

Continuing Pregnancy Despite Prenatal Diagnosis of a Life-Limiting Fetal Anomaly and Need for Perinatal Palliative Care Service Package: A Qualitative Study from Iran

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ABSTRACT

Background: Prenatal diagnosis of fetal anomalies leads to parental psychological stress and decision-making challenges to continue or terminate pregnancy. Continuing pregnancy despite fetal anomaly can cause confusion, anxiety and depression in parents, so it seems necessary to be aware of their needs and appropriately respond to them. This study was conducted to exploring experiences about Continuation Pregnancy despite fetal anomaly in the socio-cultural context of Iran.

Methods: Qualitative exploratory descriptive study, 35 participants including 15 pregnant women with Life-Limiting fetal anomaly diagnosis, 5 family members and 15 perinatal care providers were selected purposefully. Data were gathered by individual interview and were written, important phrases were coded, by grouping same codes, main and sub categories were extracted.

Results: In this study, 4 main categories, each with a number of subcategories were extracted. The main categories included: "mental health counseling, support parents to accept and cope with event, ethical consideration during end-of-life care of baby, providing perinatal palliative care)".

Conclusion: The results showed that parents who forcibly or voluntarily continue pregnancy after a wearing of fetal anomalies, have extensive care needs during pregnancy and after birth that are not sufficiently met. Therefore, it seems that a comprehensive service package of perinatal palliative care appropriate for Iran socio- cultural context is necessary.

Keywords: Fetal anomaly, Palliative care, Prenatal diagnosis, Qualitative research

Introduction

Congenital anomalies are considered as the main cause of infants' mortality and compose approximately 20% of infants' deaths (1, 2). Diagnosis of congenital anomalies is a stressful event that is associated with depression, anxiety, stress, sorrow and sadness (3) and taking decision to terminate or continuing the pregnancy is a difficult and complex issue. Limitation of medical knowledge, diagnostic techniques and uncertainty

of diagnosis and lack of assurance about prognosis and survival rate increase its complexity (4). In fact, a collection of psychological, social factors, religious, legal and moral beliefs are involved in the decision-making process of parents to terminate or continue pregnancy (5, 6). In some cases, due to social, cultural, spiritual reasons and legal restrictions in termination of pregnancy, despite anomaly of the fetus, women are forced to

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carry their pregnancies to term (7, 8). Sometimes parents voluntarily decide to continue pregnancy and suffer from anxiety and depression (9-11). Therefore, a comprehensive care approach that continues from diagnosis of fetal anomaly until after death of the infant should be provided regarding priorities and demands of families (6, 12).

Since in Iran the laws are derived from the teachings of Islam, pregnancy termination permit is limited to therapeutic abortion during the first 4 months of gestation, with the diagnosis of three specialized physicians and forensic approval, in cases where the mother's life is definitely in danger, or the fetus to be retarded and deformed (13). However, studies show that abortion is less observed in people with religious beliefs; therefore, the voluntary continuing pregnancy is also seen in Iranian women (14). Thus, considering family needs and meet them by health team during continuation pregnancy despite fetal anomaly diagnosis seems necessary (15). Therefore, this qualitative study was performed to exploring the experiences about continuation pregnancy despite fetal anomaly diagnosis.

Methods

This study was conducted by conventional content analysis, from February 2020 to March

2021. Content analysis is the process of systematically classifying data through which codes and themes are revealed (16). Participants were 35 Muslims and were speaking Persian, including 15 pregnant women with criteria for diagnosing life-threatening fetal anomalies who continued pregnancy and referred to hospitals, health centers and clinics; 5 members of their families, including 4 fathers with a mean age of 34 years, of whom 2 had primary education, 2 had university education, and one grandmother, and 15 perinatal care providers (Figure 1). Participant were selected purposefully with maximum variation regarding, education, social status, number of pregnancies and deliveries, occupation, gestational age at diagnosis time and forced/optional continuation of pregnancy, wanted and unwanted pregnancy and type of fetal anomaly. Interviews were conducted at various periods of prenatal, during childbirth, postpartum and after dying the infant. Data were gathered by semi-structured, in-depth interview.

The interview began with general questions, such as “would you please tell us about your experiences when fetal anomaly is detected?” and moved to more specific, detailed questions as the interview advanced, such as “What was it like to continue the pregnancy?”, “What were your

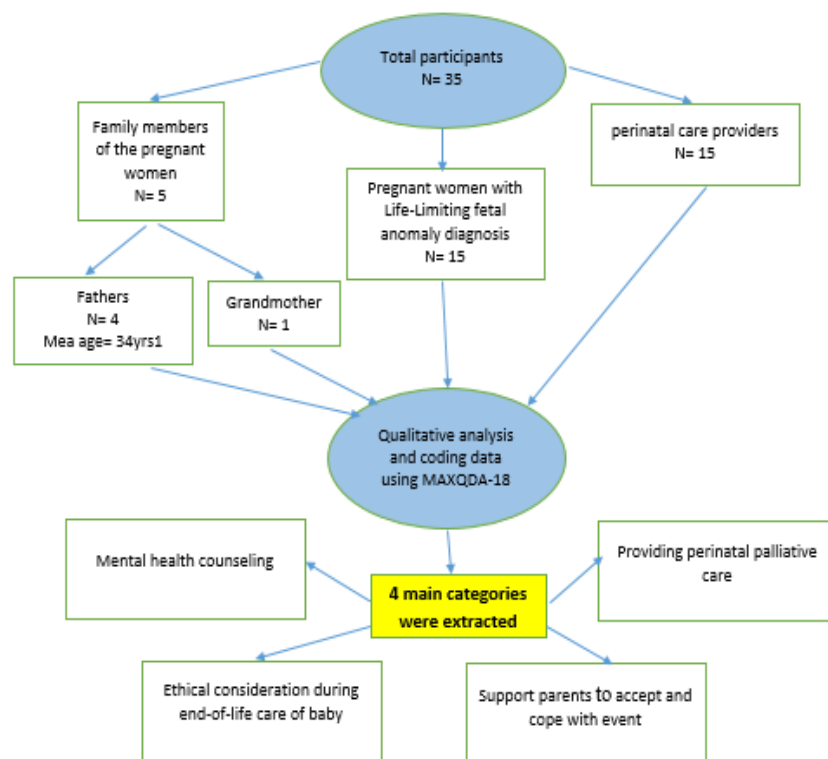


Figure 1. Flow diagram of study participants

thoughts and feelings at that moment?”, “please tell me about your experiences since you have been cared for baby at home.” In interviews with health providers was “please tell us about your experience about caring for mothers with abnormal fetuses”.

The place and time of the interview were specified based on the participants' opinions (home, hospital, health center and clinics). The interviews were planned after explaining the objectives of the research to the participants. The duration of the interview varied from 45 to 120 minutes. Sampling was continued until the time of data saturation was reached. All interviews were recorded and transcribed word by word after obtaining permission from participants. The data analysis process was performed simultaneous with data collection manually, using the Granheim & Lundman method (17).

Each of the interviews was listened several times, the researcher transcribed and read them to gain a deeper understanding of their data. Then, words, sentences or paragraphs related to each other through their content and context were identified (17), and the initial codes were extracted and categorized based on conceptual and semantic similarities in more abstract subcategories until main categories were emerged. After multiple reviews, the researcher and participants reached a semantic commonality about the categories. The data obtained in the interviews containing all the field notes, audio and video files were imported in MXQDA 2018 to organize qualitative analysis and coding data, and the data were simultaneously analyzed. Also, the text was analyzed using conventional content analysis as an inductive approach proposed by

Graneheim and Lundman. The data were analyzed using MAXQDA-18, qualitative data analysis software, and descriptive analysis technique. Main themes were generated and then the views were aligned under the themes.

Ethical Considerations

The study was conducted in accordance with principles embodied in the Declaration of Helsinki and approved by the Ethics Committee of Iran University of Medical Sciences (code: IR.MUI.REC.1398.357). All ethical considerations, including obtaining informed consent from the participants before entering into the study, preserving confidentiality and the optionality of leaving the research were observed.

Results

Out of 15 participating mothers, 9 people continued their pregnancies forcibly and due to fetal anomaly diagnosis after receiving legal abortion permit (up to the 19th week of pregnancy according to Iranian law) and 6 women voluntaries continued their pregnancy (5 cases because of cultural and belief reasons and 1 case due to lack of trust in screenings and physicians) (Table 1).

Twelve infants between 2 hours and 29 days, and 3 infants between 50-67 days survived. Health care providers included 7 physicians, 5 midwives and 3 nurses with 8-28 years of work experience (Table 2).

In this study, there were 2,578 codes, resulting from analyzing the texts. These codes were inductively classified into 15 subcategories and 4 main categories based on similarity and proportion (Table 3).

Table 1. Characteristics of Mothers with experience of continuing pregnancy despite fetal anomaly

No.	Number of Pregnancies	Age (Years)	Education Level	Type of life limiting Anomaly	Continuing Pregnancy
1	1	22	University	Trisomy 18	Optional
2	2	24	University	Skeletal Dysplasia	Forcibly
3	2	18	University	Congenital Heart Defects	Forcibly
4	4	41	University	Inherited Metabolic Disorder	Forcibly
5	1	32	High School	Down Syndrome and Congenital Heart Defect	Optional
6	2	37	Primary School	Skeletal Dysplasia	Optional
7	2	26	University	Trisomy 13	Forcibly
8	1	27	University	Trisomy 18	Optional
9	2	34	High School	Down Syndrome and Congenital Heart Defect	Forcibly
10	1	32	High School	Trisomy 13	Optional
11	1	17	Illiterate	Anorectal Malformations and Heart Defect	Forcibly
12	1	19	University	Hydrops Fetalis	Optional
13	3	38	High School	Trisomy 18	Forcibly
14	2	29	Primary School	Congenital Rubella Syndrome	Forcibly
15	1	26	University	Duodenal Atresia	Forcibly

Table 2. Characteristics of the health care providers working in the intensive care unit

Education level	Gender	Work experience
Midwife	Female	18
Perinatology specialist	Female	·1
Radiologist	Male	12
Nurse	Female	13
PhD in Clinical Genetics	Male	12
Master in nursing	Female	19
Pediatrician	Female	9
Family Physicians	Female	23
Midwife	Female	18
Gynecologist	Female	18
Midwife	Female	23
Midwife	Female	26
Midwife	Female	25
Gynecologist	Female	8
Nurse	Male	37

Mental health counseling

According to the participants, process of initial diagnosis until the next follow-ups was a stressful event and had emotional reactions like fear, shock, depression, guilt feeling, disorder in fetal/infant attachment, and needed psychological and emotional support from the care team and family to manage them. Parents emotional reactions to fetal anomaly diagnosis

According to our results, women experienced psychological crisis after hearing of a fetal anomaly. For example, one of the mothers said: "From the third month that I was told until the delivery time I had stress, I was just worried, not happy at all. I was under too much stress" (Mother No. 11). One of the nurses working in the neonatal intensive care unit said in this respect: "When the mother was here, she was always terrified. She attempted suicide twice. One time, she cut the refrigerator wire and hit herself with electricity in the hospital and repeated this behavior in her home, leading to severe burn".

Maternal-Fetal attachment disturbance

Mothers usually stated a bonding and attachment to the fetus, but with increasing gestational age and fetal anomaly diagnosis, most mothers expressed experiencing disturbance in their fetal/infant attachment. One of the mothers said: "Until I did not know my baby was like this, I was talking to him, but when I realized that he is abnormal I became like a crazy person. I was scared. It was like a strange creature in my abdomen" (Mother No. 14).

Parents' concern about repetition of anomaly in the next pregnancy

All the parents were worried about repetition of the anomaly in next pregnancy. Most of them concerned about what evaluations should do for the next pregnancy to avoid the repetition. A mother with a history of three infants' deaths with metabolic impairment said: "I had 4 cesarean sections but have only one 8-year-old child, my other children died, my first child is normal, second child died when he was 2 months old, he had a metabolic problem. The third child also died when he was 45 days old for this problem. Before my fourth pregnancy, I went to a health center and said my problems in the previous pregnancies, but I want to have a child. They did not inform me that this problem might occur again, now my fourth child has died due to a metabolic problem (Mother No. 4).

Support parents to accept and cope with event

Our data showed that parents with an anomaly fetus/ infant need to support for accept and cope with event.

Family role in supporting parents and other siblings

Most of the women stated that family has a key role in supporting them in accepting and coping

Table 3. Participants' Experiences about Continuation Pregnancy despite Fetal Anomaly Diagnosis

Main Category	sub-Category
1-Mental health counseling	Parents emotional reactions to fetal anomaly diagnosis Parents' concern about repetition of anomaly in the next pregnancy
2-Support parents to accept and cope with event	family role in supporting parents and other siblings Parents' need to interaction with peers stigma of having abnormal baby parents informational and financial needs
3- ethical consideration during end-of-life care of baby	confidentiality and privacy during mother and baby care Involve parents in decisions and gaining their consent for baby care respect parents' beliefs during baby care/death
4-providing perinatal palliative care	preparation inter-professional palliative care team empowering team for palliative caring of mother and baby development of resource and services relief baby pain/suffering

with the event.

One of the mothers who continued pregnancy despite the recommendations for abortion said "My mother, father and husband's family were always with us when informing we decided to continue the pregnancy; they supported us a lot emotionally and financially (Mother No. 8).

The results indicated that the parents had neglected caring for other children following the diagnosis of fetal/infant anomaly. One of the mothers stated her experience in a long hospitalization period of her abnormal child: "I have another daughter who is 3 years old. I have not seen her for 25 days that I have been in hospital. I do not know what she does, eats. My mother-in-law says that she has refused to eating food, she constantly takes your excuse and says when my mother comes" (Mother No. 12). Parents' need to interaction with peers

Participants had positive experiences of interacting with peers in boosting morale and going out from social isolation due to stigma of having an abnormal infant. Seeing children with the same conditions as their own child could have helped their hope and self-esteem. Participants had also need peers to reduce concern, to find answers to questions, and how to care for the infant. A mother despite of having two abnormal children said: "I would love to see these children. I see them when they were one month old, one-year-old and talked to their mothers and asked my questions, and it made me feel better (Mother No. 9).

Stigma of having abnormal baby

According to the participants' opinions, due to misconceptions about anomaly in society, having an abnormal infant affects the position of family and leads to social isolation, hiding the child and even dying the child Psychological support and counseling parents can help them accept an abnormal child. One of the midwives said: "we had a family whose child had an anomaly. They did not bring the child to the health center for care. This family had been isolated after the birth of their child. If they wanted to go somewhere, they did not take the child with themselves and left him alone in the house or car. Unfortunately, one day, the child suffocated in the car and died".

Parents informational and financial needs

Participants' experiences were full of unanswered questions about cause, nature of the anomaly, its severity and consequences and care methods. According to the mothers' experiences, no information was given to them in this regard or

the incomplete information had been offered. Although caregivers believed that the information should be provided in accordance with mothers need, appropriate answer to parents' questions had not been given. One of the fathers stated: " we wanted to continue the pregnancy, but no one gave us the right information about our baby to prepare ourselves for, even after he was born, while we were in the hospital for 45 days, none of the pediatricians and nurses gave us information about the baby that: What is my child's problem? What is his treatment? How many days will be hospitalized? What should we do? Will he survive?" (Father No. 1).

Many participants emphasized the need for family financial support and protection, treatment and diagnosis and covering the costs of infant care by the government, sponsoring organizations and insurance institutions. One of the mothers said, " I paid a lot of money for a DNA test. Then 3D and 5D ultrasounds, which were very high for me, that was my husband's 3 months' income. Many places do not accept our insurance; so I did not follow my screenings properly" (Mother No. 2).

Ethical consideration during end-of-life care of baby

Participants considered preserving the privacy and confidentiality of anomaly information to be part of their rights and expected to participate in decision makings related to fetal/infant, and their informed consent was obtained for any intervention.

Confidentiality and privacy during mother and baby care

One of the women's concerns was the invasion of privacy and informing other relatives about the fetal/ infant's anomaly. The grandmother of a hospitalized abnormal infant said: "In the same 10 days of the infant's hospitalization, the aunt of the baby came to the ward and asked a lot of questions from the nurses, and they said everything, and then took a photo of baby and put it in the WhatsApp group of their own family. My daughter also saw it and cried a lot. I told one of the nurses why did they take a photo of the child without our permission? Why did you give the child's information to everybody?"

Involve parents in decisions and gaining their consent for baby care

The analysis of the description of most parents and service providers indicated that the parents should be informed about treatment and care

stage in order not only to participate in decision makings but also to have informed consent for interventions.

Therefore, the infant treatment protocol should be provided to the family step by step and they should be given the right to decide whether to continue or discontinue treatment. The family should be given the right to choose the place of treatment. One of the fathers said: "I got more stressed every day. We were not aware of the process of his treatment and what they were doing for him? We insisted a lot to take my child to another hospital. Maybe he will survive. But the day he got sick, the doctor told us it was no longer useful, I wanted to take him home, to be with ourselves, which they did not allow either; as if it was completely out of our business" (Father No. 2).

Respecting parents' belief during baby care/death

Some families said the illness and death of their child is a divine test, and they wanted to come out proud in this divine test and not to be ungrateful to God. Under these circumstances, they expected others, and specifically the health team respect their beliefs and decision. One of the mothers who chose continuing the pregnancy despite of abortion permission following being diagnosed with a severe anomaly in amniocentesis; said: "Most of the people working in the clinic said to me, are you crazy, why you do not want to abort your abnormal baby? I said, I entrust it to God, this is a divine test. We love a child in any situation and he is a human being and there is wisdom in the birth of this child" (Mother No. 8).

Providing perinatal palliative care

Data analysis showed that caring for an abnormal fetal/ infant requires specialized inter-professional and team services. The health team must in particular have sufficient capability to provide resource and services for perinatal palliative care.

Preparation inter-professional palliative care team

Most participants stated that teamwork is very important for the effectiveness of follow-ups related to diagnosis and treatment, and expected care to be performed by a team aware of the clinical situation and palliative care, while this issue has been neglected in the medical team. In this regard a mother said: "Right now I have six different opinions from several specialists, from gynecologist

to embryologist, sonographer and geneticist, that I have been left out because of their conflicting speeches that we should terminate or continue the pregnancy. (Mother No. 10).

Empowering team for palliative caring of mother and baby

Empowerment of human resources in the field of palliative care has been a special need, and training the health team in the fields of palliative and mourning care by holding short term courses should be considered by policy makers. One of the participating fathers stated: "One of the specialists who is one of the greatest physicians and the head of the hospital treated us very badly and when we asked him what should we do, he said that he has a severe anomaly, I told him, so what should we do now? He said: Go and leave it in a corner, or he will die, or it will grow to some extent, and then he will die, and he never understood us" (Father No. 4).

Development of resource and services

Many participants called for fair access of mother and infant to the health team (perinatologist, genetic counselor, sonographer, and caregiver). The family doctor said in this regard: "The main problem is that many mothers do not have access to facilities such as genetic counselor or perinatologist same as larger cities, there are more facilities for mothers to follow fetal screenings and they face much less problems".

Relief infants pain/suffering

Most mothers have had numerous experiences of their abnormal infant's suffering and pain during medical care and interventions that have left them feeling guilty and sad for a long time. A mother stated: "I am a mother; no one wants her baby to be treated like this. I was not there all the times, whenever I was there, they took blood from him, they pierced my baby to get blood, my heart was broken, or the noise of the devices was in my baby's head. If, as they say, this baby dies in one or two days later and it is useless, why do they hurt him so much?" (Mother No. 13).

Discussion

Participants' Experiences about Continuation Pregnancy despite Fetal Anomaly Diagnosis in cultural of Iran summarized in 4 mains categorize. The results showed that the diagnosis of fetal anomaly leads to serious emotional and psychological disturbance in parents, especially mother; so that parents suffer from shock, ambiguity, attachment impairment that the results

of previous studies are also consistent with this case (2, 18). Attention to the emotional state of mothers, including level of stress and isolation, and importance of continuity and sensitivity of care in this period due to psychological problem has been emphasized and on the other hand due to the mother's attachment to her child during pregnancy, the mother's vulnerability after the diagnosis of fetal/infant anomaly is increased and even this vulnerability continues up to one year after delivery (14). Therefore, strengthening the bonding behaviors of parents with the infant after birth, such as touching and hugging the infant should be one of the working priorities of employees during and after childbirth (19).

In this study, parents request information about the infant's anomaly, factors, consequences, and treatment, as well as the decision-making for next pregnancy. In addition, providing insufficient information to the parents after diagnosing anomaly in pregnancy leads to their unanswered questions and unpreparedness in the future for the infant's care and treatment. The information should be presented to both parents in a simple and understandable language and with the cultural background and native language appropriate to the needs of the parents (20, 21). A qualitative study on experiences of women with fetal anomaly showed that when there is no interaction between the health care team and parents or being discrepancies in the information provided to them, they have to seek the information through public sources such as the internet, however, this source can also be invalid (22). In our study, mothers were also sought the information on the internet due to not receiving the necessary information from the health team. Another need of families in our study was the need to inform about the next pregnancy, they needed to know more about necessary care and follow-ups in the future to avoid repeating the anomaly and decreasing their stress. In a study, Irani et al., showed that health care providers are responsible to the mothers for giving them the information they need about the next pregnancy because it can reduce their concern for the recurrence of event in the next pregnancy (20).

The majority of mothers in this study emphasize the need for supports from their spouse, family, friends and peers as one of the most important supportive sources. Because families consider isolation as one of the ways to deal with fetal anomaly after being aware of their child's problem, leading to less communication with their families (22). Also, with initial diagnosis

of fetal anomaly, mothers do not often talk honestly about their thoughts and feelings with their friends and family members and service providers, so support of families is necessary (7). In this study, the stigma of having an abnormal infant led to isolation of the parents and even the death of the infant. Also, a study by Irani et al. showed that receiving social supports after informing about anomaly leads to a reduction in psychological harms, including stress and depression (23).

In Hudson's study, relieving the infant's pain in the last stage of life was considered and emphasized by the participants (24). For relieving the pain, non-pharmacological pain relief such as quiet environment, infant massage, mother-infant bonding and drug pain relief for infant' comfort should be used. Therefore, the use of standard pain scales, the existence of medication protocols, as well as training the health team for managing infants' pain in the final stages of life is essential (24).

Preparing palliative care team and empowering them was another need on which participants emphasized, including strengthening team and inter-professional care and the ability to provide palliative and mourning care. The study of Wool et al. showed that in palliative care, unique and synergistic cooperation of physicians and nurses has a positive effect on service delivery, so, physicians associated with these cares should consider team cooperation for supportive intervention and proper cares (25). A qualitative research showed that counseling for team cooperation is effective in coordinating and exchanging medical information which increases team understanding of the needs of families, helps families to facilitate facing with existing conditions and increases team relationship and integrating care (22). In order to increase the skill and competence of all employees who are in contact with parents who need palliative care and have end-of-life care needs, it is better to create a suitable opportunity for expansion and inter-professional training as well as becoming the most suitable for mourning and end-of-life care (26, 25). Perinatal palliative teams advocate primarily for respect of parental wishes, supporting a spectrum of goals from comfort-focused to life-prolonging care (27). This study, participants also emphasized on empowering the health team in palliative and mourning care and strengthening team and inter-professional cooperation.

The main limitation of this study is that low number of family members, especially fathers, compared to mothers participating in the study.

Future studies are recommended to address the perspective of family members.

The strength of this study was that the participants included of both the parents and the health-care providers with experiences about continuation pregnancy despite fetal anomaly diagnosis and collection of data from women in different stages in life as well as different fetal diagnoses and different gestational ages. This study was conducted on limited groups of the Iranian population, while there are numerous subcultures in the country that are different with regard to culture, lifestyle, race, and believes. In order to prevent the impact of this problem, the participants were selected from different provinces with a variety of cultural backgrounds. Furthermore, although the study results revealed the participants' experiences, they might not be generalizable due to the qualitative nature of the research.

Conclusion

This study revealed, necessity of providing perinatal palliative care for both the baby and his/her parents, especially for mothers during pregnancy, delivery and after that

by inter-professional team. The results showed that parents of fetus/newborns with anomaly diagnosis, especially mothers, need mental health support by family and peers. Also, ethical considerations such as service confidentiality and involve parents in decisions in how to care from baby and respect to parents' believes should be given importance. Therefore, the health system should provide these services for both the baby and his/her parents by preparing competent perinatal palliative care teams.

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Conflicts of interest

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Authors' contributions

SK conducted the design of the study. All authors were involved in drafting the article or revising it critically for important intellectual content. All provided final approval of the manuscript and agree to be accountable for all aspects of the work.

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