The Perceptions and Experience of Women With Gestational Diabetes Mellitus in Taiwan: A Phenomenological Study

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Research Article

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Abstract

Background: At present, most research related to GDM investigates disease control from the perspective of medical care givers. Medical professionals often lack understanding of the life context of GDM, which not only alienates them from the experience of patients with GDM but also leads to the provision of health care and the formulation of policies that are not appropriate for women. The objective of the present study was to explore the perceptions and experience of women with GDM in Taiwan.

Methods: A descriptive phenomenological approach was applied to conduct this study. Purposive sampling was utilized to select 22 women with GDM from a medical centre in northern Taiwan. Data were collected from October 2017 and July 2018 through in-depth interviews using semi-structured and open-ended questions. Data were analysed according to Giorgi's phenomenological method.

Results: Four themes emerged from the data: Unexpectedly having a high-risk pregnancy, Beliefs of effects of blood glucose control, Perceived obstacles of implementing blood glucose control and Maternal duty to ensure the safety of mother and child.

Conclusions: Health professionals must be able to understand the experience and perception of women with GDM. In addition to the medical care needs for women with GDM, their culture, the emotional impact of the disease, and their feelings and difficulties in the face of the disease must be considered to ensure that women receive comprehensive perinatal care.

Background

Gestational diabetes mellitus (GDM) refers to different degrees of glucose tolerance that occur or are first diagnosed during pregnancy [1]. With the increase in obesity, late marriages, high maternal, unhealthy lifestyles, the prevalence of GDM has increased, leading to a growing medical burden [2]. Due to the differences in genetics and diagnostic methods and a lack of universal comprehensive screening during pregnancy, the prevalence of GDM varies widely among countries, ranging from 2–25% [2]. Taiwan does not yet have relevant national statistics, although regional studies have shown a GDM prevalence of approximately 3.5–7.9% [3].

GDM is likely to cause macrosomia of the foetus, severe perineal laceration, shoulder dystocia, brachial nerve plexus injury, and stillbirth during vaginal delivery and is associated with an increased chance of caesarean section due to delayed labour [1]. In addition, the International Association of Diabetes in Pregnancy Study Group (IADPSG) issued a warning in 2010, the Hyperglycaemia Adverse Pregnancy Outcome (HAPO), which clearly pointed out the harm that high blood glucose poses for mothers and babies. Many studies have pointed out that exposure to high blood glucose in utero will increase the risk of future glucose intolerance and overweight [4]. If blood glucose is not properly controlled during pregnancy, it will cause short-term risks and long-term comorbidities to the mother, foetus or new-born and increase the lifetime risk of cardiovascular disease and metabolic syndrome [5].

Pregnancy is a special process in which a woman is no longer just a single individual; her life is intertwined with that of the foetus. In the process of conceiving a new life, everything that a pregnant woman does affects the foetus in utero because the mother and foetus form a life alliance. Therefore, health care for women with GDM should be different from care for other types of diabetes because it affects the interactive course of two lives [6]. Greenhalgh et al.(2015)'Behaviour change' interventions aimed at managing diabetes in women during pregnancy are likely to be ineffective if delivered in a socio-cultural vacuum [7]. Lindseth and Norberg (2004) pointed out that only by understanding a patient's life experience, value and health beliefs can we guide the development of culturally specific health interventions [8]. Therefore, directly investigating and understanding the life experiences and opinions of women with GDM will provide meaningful contributions to health care.

At present, most studies related to GDM examine disease control from the medical perspective [9,10] with less focus on the impact that the special role of pregnancy has on diseases. Medical professionals often lack understanding of the life context of GDM, which not only alienates them from the experience of GDM but also leads to the provision of health care and the formulation of policies that are not suitable for women. While most studies regard GDM as a disease, in the present study, we aim to understand the views and experiences of GDM from woman's perspective by considering GDM as a lifestyle issue that must coexist with pregnancy. We attempt to understand the experience when diabetes becomes a part of pregnant life from the perspective of women with GDM and try to provide a reference for medical care from the woman's perspective based on our results. Therefore, this study applied a qualitative, phenomenological approach to explore the perceptions and experiences of women with GDM in Taiwan.

Methods

Design

Husserlian phenomenology describes and emphasizes a person's lived experiences [11]. Phenomenology is a way of exploring essential themes, and through the description of the phenomenon, eidetic reduction, and interpretation and structuring of the experience, it provides a description of the woman's experience in their life and world and reveals the structural connotations of the subject's life experience [12]. Husserl proposes the concept of bracketing, which is to imagine, feel, and experience the world intuitively with a natural attitude, as well as to set aside various assumptions or thoughts about a phenomenon [11,13]. In this study applied Husserl's descriptive phenomenological method to describe, explain, and discuss the meaning and essential structure of the experience, expressions and the context of statements by women with GDM as the basis for the description of the phenomenon and truthfully referred descriptions to the meaning of the experience itself [12]. In this way, the meaning of GDM can be interpreted from the perspective of women, and the experienced meaning of GDM can be understood.

Participants

The study was conducted October 2017 and July 2018 during visits to a maternity clinic at a medical centre in northern Taiwan that experiences approximately 4,000 births per year. Using purposive

sampling, suitable research subjects were referred by obstetric outpatient doctors or nurses and invited to participate in the research. The following inclusion criteria were applied: (a) 18 years of age or older; (b) At least 28 weeks pregnant; (c) Diagnosed with GDM and agreed to be interviewed; (d) women must be able to communicate in Mandarin or Taiwanese. A total 22 women were enrolled in the study.

Data collection

The location of the interview is chosen by the women to be natural and comfortable. The women were interviewed face-to-face, the interview site at the obstetrics clinic interview room had a private space that was quiet, comfortable, and free from disturbances. The interviews lasted approximately 40-60 minutes. Opening questions to encourage the sharing of women lived experience included: "Please talk about your feelings about this pregnancy. How did you feel when you learned that you have GDM? What are your thoughts about yourself and your child? What impact has GDM had on you? How do you deal with it?" The interviews were recorded and notes were taken, and the woman's expressions, movements, tones and other non-verbal expressions were closely observed and recorded. The interview continued until the woman had expressed all that she wanted to express.

Data analysis

This study used the data analysis method of Giorgi (2009) [11]. The first step was to read the data to gain a sense of wholeness. The first author first transcribed the recorded data verbatim, and then all authors listened to the recorded conversations and read the transcripts to gain an overall impression of the phenomenon. Based on this understanding, the authors proceeded to the next step, which was to determine the meaning units of the data. The formation of meaning units is an abstract process in which the researchers move from category, sub-topic to topic, describing the life contexts and experience of the women according to the woman's internal time line. Through this process, the researchers were guided toward an understanding of the experience and opinions of women with GDM. The third step was to convert the women's natural expressions into phenomenological psychological expressions. The researchers returned to the beginning of the process include the description of the meaning unit and queried each meaning unit to determine whether it expressed the women's life experience; this process continued until the meaning and the essential structure of the woman's specific experience was appropriately expressed [11,13]. Data analysis and data collection for this research were carried out simultaneously. After each interview, the data were sorted, coded and analysed. When new themes stopped emerging from the analysed data, saturation was reached, and data collection was stopped.

Rigor

Rigor was ensured via the criteria of credibility, transferability, dependability, and confirmability developed by Lincoln and Guba (1985) [14] and Sandelowski (1993) [15], The credibility of the data analysis in this study was increased by co-analyses that were jointly conducted by the authors, members of the research committee and peer debriefing. Transferability concerns the aspect of applicability. The researchers provided a rich account of descriptive data, such as the context in which the research was carried out, its

setting, sample, sample size, sample strategy, demographic, socio-economic, and clinical characteristics, inclusion criteria, interview procedure and topics, and excerpts from the interview guide, to enable the reader to assess whether your findings are transferable to their own setting. A clear audit trail was used to ensure dependability. This audit trail included reflective notes and self-awareness memos that were generated during the data collection and analysis process. Moreover, the first author and members of the research committee continuously compared and confirmed the data and analyses, helping reduce the risk of individual bias. During the study, the recording materials, texts, analysis procedures, and research logs were properly kept, and the research process was recorded in detail for auditing purposes and to serve as a reference for future research interpretation to allow confirmability.

Ethical considerations

The study was approved by the Chang Gung Medical Foundation Institutional Review Board, Taiwan, and the participating maternity departments granted approval (IRB NO.106-2950C1). The researcher explained the purpose of the study, the protocol, the interview questions and the duration of expected participation to the women and assured them that their data would remain confidential. The women were allowed to withdraw from the study at any time. Written informed consent was obtained from all women.

Results

A total of 22 women were contacted. The average age was 35.6 years, the pre-pregnancy body mass index (BMI) was 17.0-39.1 kg/m² (mean of 26.4 kg/m²), and 68.2% were overweight before pregnancy. Only one was unmarried, 59.1% had a college degree or above, 45.5% were primiparas, 54.5% had a family history of diabetes, and two had GDM in a previous pregnancy. The characteristics of the participants are provided in Table 1.

This study focuses on the perceptions and experience of women with GDM, four themes emerged from the data: Unexpectedly having a high-risk pregnancy, Beliefs of effects of blood glucose control, Perceived obstacles of implementing blood glucose control and Maternal duty to ensure the safety of mother and child. A summary of the four themes and 12 subthemes is revealed in Table 2.

Unexpectedly having a high-risk pregnancy

The women did not expect to be diagnosed with GDM and have a high-risk pregnancy. In addition to determining the cause of the illness, they were increasingly concerned about the impact of GDM on the foetus and themselves.

Unexpected diagnosis of GDM?

Because the women did not have diabetes, they didn't have any symptoms of diabetes during this pregnancy, blood test to find out about GDM, the diagnosis of GDM was unexpected.

'I heard the doctor say that I have GDM in this pregnancy, and I was surprised and asked the doctor: I don't have diabetes; how could I get GDM?... I would never have known without the blood test' (in raised voices) (Case O)

There was no discomfort and no symptoms of diabetes during this pregnancy. Some women wonder why this is considered GDM:

'I don't have morning sickness, I eat the same thing as before this pregnancy, and I do not have any physical discomfort. After 6 months of pregnancy, the doctor said that I have GDM... If it is GDM, there should be uncomfortable symptoms...' (Case D)

Looking for the cause of GDM

The women tried to determine the cause of GDM by looking back over the pre-pregnancy period and the pregnancy itself to clarify the relationship between events experienced during pregnancy and GDM. Looking back over this pregnancy, advanced maternal age is one factor that is different from previous pregnancies and may be the reason they have GDM:

'My age at the time of this pregnancy is older than it was for the previous two, the time of this pregnancy is 41 years. The first two pregnancies were both normal. It could be due to the older age that GDM is occurring in this pregnancy.' (Case N)

Some women were obese before pregnancy; that is the cause of GDM:

'I knew I was 90 kg when I was pregnant, and I could not lose weight when I was pregnant.... Is it being overweight that made me get diabetes?' (Case S)

Could changes in tastes during this pregnancy be the cause of GDM?

'During this pregnancy, I like to eat sweets, cakes, breads, sugarcane juice... and drink sweetened beverages after meals. I do not know if it is this change in tastes and preference for sweet tastes that make me have GDM....' (Case N)

Hidden worries about the adverse effects of GDM

The women indicated that once they knew that they had GDM, they began to worry about the impact of the disease on the foetus and themselves.

'With GDM, the issue that I worry about the most is the potential effect on the baby and whether it will be passed on to the baby and the baby will have diabetes later...' (Case O)

In addition to worrying about the foetus, they began to worry about the impact of the disease on themselves.

'I am worried about GDM and complications during pregnancy, whether I will be diabetic after giving birth, and whether diabetes will always follow me and will not disappear...' (choking) (Case J)

Beliefs of effects of blood glucose control

Facing GDM, the women experienced different perceptions and challenges, including whether controlling their diet would affect foetal development and whether exercise would hurt the foetal spirit, offend the guardian god. Additionally, they described emotional challenges related to GDM.

Worrying negative effects of diet control on fetal development

In Taiwan's traditional culture, it is believed that 'one person eats, and two people benefit'; that is, that the nutrition of pregnant mothers affects the health of the foetus. When GDM requires diet control, women worry that controlling their diet will affect foetal development.

'People often say that 'one person eats, and two people benefit'. What you eat during pregnancy is very important. The food the mother eats is the source of nutrition for your baby. If you cannot eat this or that during pregnancy, will it limit the growth of your baby...?' (Case E)

Concerns about whether exercise will cause preterm labour

Exercise plays a very important role in the control of blood glucose in GDM. However, according to traditional Chinese concepts, women face many taboos during pregnancy. If these taboos are violated, preterm labour symptoms will cause premature birth or disaster.

'I know that exercise can help blood glucose control, but my mother-in-law warned me not to move anything during pregnancy because exercise may cause preterm labour symptoms, and the child will be born prematurely or have problems after birth or something else... what should I do...?' (Case R)

Psychological stress

As the women had to maintain their blood glucose during pregnancy for health concern, they were advised to have some diets control. However, most of them experienced the sense of failure which came from repeated warnings from family members and comparisons with others with previous pregnancies. These improper feedbacks might result in emotional reactions of frustration, isolation, and depression.

'After learning about GDM, I eat only one portion. Even if I eat less, my blood glucose is still as high... Isn't it frustrating...?' (Case G)

The repeatedly warning of family members make women feel sad and isolated:

'The family keeps telling me to walk around after meals so that my blood glucose will not be high and will not affect the baby.... My family only cares about the baby's health.... It makes me feel very isolated...' (choking) (Case B)

When compare with the pregnancy of others it makes women feel depressed.

'Others can eat anything when they are pregnant. I have to limit what I want to eat. When I think of this... I feel very depressed...' (Case R)

Perceived obstacles of implementing blood glucose control

Blood glucose control is extremely important for managing GDM in women. However, the actual implementation of blood glucose control in real life presents dilemmas, including challenges with diet during social gatherings, the difficulty of apply what is learned, and the psychological burden of living with diabetes.

Diet challenges during social occasions

During social gatherings, eating issues become the focus of the family's attention. The women indicated that when they stop restricting themselves and lose control, guilt usually followed, causing tension between control and loss of control.

'My family knows that I have GDM. Everyone's eyes look at every bite of food I eat. As long as there are sweets, they will say, 'Don't eat this..., eat less....' I can't eat what I want, so I can't eat enough... I still eat what I want in the end.... I feel very sinful after eating....' (Case K)

To know is easier than to do' in exercise implementation

The most difficult part of exercise implementation is usually the feeling that "to know is easier than to do." Although women know that exercise is critical, they usually cannot put it into practice.

'When walking and exercising, my belly keeps falling down. It feels like my belly is about to fall. It is really difficult to do it.... I know that diet control alone is not enough without exercise, and my blood glucose control is not good.... But it's really difficult to exercise....' (Case R)

Psychological burden of living with GDM

GDM control is closely related to lifestyle. To live with GDM, it is necessary for women to change their original living habits, including their daily diet and exercise, and to perform regular blood glucose monitoring. In real life, these self-care rules must be implemented, and related restrictions must be accepted, which places a considerable psychological burden on women.

'For three meals a day, you have to deal with 'What you can eat? What can't you eat?....Every time I eat, I feel a lot of psychological pressure. I have to exercise again after meals. I am afraid that my blood glucose will be too high if I eat without exercising... I think about diabetes all the time.... It is very stressful....' (in raised voices) (Case D)

Maternal duty to ensure the safety of mother and child

The goal of diabetes control is maternal and child health. Women are responsible for protecting their infants from harm. They change their attitudes towards health, adjust their lifestyles, and become cautious about their health during pregnancy to ensure the safety of themselves and their children.

Change attitudes and behaviours towards health

The women realized that if they did not care about their health, it will affect both themselves and their baby; thus, they changed their attitudes and behaviours toward health to ensure their own and their baby's health.

'Now in the afternoon, I will drink a cup of soy milk or milk.... I choose my food and will not consider junk food.... I eat healthy, and the baby can be healthy.' (Case R)

In addition to choosing foods more carefully, the women paid attention to the ingredients of the food to ensure their health and that of their baby:

'GDM affects my life and my baby. Now I will definitely look at the label and content of food ingredients before making a choice. It's not just me who eats; the baby eats with me....' (Case Q)

Increased caution about health during pregnancy

Faced with an uncertain pregnancy and concerns about their health and that of their foetuses, women pay attention to physiological changes, realize the importance of regular check-ups and take cautions regarding their health during pregnancy.

'I will notice that if I am always hungry, thirsty, or go to the bathroom often, it may be due to high blood glucose... foetal movement... After dinner, I will calculate the foetal movement and know about the baby's condition....' (Case J)

In addition to paying attention to symptoms of high blood glucose and foetal movement, the women also paid attention to regular check-ups to understand their condition and that of their foetuses:

'I know that I have GDM, and I will be very careful. Regular prenatal check-ups are very important. Urine glucose testing, weight, blood draws and ultrasounds at the prenatal check-up can help to understand the condition of myself and the foetus and make me more at ease....' (Case R)

Adjusting lifestyles

The health of women has a direct impact on the development of the baby. Lifestyle adjustments are made in the areas of diet, exercise, and sleep to maintain stable blood glucose and ensure the health of mother and child.

'You have to learn to eat alternatives so that you can choose different foods and pay attention to the amount of food.... You need to control the amount and be 80% full... Walking exercise after a meal...; my

blood glucose is stable, and the baby will be stable....' (Case V)

In addition to diet and exercise, sleep, work, and rest schedules also need to be adjusted to maintain blood glucose stability and ensure the health of mother and child:

'Before, I went to bed after 12:00, my schedules were irregular, my blood glucose fluctuated high and low.... Now I go to bed at 22:00... the blood glucose will not fluctuate a lot... so it doesn't affect the baby....' (Case O)

Discussion

The initial reaction of women diagnosed with GDM is 'unexpectedly' [16]. In addition to wanting to know the cause of the illness, they also begin to worry about their health and that of their foetuses, fearing that it might change and cause potential issues for the foetuses. To ensure the health of themselves and the foetus, women will take appropriate actions to control GDM through diet and exercise [17].

Taiwanese tradition indicates that during pregnancy, 'one person eats, and two people benefit; the mother is healthy, and the foetus is strong' and 'the ability to eat is a good fortune' [18]. Therefore, eating a lot and getting hungry easily is often regarded as an indication that the baby is absorbing food well, and changing tastes with particular preference for sweets and white rice are often considered a natural phenomenon in pregnancy. These changes are rationalized, and the possibility that they are warning signs of high blood glucose is ignored. The results of this study are similar to those of Greenhalgh et al. (2015) which found that South Asian pregnant women living in the United Kingdom believe that the body is like a machine, food is the fuel that drives the machine's activities, diet is the source of power for the mother and the foetus, and dietary restrictions can cause nutritional deficiency in the mother and the foetus and put their health at risk [7]. Women in South India also have a similar situation: They think that the foetus will be unhealthy if they do not eat enough, and diet control violates old ideas [19]. This low self-awareness may be an obstacle to health management in GDM. A systematic literature review also indicated that in order to help women self-manage GDM, more attention should be paid to the disadvantages of GDM health management, including role expectations, cultural issues, and economic barriers [17]. In addition, it is necessary to pay attention to favourable factors, improve women's health literacy and make full use of women's motivation to implement a healthy lifestyle. Health professionals should be culturally sensitive and provide women with clear, specific, and tailored health information and guidance [20,21]. When health education is limited to telling women to control their diet and exercise more often, women do not know where to start and do not feel cared for [22].

Nurses and health professionals need to remain cognizant of the intense impact diabetes has on pregnant women's lives [23]. Pregnant women's stories need to be heard to facilitate our understanding how they are coping with their pregnancy and diabetes self-management [20]. Unconditional respect for the lived realities of these women is needed as they try to cope with their diabetes and set self-defined goals. By being present with the pregnant woman, listening to her concerns and identifying with their challenge's nurses can shift their focus away from the pregnancy itself and more towards the woman as

a person first who is pregnant and has diabetes [24]. Working in partnership with the pregnant woman, health professionals can assist in the development of a diabetic regime that is congruent to the woman's culture and priorities and fits within the context of her life [20, 23, 24].

Regarding sports, Taiwan's folk traditions state that there are gods for everything in the world, and pregnancy is the beginning of a new life. Therefore, there are gods that specialize in pregnancy to protect the safety of the foetus in the mother's body. This god is the 'foetal god' [25]. Foetal gods are usually around pregnant women, either in fixed positions or attached to certain objects. People are not allowed to offend them. Offense will cause pregnant women to suffer from abdominal pain or miscarry or will cause the foetus to be deformed or even die [25]. Therefore, during pregnancy, pregnant women should fully rest, avoid lifting heavy objects, overworking, and vigorously exercising to avoid miscarriage-related symptoms or affecting the pregnancy [26]. Therefore, in the past, most women have not developed the habit of exercising during pregnancy. If they did, most of them just walked or climbed stairs [18].

A review study revealed that the factors that the influencing factors of the exercise habits of women with GDM included poor weather, lack of time, the need to take care of other children in the family, lack of motivation, the feeling that housework is always more important than their own health, and psychosocial factors [27]. However, in the present study finds that in addition to these factors, sixteen women (16/22) spoke of traditional contraindications also affect the exercise habits of women with GDM. Although we are currently in the high-tech information age and the level of education of the population has been greatly improved, culture is still an important factor affecting health beliefs and behaviours. In addition to actively seeking modern medical care, women still accept pregnancy-related traditional customs to ensure that they and their foetus can stay safe during pregnancy and that they can fulfil their maternal tasks.

Previous studies have found that women with GDM experience many negative and lonely emotions, the support of their spouses and family members is an important factor in helping them implement health-promoting behaviours and self-management [17, 22]. However, this study has different findings. Women with GDM feel that their family members often play a supervisory role, monitoring them to prevent them from eating too much or urging them to walk around after meals. Sometimes they feel that their family members only care about the foetus' health and ignore their own feelings. This may be because the concept of family unity is a cultural ideal embodied in Confucianism in Chinese society. Parents are obliged to take care of their children and do their best to ensure the happiness of themselves and their families [28]. Therefore, spouses and elders often offer continuous reminders to pregnant women. These emotional expressions are restrained and reserved, and they can easily make women feel uncared about.

From the beginning of pregnancy to the end of childbirth, the most important task for pregnant women is to ensure the safety of themselves and their baby. Although GDM presents many challenges, the main motivation for changes in lifestyle is minimizing risks to the unborn baby; thus, women prioritize the health of the baby over their own health and are willing to take all measures necessary to ensure that the baby is not harmed [17]. Faced with the uncertainties about the pregnancy process and the health of

themselves and their foetuses, women with GDM pay attention to the physiological changes they experience, realize the importance of regular check-ups, and are cautious about their health during pregnancy [29]. This finding can help health providers to take the perspective of women with GDM, and understand the meaning underlying their behaviours so as to provide the women with the attention and care they need.

Conclusions

In this study, many women are unexpectedly diagnosed with GDM, their truth perceptions and experience. They worry about the health threats that GDM poses to mothers and children. Therefore, women seek answers through various channels, hoping to control their blood glucose. In this context of chaotically presented and divergent information, the adoption of dietary control and developing and maintaining exercise habits differs from the traditional concept of nourishing a foetus; thus, the women experience psychological stress. When lifestyle changes are required, subjecting women to many restrictions, but blood glucose is still poorly controlled, women feel even more frustrated and uncertain. In addition to actively seeking modern medical care, women still attend to pregnancy-related traditional beliefs to ensure that they and their foetus can stay safe during the pregnancy and they can easily fulfil their maternal tasks. Health providers should be culturally awareness and sensitive when providing health education to help women strike a balance between traditional beliefs and modern medical care.

Abbreviations

GDM

Gestational diabetes mellitus

Declarations

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Authors' contributions

Study conception and design: MCS, JCS; Data collection: MCS, JCS; Data analysis and interpretation: MCS, MYC, JCS; Drafting of the article: MCS, JCS; Critical revision of the article: MCS, MYC, JCS. All authors read and approved the final manuscript.

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Availability of data and materials

Data analyses were performed with semi-structured interviews, which are not available to other researchers, due to ethics and confidentiality issues. The datasets used during the current study are available from the corresponding author on reasonable request.

Ethical approval and informed consent to participate

The study was approved by the Chang Gung Medical Foundation Institutional Review Board, Taiwan, and the Chang Gung Medical hospital maternity departments (IRB NO.106-2950C1). Informed consent for the use of anonymous direct quotes in reports was obtained from all participants. All methods were performed in accordance with the relevant guidelines and regulations (Declaration of Helsinki).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Tables

Due to technical limitations, table 1,2 is only available as a download in the Supplemental Files section.

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