of moral distress: the unspeakable nature of the death of a child or infant; the seemingly lack of honest and transparent communication with parents; the apparent loss of situational awareness among clinicians; the perceived lack of recognition for the role of nurses and the variability in end-of-life decision-making; the length of time it takes clinicians to take important treatment decisions, especially if the treatment was considered as not being fully purposeful anymore; the resource intensity of an ECMO treatment. Our findings suggest that the creation of a multidisciplinary moral community with transparent information among all involved health care professionals and the definition of clear treatment goals should become a priority if we want to mitigate situations of moral distress for nurses and other health care professionals. Finally, close collaboration between paediatric intensive care teams, PPC teams and regular ethics consultations is necessary to ensure child-centred and family-oriented care and to reduce moral distress.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT
The study was approved by the Ethics Review Board of the University of Zurich (Institute of Biomedical Ethics and History of Medicine).

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