



Full Length Article

Parent-infant closeness and care practices during therapeutic hypothermia in Swedish neonatal intensive care units

Pyrola Bäcke^{a,b,*}, Anna Axelin^c, Johan Ågren^{a,b}, Ylva Thernström Blomqvist^{a,b}

^a University Hospital, Neonatal Intensive Care Unit, Uppsala, Sweden

^b Uppsala University, Department of Women's and Children's Health, S-751 85 Uppsala, Sweden

^c Department of Nursing Science, University of Turku, Kinakvarngatan 10, 20520 Turku, Finland



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ABSTRACT

Objectives: The aim of this study was to investigate care practices among Neonatal Intensive Care Units (NICU) providing Therapeutic hypothermia (TH), and more specific to investigate staff's experiences of parental participation, presence, and possibilities of being close with their infant during TH.

Methods: A descriptive, qualitative, and quantitative study. All Swedish NICUs providing TH (n = 10) participated. Data were collected during January–April 2021 via a questionnaire followed by a semi-structured interview with the registered nurse and the neonatologist responsible for TH at each unit. Descriptive statistics were calculated, and a qualitative content analysis was performed.

Results: All NICUs allowed parents unlimited stay with their infants and were keen to support parental presence, which was a prerequisite for promoting parent-infant closeness. Standardized routines regarding the infants' care space and course of action were described as time-efficient and staff-saving, which freed up time to focus on the families.

Conclusion: Standardized routines regarding the care space setup and the medical and caring approach, as well as the NICU environment and practices around the families, can promote or curb the possibilities of parent-infant closeness. Well-established care practices and good environmental conditions with flexibility regarding the family's needs are therefore required.

Introduction

Therapeutic hypothermia (TH) is the standard treatment for infants affected by birth asphyxia followed by hypoxic-ischemic encephalopathy (HIE). The incidence of HIE varies from 1 to 3/1000 live births in developed countries to 6–8/1000 live births in low-middle income countries. [1] TH has been shown to reduce both the risk of neurodevelopmental impairment and the risk of mortality. [2] Asphyxiated infants who meet the criteria for TH [3] undergo moderate whole-body cooling for 72 h, followed by slow, controlled re-warming to normal temperature. During treatment, the infant is wrapped in a cooling blanket that adjusts the surrounding environment to ensure that the infant's temperature remains at 33.5 degrees during the 72-hour treatment.

Skin-to-skin care (SSC) has become standard in Swedish neonatal care and is an important element of evidence-based care including stabilizing the infant's physiology, promoting exclusive breastfeeding, supporting bonding, [4] providing pain management [5], and reducing mothers' depressive symptoms. [6] Early initiation is an important factor in the success of SSC and will affect the extent to which the infant is cared for skin-to-skin during the rest of the care period. [7] Along with many medical advantages, SSC is described as an important factor to support the development of motherhood [8] and has also been recognized as an empowering experience that enhances parents' opportunity to bond with their infant. [9] However, the thermal management principles necessary for the success of TH mean that the conditions for promoting parent-infant closeness are radically different, as it is not possible to practice SSC because this would counteract the cooling

Abbreviations: HIE, Hypoxic-ischemic encephalopathy; NICU, Neonatal intensive care unit; RN, Registered nurse; SNQ, Swedish National Quality Register; SSC, Skin-to-skin care; TH, Therapeutic hypothermia.

* Corresponding author at: Department of Women's and Children's Health, S-751 85 Uppsala, Sweden.

E-mail addresses: pyrola.backe@uu.se (P. Bäcke), anmaax@utu.fi (A. Axelin), johan.agren@uu.se (J. Ågren), ylva.thernstrom_bloomqvist@uu.se (Y. Thernström Blomqvist).

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effect.

Striving to avoid separation between the infant and parents after birth and ensuring that parents are integrated into the infant's care are high priority in Swedish NICUs. [10] Parental leave in Sweden entitles both parents of a critically ill infant to unlimited stay with their infant, including financial compensation for this. [11] Previous research has shown that parents of infants undergoing TH want to be well informed, to be actively involved in rounds and the infant's care, [12] and to have the possibility to be close to and interact with their infant. [13] Parents have also expressed how the physical separation and the high-tech equipment and surrounding environment [14] negatively affected their ability to bond with their infant. [12] The "unnatural" treatment given in an unnatural environment made them feel that the infant was not theirs. [15] Also, parents of in-born infants tended to be more present and involved compared to out-borns, and that parents who were able to stay in the NICU were more likely to be present and involved in the infant's care. [16].

The possibilities to prepare parents for the infant NICU stay (by visiting the NICU, giving information and answering questions before the infant is being born) is limited since the asphyxia is unpredictable. In absence of SSC, there has been recent research interest in the "CoolCuddle" protocol, which enables parents to hold their infant wrapped in a cooling blanket during TH. The results so far show that both NICU staff and parents are unanimously positive [17] that the CoolCuddle protocol enhances the parent-infant bonding and has a positive effect on breastfeeding [18] without jeopardizing the treatment. [19] TH aims to improve the infant's cognitive and neural development; and if parental presence, closeness, and participation in care are enabled during treatment, another crucial element to support infant development is secured. [20].

The aim of this study was to investigate care practices among NICUs providing TH, and more specific to investigate NICU staff's experiences of parental participation, presence, and possibilities of being close with their infant during TH.

Methods

Design

The data for this exploratory and descriptive, mixed method study were collected with a questionnaire and semi-structured interviews with NICU staff from January to April 2021.

Settings and participants

According to the Swedish National Quality Register (SNQ), [21] at the time of the study 22 NICUs in Sweden had the equipment for performing TH. All these NICUs were contacted to ask whether they provided TH, and 10 of them replied in the affirmative. These 10 NICUs were then sent an email invitation to participate in the study. SNQ was used to provide basic information about the 10 participating NICUs. All 10 NICUs who received the email chose to participate. The interviewees comprised one neonatologist and one registered nurse (RN) from each unit, all of whom were responsible for TH or neonatal neurology at their units. By doing this, we aimed to ensure that we received responses from those with the most insight and knowledge about TH. Most likely, they have the most relevant experience and are best positioned to provide informed and detailed answers. Additionally, having a standardized selection of respondents (on physician and one RN per NICU) makes the responses more comparable between NICUs, which could help interpreting the results. By focusing on a smaller number of staff, we could conduct a deeper and more focused study that includes both a survey and an interview. Six of the 10 participating neonatologists were men, and all 10 participating RNs were women. Written informed consent was obtained from all participants. During 2021, a total of 122 infants received TH in Sweden, [21] though the numbers of infants receiving TH

at each included NICU during the year varied from 0 to 33.

Data collection

The participating RNs and neonatologists were first approached by email, followed by a phone call to confirm their approval, and were then asked to fill in a questionnaire. The questionnaire was followed by a virtual interview at a date and time of the participants' choosing.

Questionnaire

The questionnaire (see [appendix](#)) was developed based on the Swedish TH criteria, previous research findings, clinical experience, and dialog with experienced NICU staff. It consisted of 70 questions, 3 of which were open-ended. The questions focused on different areas of the care during TH, such as structural solutions and routines, opportunities for parents to stay at the NICU, visiting opportunities for siblings and other relatives, and strategies for the infants' pain management and sedation. The questionnaire was pilot tested with two NICU nurses and two neonatologists with experience of caring for infants undergoing TH, and some minor changes were made before the questionnaire was sent to the participants. Participants received the questionnaire by land mail. The neonatologist and RN at each unit were asked to fill in the questionnaire together, and then return it either by land mail or via scanning and emailing before their interview took place.

Interviews

Semi-structured virtual interviews were performed by the first author, with the aim of elaborating the information received from the questionnaire. One interview was conducted for each NICU, with both the neonatologist and the RN participating. The interviews were conducted in Swedish, and were audio recorded. They followed a semi-structured guide (see [appendix](#)) that was developed by the authors based on previous studies and clinical experiences, and gave the participants the possibility, if they wished, to explain, exemplify, and add more information to their questionnaire answers. The opening question was: "Can you tell me about what happens and what you are thinking when an infant is admitted for hypothermia treatment?" Subsequent questions focused on attitudes regarding parents' involvement in their infants' care and the parental presence at the NICU. The respondents were encouraged to exemplify both concerns and risks and benefits of present and participating parents. At the end of the interview the respondents were asked if there was anything more to add. Each interview lasted for 30–56 min.

Analysis

The quantitative data was presented with descriptive statistic summarizing the answers in number of Yes and No. The answers from the open-ended questions in the questionnaire and the transcribed interview data were analyzed with qualitative content analysis. [22] In the first phase, the recordings were listened to and transcribed. Next, the transcripts were read through while listening to the recordings to obtain understanding and avoid losing important content. Meaning units were identified by the first author and then condensed by the last author. Codes were used to group the meaning units, and then categories were created by tracking similarities and differences in the data. At the end of the process, three categories were formed. All authors were involved in the analytical process. Quotations were included in the results to exemplify the findings and give the reader a broader understanding. Integration occurred in data analysis and interpretation phase and results from both qualitative and quantitative data are presented under each category.

Ethical considerations

The study was conducted in accordance with the Declaration of

Helsinki and was approved by the Swedish Ethical Review Authority (Dnr 2020–01332).

Results

During the data analysis process, three categories were identified, these are: The importance of standardized routines, The influence of care environment on parent-infant closeness and Practices around parent-infant closeness and parental involvement in care. Both qualitative and quantitative data are integrated in the analyses and presented under each category.

The importance of standardized routines

At nine of the NICUs the infants were routinely sedated during TH, and at three units' infants were routinely intubated. All NICUs routinely give enteral food to the infant during TH (Table 1). The staff described the importance of standardized routines and procedures regarding the preparation of the infant's care space and how the care should be conducted for infants in need of TH. Staff with experience of working at NICUs with clear and well-functioning routines described this as secure, time-efficient, and staff-saving.

“It feels like we've managed to make it a 'typical patient'. Everyone knows exactly what they should do, what equipment we should have, and everyone knows where everything stands. These are incredibly good, well-established routines.” (NICU 1)

Many described the preparatory work, including preparation of the care space and the technical equipment, and the first few hours after the infant arrived, as very busy and staff-intensive. If the infant was out-born, time was automatically released for this preparation, as the care space and the medical equipment could be prepared while the infant was in transit to the NICU. If the infant was in-born, this period was experienced as even more intense. During this intensive phase, some of the staff desired to have the parents present, to enable them to follow the process and ask questions. Others identified the intensive startup phase as a good time to suggest that the parent who had not given birth could take a break, rest, or look after the birthing parent. This resulted in the parent leaving the infant at the NICU and created a separation between infant and parent. However, if the routines allowed free time and the staff were settled, this was a moment for the staff to focus on parents and keep them informed and close to their infant.

“You can sort of turn your eyes to the family, because you know that everything else [equipment] just works. So, I guess, it's a matter of experience and routine, that you can feel relaxed about those other things.” (NICU 1)

Varying and numerous tasks as well as the complex assessments were easier to handle if the staff responsible for the infant were well-prepared. If these staff were experienced and comfortable with the TH equipment and the surrounding care environment, a greater focus could be directed

Table 1

Practical caring approaches during therapeutic hypothermia (TH) at the NICUs (n = 10).

	n(%)
Neonatologists present at the NICU 24/7	7(70)
Both in-born and out-born infants at the NICU	9(90)
During TH:	
Infant routinely sedated	9(90)
Infant routinely treated for pain	9(90)
Infant routinely intubated	3(30)
Enteral food routinely given to the infant	1(10)
Continuous cerebral function monitoring (CFM)	1(10)
Attachment of CFM electrodes:	
Needles/cup electrodes	2(20)

towards the infant's family and their individual needs.

“It [transferring the infant from the incubator to the parental bed] doesn't always work. But sometimes it does, and this all depends on how stressed the staff are, how experienced they are, and how many patients there are in the NICU.” (NICU 2)

Assessment and treatment of the infants' pain and stress was also described as a challenge that was different for these patients in comparison to others in the NICU. Some of the TH infants did not give any behavioral signs due to their brain damage, which led to the staff becoming worried about their pain. Other TH infants were very irritable, which also caused challenges to the staff regarding assessing and treating pain. Pain during TH was assessed with various scales: the Astrid Lindgren and Lund Children's Hospitals Pain and Stress Assessment Scale for Preterm and sick Newborn Infants (ALPS-Neo), the Neonatal Pain, Agitation, and Sedation Scale (N-PASS), or the Neo Comfort Scale. However, only four NICUs reported that the scale they used was perceived to be reliable; instead, the staff relied on their clinical experience, changes in the infant's vital parameters, changes in the temperature of the blanket, and the infant's behavior. The first-choice medication for sedation was morphine (4 units), morphine together with clonidine (2 units), midazolam (1 unit), and fentanyl together with clonidine (1 unit). All NICUs gave phenobarbital as first-choice drug for seizures, and all NICUs gave morphine (sometimes combined with clonidine and/or paracetamol) as the first choice of drug for managing pain. On one hand, the staff were concerned that the infants might be experiencing pain and discomfort, but on the other hand, they were also anxious about giving too many drugs that could negatively affect the infants' damaged brains. Non-pharmacological treatment methods such as parental presence and a quiet environment were mentioned as important ways of increasing the infant's comfort.

“The parents' presence can calm the infant in a way, so that the infant feels better now and might have less need for sedatives.” (NICU 3)

The staff expressed a strong wish for clearer and more comprehensive national evidence-based recommendations regarding both medical and nursing care and medical assessments. For example, the transfer of unstable infants was experienced as especially demanding due to the risk of unintentionally disconnecting wires or cables during transfer, which could be harmful for the infant. A wish was also expressed for even clearer criteria regarding which infants should receive TH. Some described the current criteria as difficult and subjective, and therefore saw a possible benefit of implementing cerebral function monitoring as an additional criterion to facilitate the assessment.

The influence of care environment on parent-infant closeness

When choosing where to place the infants in the NICU, only two of the NICUs could offer single rooms (SR). Many stated that they wished to be able to offer these infants a SR, but the reasoning behind this varied between the respondents. Some considered that a SR would be more suitable as the TH equipment required more space, while others justified the choice or desire for a SR by the fact that the sound from the equipment could disturb the other infants. Some reasoned that a SR would enable a calmer and quieter care environment, which would be favorable both for the injured brain of the infant and for the parents' possibility to remain with their infant. The availability of SR and other conditions at the NICUs that might have had an impact on the extent to which parents were able to remain at the NICU, close to their infant, are given in Table 2. Half of the NICUs always placed a parental bed next to the infant's care space. One NICU used the parental bed as the infant's primary care space, and one NICU reported that they chose either an incubator or a parental bed as primary care space. In the remaining NICUs, the infant's care space consisted of an open incubator or crib. The NICUs that chose to provide a parental bed found this to be a way of promoting closeness, encouraging the parents' presence, and creating

Table 2
Environmental conditions for the family at the NICUs (n = 10).

	n(%)
Possibility to stay overnight	9(90)
Single room	2(20)
Private shower and toilet	5(50)
Kitchen with cooking facilities	9(90)
Food and drinks available to buy at the NICU	8(80)
Washing machine	2(20)

better conditions for the whole family to be together.

“It gives a signal to the parents that the idea is for them to be here, next to their infant, close to their infant. I think this is a signal that the parent is part of the infant’s place of care.” (NICU 4)

All NICUs except one cared for both in-born and out-born infants. NICU staff who also cared for out-born infants identified a challenge in the separation that often existed between the birthing parent and the infant if the former needed continued care at the hospital where the birth took place. Attempts were made in various ways to compensate for the expected separation, for example by letting the birthing parent meet, touch, or have the infant in SSC before the transport to another hospital or before the TH was started. There was a desire and urgency to unite the infant and the birthing parent as soon as possible.

Practices around parent-infant closeness and parental involvement in care All ten NICUs allowed parents to stay with their infant around the clock (Table 3), which was seen as a prerequisite for promoting closeness between infant and parents. The NICU staff reasoned about and strived to create opportunities for closeness despite the lack of SSC in the high-tech environment. Some staff imagined themselves in the situation parents were going through, and the chaos and trauma that the parents were suddenly facing. There was a willingness to actively involve parents in the infant’s care by encouraging, supporting, and guiding them. The staff aimed to normalize the care regarding closeness by providing the parents opportunities to cuddle and be really close to the infant, even though the infant was cold and attached to high-tech equipment.

“Usually we emphasize that they [the parents] can speak or sing, that the babies still have all their senses, or however we say it. And that they are allowed to kiss and smell their baby. It must be hard for the parents not to know how close they can get. So, I found it important to say that it’s perfectly fine to kiss your baby even if there are a lot of wires connected to the baby. So they understand that they can be close if they want to.” (NICU 6)

Many staff members perceived that the parents of TH-treated infants had a more extensive need for information compared to other NICU parents, and that there was a great need for repetition of information. Some therefore considered that standardized written information could fulfill a function, without excluding the conversation and the physical meetings. The staff expressed the benefits of having parents present and involved throughout the care process. This facilitated the flow of

Table 3
Family integrated practices during TH at the NICUs (n = 10).

	n(%)
Parent present during transportation (out-born infants)	6(60)
SSC before start of TH	3(30)
Parental bed at the infant’s care space	6(60)
Parents and siblings allowed to stay at the NICU 24/7	10(100)
Parental presence during medical rounds	8(80)
Parental presence during care procedures	7(70)
Care procedures performed in parents’ arms/bed	1(10)
Parents invited to revisit the NICU after discharge	4(40)

information, and the staff felt that the parents were better able to understand the information they were given if they had been with their infant and seen and experienced what was going on at the NICU.

“The closer they are to the care space, the more natural the information that the parents receive about the care process also becomes. They see what we do, and hear what we say in a different way.” (NICU 7)

A positive approach towards parental presence pervaded the NICU staff. Some described a feeling that both parents and their infants seemed to be more comfortable and less stressed in each other’s presence, no matter how critical the condition of the birthing parent or infant. The parental closeness increased the opportunity to create comfort for the infant and gave the parents a chance to become parents. Some expressed the need to create as many “closeness experiences” as possible; since the outcome might be unclear for infants undergoing TH, it felt meaningful both in a short-term and a long-term perspective to help the parents to create positive memories of their NICU stay.

All respondents were asked to estimate the extent to which parents were close, present, and involved during the period that the infant was undergoing TH (Table 3). They were also asked to give examples of tasks that the parents were allowed to do regarding the infants’ care. All NICUs were keen to encourage parents to be actively involved in their infant’s care, but they would not let the parents perform medical tasks such as establishing a venous line, intubation, and administering intravenous drugs. At some NICUs, caring tasks (changing the infant’s position, weighing the infant, suction in the mouth, nose, and endotracheal tube) were considered unsuitable for parents to perform, while other NICUs did not see any hindrance to letting parents perform such tasks.

The TH posed challenges for the staff in their work of promoting and supporting closeness between infant and parent. The staff described the TH blanket, wires, and cables as obstacles that made it difficult to move the infant to or from the parents’ arms.

“It’s not about ignorance or reluctance, but it requires resources to transfer such a baby to their parents.” (NICU 3)

After TH completion, all NICUs were eager to enable SSC. The infant was allowed to breast feed immediately, or as soon as the infant showed signs of interest.

Discussion

Our findings make it clear that creating conditions for promoting parent-infant closeness is important, especially in contexts where environmental circumstances curb the possibilities of SSC and closeness as well as the parental trauma that precedes the TH. This further increases the motivation to find alternative solutions to enable and encourage parent-infant closeness. This study found that NICU staff in Sweden have well-settled routines regarding TH treatment and a clear focus on both the infant and the infant’s family. There was a united willingness among staff to try to encourage parent-infant closeness despite the constraints of the conditions. Sweden has a long tradition of including and wanting parents to be with their children in need of care around the clock, even though infants in NICU still do not always have a parent with them at all times. Contributing factors to this could be that Sweden is a relatively small country and that UNICEF’s Convention on the Rights of the Child is a law in the country. [23] This means that all children, regardless of age, have the right to have their parents with them around the clock when they are hospitalized. Additionally, we have a paid parental insurance that allows both parents to be present throughout the entire hospital stay. The unlimited possibility for parents to stay at the NICU with their infant was a prerequisite for promoting parent-infant closeness, and this was no different for these families than for the families of other infants being cared for at the NICUs. However, barriers in supporting parent-infant closeness could occur, for example, staff’s level of comfort with the admission procedure, lack of space, and logistic problems.

Regarding environmental settings, previous research shows that parents' ability to bond with their infant is affected by the environment, [24] and that the environment can create different conditions for closeness and parental participation. [16] A SR significantly increases the time that parents spend with their infant [25] as well as their involvement in care, [26] if there is support and interaction between staff and parents. [27] Welcoming parents to the NICU 24/7 has been described as a "game changer" in developing care that is individualized for a specific infant and family. [28] Previous studies have concluded that there is room for improvement in providing continuous and transparent information flow in an everyday language that the parents can understand. [12,13] Promoting parental presence and encouraging closeness throughout the entire care period can give parents an increased opportunity to understand the information that is given. It also seems to facilitate the flow of information from the perspective of NICU staff.

"Stable enough" is a commonly used saying, meaning that infants that are considered stable can be transferred from the incubator/crib and moved closer to the parent. It is not uncommon for unstable infants to be excluded from clinical trials on parental closeness during TH [17] and SSC. [29] This might indicate that critically ill or unstable infants do not get the chance to be really close to their parents. To minimize the critical transfers, caring for the infant in the parental bed instead of the incubator or crib could be an option. Without transfer risks, parents then have free access to their infant and can be close to their infant regardless of staff attitudes, staff competence, and the staff-parent ratio. Given the many advantages of SSC, it is clear that the lack of SSC during ongoing TH might present a challenging situation in promoting parent-infant bonding and closeness. Additionally, it seems that immediate SSC after birth has positive effects on cardiorespiratory stabilization. [30] Enabling SSC for a short period of time before initiating TH could therefore be motivated and justified as long as it does not significantly delay initiation of TH. Another way of enable closeness is to make holding during TH possible, which according to the respondents does not seem to be standard care. This is an area that needs more research.

Trustworthiness in this study is supported by the researchers' knowledge and experiences of TH, this preunderstanding has helped us formulate clinically relevant questions and interpret the answers. Credibility was strengthened by discussions within the whole research team during the analysis, and confirmability strengthened by the description of the analysis process and the quotations. One strength of this study could be that all NICUs providing TH in Sweden choose to participate. However, there are limitations of this study. For example, the small size sample hand-picked by the head of the unit that might be the "true believers" at their units and there for not quite reflect the unit. We also might have missed important perspectives and insights from other staff who also play a critical role in the care of these infants. Furthermore, the selected respondents might have personal opinions or views of the entire staff, which could lead to bias of the results. The respondents might also be more likely to give answers that reflect an idealized version of the care rather than the actual practice. They might also be more cautious about criticizing care practices because they are directly responsible for them. However there is no need to doubt the respondent's trustiness but there is always a risk overestimate capacity and numbers. Nevertheless, the results are based on reports from only one physician and one RN per NICU, rather than incorporating input from the entire staff or, ideally real-life observations. This approach may lead to variations in how questions were understood by different respondents. Additionally, there is a possibility that respondents answered in a way that reflects their ideal practices rather than their actual routines. Nevertheless, the findings providing us with a comprehensive understanding of the current practice. Since this was a rather small study, conducted in a small country with low annual numbers of infants undergoing TH and a strong tradition of parental presence and involvement at NICUs the generalization and transferability of the findings are limited. Although the purpose of this study was not to

generalize, the results anyway might be transferrable to similar settings, or at least be a source of inspiration that it is possible to perform neonatal intensive care such as TH and at the same time sustain some kind of parent-infant closeness.

Conclusion

Enabling parent-infant closeness and parent participation during the infants stay at the NICU is important, and the period of TH is no exception. This study found that standardized routines regarding the care space setup, the medical and caring approach, and the NICU environment and practices around the families seems to either promote or curb the possibilities of parent-infant closeness and presence. Good NICU environmental conditions including a SR, and staff with flexible way of working regarding the family's needs are therefore required.

Key notes

- This Swedish study investigate care practices and staff's experiences of parental presence and possibilities of being close with their infant during therapeutic hypothermia.
- During therapeutic hypothermia the conditions for parent-infant closeness are completely different than in other NICU care.
- Standardized routines regarding the care space setup and the medical and caring approach, as well as care practices around the families, can promote or curb the possibilities of parent-infant closeness.

CRediT authorship contribution statement

Pyrola Bäcke: Project administration. **Anna Axelin:** Project administration. **Johan Ågren:** Project administration. **Ylva Thernström Blomqvist:** Project administration.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.srhc.2024.101010>.

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