

Parents' experiences of family health conversations after having a child in need of neonatal intensive care

Marie Åberg Petersson RN (PhD Student)^{1,2} , Carina Persson RPT, PhD (University Lecturer)² , Pamela Massoudi LCP, PhD (Licenced psychologist)^{3,4} , Eva Benzein RN, PhD (Professor)²  and Ingrid Wåhlin RN, PhD (Research Leader)^{2,5} 

¹Clinical Training Center, Region Kalmar County, Kalmar, Sweden, ²School of Health and Caring Sciences, Linnaeus University, Växjö, Sweden, ³Department of Research and Development, Region Kronoberg, Växjö, Sweden, ⁴Department of Psychology, University of Gothenburg, Gothenburg, Sweden and ⁵Research Section, Region Kalmar County, Kalmar, Sweden

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Background: When a newborn child requires neonatal intensive care, it is often the beginning of a journey of stress and worry for the parents. Such situations could cause difficulties in problem-solving and communication within the family and result in decreased family functioning. Studies have shown that nurse-led interventions in the form of Family Health Conversations promote family's well-being and functioning and strengthen their relationships. However, this model has not previous been used and evaluated with families who have a child in need of neonatal intensive care.

Aim: To describe parents' experiences of participating in Family Health Conversations after having a child in need of neonatal intensive care.

Method: Family interviews were conducted with 12 families from three neonatal intensive care units in southern Sweden, six months after a Family Health Conversations intervention. Data were analysed using qualitative content analysis.

Findings: The parents experienced the Family Health Conversations as an opportunity to co-create a comprehensive picture of what had happened after their child was born. Parents shared their experiences of the Family Health Conversations in terms of feeling validated and strengthened as individuals, as a couple, and as a family. They found the conversations to be supportive to their well-being and to processing experiences and becoming equipped for the future. The parents reported that it was valuable to talk with conversational leaders who had knowledge in neonatal care and who thereby understood what the parents were talking about. This provided a different type of support compared with other conversational contacts.

Conclusion: These results highlight the importance of having an early onset of family conversations in order to help the parents to cope with their challenges and improve their well-being.

Keywords: family systems nursing, family health conversations, neonatal intensive care, parents, nurse-led intervention, qualitative content analysis.

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Introduction

When a child is born prematurely (delivery before 37 weeks gestation) or born full-term with medical conditions requiring care at a neonatal intensive care unit (NICU) it is often the beginning of a stressful and worrying journey for the parents (1-3). Parental stress can be caused by factors such as feelings of guilt, fears regarding the infant's survival (2), feelings of helplessness and anxiety, depression, or loss of control making it difficult for

them to recognise their own and their partners' reactions (2,3). Long-term hospital care can also place great demands on the parents and contribute to distressful experiences (4).

It is important to address parental distress, as many studies have demonstrated its serious consequences both at the individual and relational level (4-6). A decline in family functioning, in terms of a lack of an ability to make changes, maintain balance, and function, as a result of a stressful event, was discovered three months after the birth of a sick newborn in need of care in NICU. This change was sub-pathological but remained stable during the whole first year as compared to the assessment at the time of admission to NICU (3). Another

Correspondence to:

Marie Åberg Petersson, Clinical Training Center (KTC), Kalmar Hospital, S-391 85 Kalmar, Sweden.

study found that a preterm birth has a negative influence on parents' mental health and family functioning even when followed up seven years after birth, for example increased difficulties in solving problems within the family and poorer family functioning affective responsiveness (5). Parents with high levels of anxiety, depression or parenting stress have also been shown to have a high risk of bonding difficulties with the infant (4-6). These difficulties could affect child-parent relationships in the long term, increase the risk of problematic child behaviour, and affect the infant's growth and development (5).

Studies have shown the need of mental health support for parents in the NICU, delivered through multidisciplinary care models or nurse-support programmes (6,7). A systematic review of parent communication needs demonstrated that parents wanted more conversations with nurses because they showed compassion and trust and shared positive outcome stories, which were a source of support and hope for the parents (8,9).

The Family Assessment and Intervention Model developed in Canada is a nurse-led intervention focusing on the family system (10,11). Results from an integrative review show positive family outcomes of the intervention in terms of cognitive, affective, and behavioural changes in family functioning (12). This model has been adapted to the Swedish culture and context, in form of the Family Health Conversation Model (FamHCM) (13). The intervention comprises a therapeutic conversation within the nurse-family relationship with its focus on family well-being and functioning (13,14). The essential core components are narration, listening, and reflection on family experiences and problems to find new meanings of their situation (14-16). The FamHCM has been used and evaluated in different Swedish contexts, such as palliative care (15), critical illness (17), chronic illness (18), stroke (19,20), and for older people living in residential homes (21,22). Findings demonstrate that the FamHCM promotes family well-being and functioning and strengthens family relationships. However, only one study using the FamHCM has been reported from a paediatric context; a qualitative study with family members of a child newly diagnosed with cancer. The participating families reported experiencing that they received help by gaining insight into each other's inner feelings, and that the intervention increased their ability to cope and regain control (23).

Thus, after having a child in need of neonatal care, parents often experience stress, decreased family functioning and difficulties in problem-solving and communication within the family. As studies have indicated a need for nursing interventions that promote improved family functioning, the FamHCM is evaluated for that purpose in this study.

Aim

The aim of this study was to describe parents' experiences of participating in Family Health Conversations after having a child in need of neonatal intensive care.

Method

Context

This study was conducted at three level II (24) neonatal intensive care units (NICU) in southern Sweden. One of the units cared for newborns from 27 weeks gestation, the second from 29 weeks, and the third from 30 weeks. All units provided standard care based on Family Centred Care (FCC) with interventions such as Neonatal Individualized Developmental Care and Assessment Program (NIDCAP), Kangaroo Mother Care (KMC), family rooms at the unit and neonatal home care. When needed, infants or expecting mothers were transferred to a hospital with a higher level of care and then back again when the condition had stabilised.

Intervention

The Family Health Conversations (FamHC) (13,14) was conducted as a series of conversations with two to four-week intervals and most of the conversations started two to six weeks after admission. Most parents participated in three conversations ($n = 7$), some were satisfied with two ($n = 3$) while others wanted four ($n = 2$). Each conversation lasted about one hour and was led by two conversation leaders who took the family through the conversation series. Five nurses, of whom four were specialists in paediatric care, and one researcher in family systems nursing, conducted the conversations. All conversation leaders had university training in FamHC. The first conversation usually took place at the NICU, while the following conversations took place at the family's home, in accordance with the parents' preferences. During the first FamHC, the parents narrated their experiences and listened to their partner's experience of having a child in need of neonatal intensive care by using circular questions, aiming to stimulate reflection. Such questions often begin with "where?," "what?" or "how?" and address the cognitive, affective and behavioural level. For example: "What are your thoughts after listening to your husband?" and "How can your partner comfort you when you are sad?" Topics were further explored and reflected on in terms of what the parents considered as important in their situation. The focus of the second conversation was exploration of problems identified by the parents in relation to the current situation. The third conversation focused on the future and the family's

strengths and resources. After the final conversation a closing letter, highlighting the nurses' reflections from the conversations, was sent to the parents.

Participants and recruitment

The present study was a part of a larger intervention research project with the aim to explore the FamHCM in the context of neonatal care. Parents whose newborn infants needed neonatal intensive care with respirator or Continuous Positive Airway Pressure (CPAP) were included in the project. The infants were born in gestational weeks 26–40, from preterm to full-term with wide variations, to single- or multiparas, had different lengths of stay (weeks to months) following birth, had various diagnosis, and some were born with a congenital anomaly. Contact nurses at the three NICUs gave oral and written information about the intervention study and the follow-up interview study (the current study) to the parents who met the inclusion criteria. The parents who wanted to participate gave their written consent and were thereafter randomly assigned to either the intervention or the control group.

After the intervention was completed, and all questionnaires in the larger research project were answered, a consecutive sample was selected by inviting the first 13 families in the intervention group to participate in interview for the present study, focusing on their experiences of the intervention. The first author (MÅP) contacted the families by phone approximately six months after the intervention and confirmed whether they were still interested to participate in the interview. They were given updated information of the study and that one of the conversation leaders would call them to set time and place for the interview. All but one family agreed to participate. Seven families were first-time parents, while five families had one to three children before. Ages of the participants varied between 25 and 52 years; all but one participant were Swedish; one family was same sex; and care time at the hospital and home varied between one and seven months.

Data collection

Approximately six months after the last conversation, the parents were interviewed about their experiences of the intervention (from February 2016 to May 2018) by a researcher who had not met them during the FamHC. The parents were interviewed together as a couple in all cases except for one, where only one of the parents could participate. Each interview, which was conducted in a secluded room at the hospital ($n = 1$), at the participants' homes ($n = 4$), or by phone ($n = 7$), lasted between 20 and 45 minutes. A semi-structured interview guide was used, starting with an open question about the parents'

experiences of the FamHC and the closing letter, followed by questions about positive and negative experiences of participating, and if and how the conversation had an impact on them and their family. Clarifying questions were asked when necessary and both parents' experiences were sought. All interviews were audio-recorded and transcribed verbatim.

Data analysis

Qualitative content analysis was used (25) to describe the parents' experiences of the FamHC. The entire text was chosen as the unit of analysis. First, the text was read and reread several times by the researchers to obtain a sense of the whole. It was then divided into smaller meaning units, which were condensed and sorted into subcategories and categories. The analysis process involved a back and forth movement between the whole and parts of the text. The first author was primarily responsible for the analysis, but the meaning of the whole and the identified subcategories and categories were regularly discussed and revised within the author team to strengthen the trustworthiness of the results. Four of the authors had previously worked with children and parents in various care contexts and had experience of meeting families in need of care and conducting health-related conversations. This pre-understanding was managed by the researchers throughout the interpretation process by balancing their awareness of their personal history and 'letting the text talk' (25,26). An example of the analysis process is shown in Table 1.

Ethical considerations

Ethical approval for this study was obtained from the Regional Ethical Review Board in Linköping, Sweden (D-nr: 2015/83-31, 2017/248-32). The study was performed in accordance with the declaration of Helsinki (27). The researchers were aware of the potential ethical challenges that can occur when conducting joint interviews, such as exposing relationship-related conflicts, partners having differing views, or sharing something unknown to the other (28). However, these situations were avoided by giving the parents comprehensive information of the study and building a respectful atmosphere during conversations.

Results

The analysis resulted in three main categories: *Co-creating a comprehensive picture*, *Feeling validated* and *Feeling equipped for the future*.

In addition, the parents also talked about how they perceived the structure of the model. The parents appreciated the flexibility and sensitivity shown by the

Table 1 Example of the analysis process

Meaning unit	Subcategory	Category
'I think it is pretty much that we got time to talk, just the two of us, even though X (their sick child) was there but it was not about her, her medicine, or her spasms, it was about us'.	Time for focusing on us	
'It felt so good to talk, otherwise you keep things bottled up inside and maybe get angry and go around worrying about things you feel bad about, but don't bring up, it felt like letting the steam off a little bit'.	Opening up for a different dialogue	Co-creating a comprehensive picture
'We haven't talked about it a lot just the two of us. I think we understood a lot when we sat here and talked, he told his version, then I could tell my version, how I felt and how he felt. I thought it felt really good, we didn't exactly do that at the hospital'.	Learning to listen to each other	

conversational leaders when scheduling conversations with the parents. They also appreciated the 2-4 week intervals between the conversations, allowing time for reflection. The extended time span for the conversations made the parents feel supported by the conversational leaders during this transition in their lives. Having the second and third conversation at their own home was described as being more relaxed and comfortable and they appreciated not having to go to the hospital. They felt validated by the conversational leaders' closing letters reminding them of their strengths, their individual contributions, and how they had supported and complemented each other. These were perceived as helpful.

Co-creating a comprehensive picture

Time for focusing on us. The parents expressed that the FamHC were helpful in that they involved taking out time for focusing on themselves during a period when focus tended to be totally on their newborn child.

'I think it is pretty much that we got time to talk, just the two of us, even though X (their sick child) was there but it was not about her, her medicine, or her spasms, it was about us' (Mother, family 6)

Parents also confessed that it was difficult to find time to talk about how they experienced their situation

because of hospital routines and being occupied with organising their daily lives. They expressed that by focusing on themselves, their experiences, and well-being, they better understood both themselves and their partner, which in turn made it easier to manage their reactions.

Opening up for a different dialogue. The family health conversations were recognised by the parents as an opportunity to have a dialogue that was different from other conversational support they had experienced. Additionally, the conversations were perceived as different from their ordinary family talk. They found the conversational leaders' questions helpful in expressing their experiences, thoughts and feelings.

'We had talked, we talked to each other all the time, but I think it really made a difference to talk to someone else and to be asked questions' (Mother, family 8)

Parents described that the conversations opened opportunities for speaking with, and talking about each other, in a way they not were used to. They also reported that the presence of the conversational leaders made it possible to talk about topics that they normally would not feel comfortable talking about, and which never would have been brought up otherwise. Some parents described it as venting. They felt relieved after talking about what they had kept inside, what bothered them, and what they were ruminating about.

'It felt so good to talk, otherwise you keep things bottled up inside and maybe get angry and go around worrying about things you feel bad about, but don't bring up, it felt like letting the steam off a little bit' (Mother, family 8)

The parents described how opening up in this way made them feel better, it helped them widen their perspectives, and to also see the positive aspects of the situation.

Learning to listen to each other. The parents described the conversations as a learning experience of listening to each other, as they could have different experiences and perceptions of the same experience. For example, after a Caesarean section, a father was with his newborn, while the mother was on her own in the intensive care unit, missing the first hours of her child's life. Consequently, listening to the partner's experiences, thoughts and feelings became important to get a more comprehensible picture of what had happened after their child was born. Sometimes the family was together during a prolonged hospital stay, but in some cases, the father had to go back to work while the mother and the newborn child spent several weeks at the neonatal unit.

'We haven't talked about it a lot just the two of us. I think we understood a lot when we sat here and

talked, he told his version, then I could tell my version, how I felt and how he felt. I thought it felt really good, we didn't exactly do that at the hospital' (Mother, family 9)

Listening to each other's experiences could, however, be tough. At times, things came forth that the other parent experienced as difficult to hear and it could be emotionally challenging to share the partner's suffering. Despite this, the parents expressed that this type of information was valuable and that they would rather 'have it than miss it'.

Feeling validated

Being seen. The parents talked about their experiences of meeting conversational leaders who were sensitive and caring. Being asked about their well-being, their feelings, and how they were managing was perceived as valuable. This was especially true for fathers who expressed that they had felt invisible and had not been included by the personnel at the maternity clinic and child health centre, where focus was on the mother and the child. Participating in the family health conversations led to a feeling of being seen as a parent and a part of a parental system.

'When it comes to childbearing today... It is like there is more focus on the mother than on a couple who have become parents, I think... It is more like the mother has had a child, and then the father is on the sidelines somewhere. That's my experience' (Father family 9)

Parents expressed that they became conscious of their own growth as parents to a child in need of special care. This process was facilitated by the conversational leaders' feedback based on what they observed from one visit to the next.

'I feel that was good, to get some feedback on their thoughts on what we had done well from one time to another. Sometimes, maybe you could feel that you hadn't moved forward but then after talking to them you realized that you had' (Father, family 1)

Being understood. The parents felt that it was valuable to talk with conversational leaders who had knowledge in neonatal care and who thereby understood what the parents were talking about. This provided a different support compared with other conversational contacts. Being understood was also linked to the conversational leaders' sharing of their experiences from meeting other parents in similar situations. As compared to other types of conversational support the parents had participated in, this made a significant difference to them.

'Being supportive by believing in us, that they actually know what you are talking about, and they know that what we have been through is not that

easy, they backed us up in that way, oh I think it was great' (Mother, family 7)

Parents expressed feelings of normalisation by participating in the conversations. When their expectations of becoming a parent differed from how it actually turned out, or when feelings of joy and happiness were absent or delayed, the parents were relieved by a reassurance from the conversational leaders that they shared those experiences with many other parents.

'Precisely those feelings I know everybody talks about, that it is so wonderful, and it is so good, and you love the baby from the very first second and all that stuff. I didn't feel that, it had to develop slowly and I thought it was so relieving to talk to them about this and get their feedback that it is not so unusual to feel that way' (Mother, family 3)

Feeling equipped for the future

Processing experiences. The conversations were perceived as helpful, facilitating reflection and providing opportunities to summarise what the parents had been through. The interactions with the conversational leaders gave rise to reflective processes, making it possible to find words for experiences. This was perceived by the parents as helpful in 'working through' the unexpected event of giving birth to a child in need of intensive neonatal care. Parents expressed that 'working through' their experiences could be emotionally challenging. It was hard to face what had happened, but also what could have happened. This was, however, understood as a phase in their processing and was therefore perceived as meaningful by the parents.

'Well, you go back to all these things that potentially could have happened, you go back there...It is rather challenging in a way. But that is a part of the working through of course... That was really good because then you processed, so that was really good. I think that is the point, that you are able to talk things through and sort things out' (Father, family 11)

Gaining strength. The parents described that participating in the conversations had strengthened them, in that they learned new things about themselves, they gained self-confidence, and that their worrying reduced. They explained that these changes in their self-trust were evident in other everyday situations too, and not only linked to the actual conditions reflected on in the conversations.

'And I think I have become more secure, about what I believe in, and I know that just because I am not a physician, it doesn't mean that I don't have a sense of what is right or wrong, kind of, but it can be in other situations too, that you sort of have the

courage to trust your own gut feeling you know, is this right or this is not ok, or this is how it should be, that you have become a bit stronger in that regard too' (Mother, family 7)

Parents also described that they were strengthened as a couple by learning new things about each other through the conversations. They expressed that by (starting to talk and) talking about things that they otherwise found difficult to talk about they developed a new understanding of each other.

'I think that for each conversation we had with the conversation leaders, we grew stronger together and could sit down and talk about what had happened afterwards, that you got a completely different picture of it. You could understand each other in quite a different way too' (Mother, family 9)

Furthermore, parents described that their attitudes towards their individual differences changed, now seen as being positive for the family. Through the conversations, they discovered that their various individual strengths were often complementary and thus strengthened them as a couple.

'Differences have come to be something good for us. Now, it is something that can help us instead' (Father, family 1)

Moreover, participating in the conversations strengthened their togetherness and well-being. By narrating and listening to each other's experiences, the parents felt that the child became more of a shared responsibility and the relational bonds to the children were strengthened.

'What was good about this conversation, for example, was to be able to talk in peace and quiet, talk from our hearts, both of us, and then it sort of became our child and not only the mother's child, if you know what I mean?' (Father, family 9)

Help to move on. The parents found the conversations helpful for moving on. They felt strengthened, ready to take on future challenges after having reflected and processed what they had been through.

'You haven't suppressed anything and you haven't hidden anything and you can kind of talk and handle things, and that I think has been an incredibly good foundation for the new challenges we are in the midst of just now, otherwise it would have been very difficult. That it just doesn't escalate, but that you have been able to overcome the initial days and weeks' (Mother, family 6)

Throughout the conversations, the parents became aware of the gravity of the mental distress the situation had brought about. This awareness facilitated help-seeking if they should need further medical- or psychological support. Families also expressed that by having experienced the significance of participating in the

conversations as a couple, they felt confident in seeking future family conversational support, if needed.

Discussion

The results showed that the parents experienced the FamHCs as an opportunity to co-create a comprehensive picture of what had happened after their child was born. They felt validated and strengthened as individuals, as a couple, and as a family. They found the conversations supportive for their well-being, helping them to process experiences and be equipped for the future.

The conversations were found to help parents create a comprehensive picture of their experiences through a new way of talking, helping them put words to their feelings and thoughts. They also expressed that by focusing on themselves, their experiences, and well-being, they better understood both themselves and their partner. This is in line with Persson & Benzein's (14) findings, who reported that the working components in FamHC were the alternation between families' narration and exploration in the dialogue with conversation leaders, whereby family members developed an increased understanding of themselves, others, and of their interactional patterns. Further, two other studies within the contexts of chronic illnesses (19) and intensive care (17) have reported that family members experienced that talking about the 'unspeakable' facilitated healing. The current study showed that the intervention opened opportunities for a new understanding of each other. This is a useful finding as previous research has shown that having a very preterm child was associated with difficulties in solving problems and communicating within the family when the child was two years old, and the difficulties seemed to persist when they were followed up five years later (5).

Our results further showed that parents felt validated by realising that other parents in the same situation may have similar reactions and feelings. This contributed to a sense of normalisation. The parents appreciated that the conversations were led by staff that had knowledge about neonatal intensive care and an understanding of what the parents had gone through. This might be of special value since the birth of a child comes with expectations and beliefs that are often challenged when having a child born in need of neonatal intensive care (29) which could contribute to parents' depression and stress and a weak coherence (30). If early support is introduced, the negative impact on the individual family members and the family system could be reduced and the family could find new meaning and hope (31,32). Results from the current study identify the conversations as bringing about a feeling of being validated through being seen and understood as a person by the conversation leaders. Previous studies on family experiences of FamHCs have discussed

similar findings in terms of being confirmed. Confirmation has been linked to commitment and reflections from the conversational leaders (21), but also to the possibility of relational sharing and listening to other family members where one's own view is confirmed, and the family's understanding of the situation is acknowledged (19). Additionally, in our study, specifically the fathers shared their experiences of being seen and listened to in the FamHCs, something they had not felt during the pregnancy, the care in NICU, or afterwards in the child health care. Historically/traditionally the mother-child relationship has been in focus. Nowadays, fathers' participation is acknowledged as equally important (33), but the experiences of fathers in our study highlight the need for the health professionals to take an active interest in fathers. Fathers' mental health is important to consider since previous studies have shown that symptoms of anxiety and depression may show up at later stages as compared to mothers (34,35).

Parents, in our study, experienced feeling equipped for the future through the FamHCs supporting their well-being by venting and working through what had happened and what could have happened. This can be compared to a study with a FamHC intervention at a paediatric oncology centre, where parents experienced that becoming aware of their own and the family's feelings and experiences, and putting words to their feelings, unburdened the family members (23). In the current study, parents also described that they were strengthened as a couple by learning new things about each other. Through developing new understanding of each other they could see benefits in being different as individuals and the child became a shared responsibility. This has not previously been highlighted in studies with FamHCs, but a similar finding was reported in a study where nurse-parent communications were evaluated in the frame of FCC in NICU (36). It may be that sharing of experiences by listening to each other is especially important in this context since parents are often separated after the child is born. Family experiences of being strengthened by participating in FamHCs have also been found in previous studies from other contexts (17,23). In a study within an intensive care context, family functioning and feelings of togetherness were found to be strengthened by working through their emotions together (17). Marklund et al. (23) also reported that families in a paediatric oncology centre were strengthened by the insight gained from reflecting on their own and each other's experiences(37).

Although the parents' overall experiences of the conversations were very positive, they also described the conversations as emotionally challenging. This finding is also reported in other contexts where families report that going through everything once more is emotionally demanding, but worth the effort, since it strengthens their sense of well-being (21,38)

Methodological considerations

The strengths and limitations of this study are partly linked to the larger intervention study. Even though the participants were sampled consecutively, and not based on purposive sampling, there were large variations among the recruited families in terms of varied diagnoses resulting in need for neonatal intensive care, and diverse family constellations. A potential weakness of this study is that parents who were not fluent in written and spoken Swedish language were excluded. Thus, their voices were not heard. Additionally, although all conversation leaders had university training in FamHC, no verification has been made of whether or not all core components in the model had been included in each conversation. Nevertheless, the majority of interviews included statements reflecting most of the core components, such as exploring the family structure, giving both parents opportunity to narrate their experiences, and jointly reflecting with the parents (16).

To strengthen the credibility of the study, interviews were always conducted by someone who had not met the parents in any conversation and using a semi-structured interview guide. One researcher was responsible for the analysis but to improve comprehensibility and provide sound interpretation of data, all researchers subsequently discussed divergent options concerning categorisation to consensus (25). The findings of this study can potentially be applied to similar contexts in other countries with parents having a child in need of intensive care.

Conclusion and clinical implication

These results seem promising as a way of supporting and strengthening the well-being of families with a child needing neonatal intensive care as a newborn. The findings highlight the importance of having an early onset of family conversations in order to help the parents to cope with their challenges as early as possible. A further conclusion is that all parents in similar situations should be offered FamHCs or a similar type of conversation opportunity as an ordinary caring intervention at the neonatal clinic. We therefore propose that managers must facilitate educational courses for nurses to learn about family nursing in general and about how to perform joint conversations with parents/families. As the findings of this study are consistent with previous research, irrespective of the care context, there is growing evidence on the positive impact of the conversations from families' perspective. The impact of the conversations needs to be further validated through quantitative follow-up studies.

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Conflict of interest

The authors have no conflicts of interest to report regarding this study.

Author contributions

We declare that all authors made substantial contributions to conception and design, or acquisition of data, or data analysis and interpretation; were involved in drafting the manuscript or revising it critically for important intellectual content; and gave final approval of the submitted version.

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