

Lived Experience of Refugee Women Residing in Gaza Strip, Palestine Following Diagnosis of Gestational Diabetes

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ABSTRACT---

OBJECTIVE: This qualitative descriptive study was conducted to explore the lived experience of refugee women residing in Gaza Strip following a diagnosis of gestational diabetes mellitus (GDM).

DESIGN AND PARTICIPANTS: The study design was informed by grounded theory analysis. Twenty women who were recently diagnosed with GDM were recruited from the United Nations Relief and Work Agency (UNRWA) primary health care clinics in the Gaza Strip. Data was collected using semi-structured interviews.

RESULTS: Three themes were identified: lack of awareness, coping with the situation, and maintaining sustainability.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE: Our findings highlight the positive and negative magnitudes experience among GDM women to sustain a new lifestyle, which may inform the UNRWA health care professionals to focus on the barriers that prevent sustaining a healthy life style after the diagnosis of GDM to prevent diabetes type II in the future.

Keywords--- Gestational Diabetes, Refugee Woman's Experiences, Pregnancy, Gaza Strip

1. INTRODUCTION

Gestational Diabetes Mellitus (GDM) is a major threat to public health which has a high prevalence rate all over the world (Ferrara, Kahn, Quesenberry, Riley, & Hedderson, 2004; Lamberg, Raitanen, Rissanen, & Luoto, 2012). There are various risk factors for GDM which include advanced maternal age, family history of diabetes and increased pre-gravid body mass index (BMI) (Di Cianni et al., 2003; Metzger et al., 2007; Rajab, Issa, Hasan, Rajab, & Jaradat, 2012). The prevalence of GDM is constantly increasing globally (Lamberg et al., 2012; Seshiah et al., 2008; Yang et al., 2009) and it is increasing in parallel to the ongoing epidemic of obesity and type II diabetes among women who are at their reproductive age (Lawrence, 2011; Rajab et al., 2012). It was reported that approximately 50% of GDM women will develop type II diabetes in five to ten years following their pregnancies (Rajab et al., 2012). Recent reports also provide a convincing evidence of an increasing prevalence of GDM around the world (Lamberg et al., 2012; Metzger et al., 2007).

Pregnant women with GDM are at higher risk for multiple complications that affect both the mother and her fetus. The impact of being diagnosed with GDM leads to developing medical complications and demanding changes in lifestyle as part of the treatment. This topic was not investigated in the Gaza Strip before. Living the experience with GDM encourages some women to adapt to the new situation and lifestyle later on. However, for these women to adapt to the

new lifestyle, they need self-commitment and support for achieving future lifestyle sustainability (Persson, Winkvist, & Mogren, 2010). On the other hand, higher levels of stress and anxiety during pregnancy and lack of support reduce women's desire to keep and sustain new behavioral changes after delivery for a long period of time which force some women to go back to previous life style (Bandyopadhyay et al., 2011). Being a responsible mother caring for a new healthy baby, motivation and sense of control are factors that push mothers diagnosed with GDM to be in control and to balance their lives during their pregnancy periods (Lawrence, 2011; Persson et al., 2010). Mothers who had adequate self-management perceive better confidence and personal control, which contributes significantly to their positive GDM experiences (Lawrence, 2011). Despite the challenges experienced by GDM women, studies also reported that women with adequate knowledge were more motivated and cognizant of the medical complications and perinatal outcomes. This triggers GDM women to adopt a new healthy behavior such as dietary modifications (Lawrence, 2011; Stage, Ronneby, & Damm, 2004). GDM symptoms cause functional limitations that often require pregnant women with GDM to make significant lifestyle changes and cope with formidable psychological challenges as they face this disease (Persson, 2009).

The pregnancy experience of women diagnosed with GDM were expressed as living a controlled pregnancy, balancing in order to gain control of their situation, being a responsible mother caring for the health and well-being of the fetus and being transformed, since the women's view of their health status had to be altered (Sjögren, Robeus, & Hansson, 1994).

Due to the scarcity of qualitative studies on the experience of mothers diagnosed with GDM, the variation of women's experience among women diagnosed with GDM, and the fact that most of these studies were conducted in the 1990s (Persson et al., 2010) there is a need for updated research on this field. Therefore, the aim of this study was to explore refugee women's lived experience following diagnosis of gestational diabetes mellitus (GDM) in the Gaza Strip.

2. METHODS

A descriptive, exploratory design, based on a qualitative approach was employed in this study. Participants were purposely selected. Inclusion criteria included the following: females who are pregnant and diagnosed with GDM, being a refugee who receives antenatal care at the United Nations Relief and Works Agency (UNRWA) primary healthcare service clinics in the Gaza Strip; had no mental disorders that would impair their communication abilities; and at least 18 years old. The sampling design adopted was based on the population of interest in accordance with World Health Organization (WHO) criteria (gestation week ranged from 24 to 28 weeks) and without any previous medical disorders or having diabetes type II, attendances at the UNRWA primary health care clinics, age ranged from 18 years and above (Parahoo, 2014; Procter & Allan, 2007). Data saturation was used to determine the number of study participants, which was achieved with twenty interviews.

The study was approved by the Research Ethics Committee at the Palestinian Ministry of Health and the Director of UNRWA primary health care clinics. To guarantee participant's anonymity and confidentiality, the names used in the present report are fictional and the interviews occurred after the participants provided written consents. The aim of the study was explained to each participant and they were informed that they can refuse to answer any question and that they can withdraw from the study at any point without affecting the care they receive. A permission from each participant was obtained to tape-record the interview.

Participants were recruited from four different UNRWA clinics at Gaza Strip. The researchers contacted these women and sat a suitable time for the interviews. The interviews took place in a private room at the UNRWA clinics. A semi-structured interview guide was developed by the researchers to direct the interviews. The interview guide was based on literature review and the scope of the research objectives. Examples of the questions included in the interview are: (a) What is your own understanding and definition of gestational diabetes mellitus?, (b) Can you talk about your first experience with gestational diabetes mellitus? How is this problem affecting your daily life? Can you tell me more about that? (c) How do you adapt with gestational diabetes problem through your pregnancy? Can you tell me more about that? (d) In your view can you tell us about the possible risk factors, complication, and effect of gestational diabetes on you and your baby? (e) Can you explain how you will sustain your new life style after delivery? (f) Do you have other comment you want to say?

Data collection was achieved through private, face-to-face interviews that were held at the UNRWA clinics where the participants receive their care. All interviews were tape-recorded in their original language and transcribed verbatim from Arabic to English by the researchers. Demographic and clinical data were collected from medical records from the UNRWA healthcare service clinics and the participants during the interview.

In order to achieve accurate translation of the data, two bilingual experts in Arabic and English were sought to reviewing the original data and translate them from Arabic to English and back translate them from English to Arabic. For

better organization of the raw data, NVIVO software version 9 was used. Open coding was applied to identify ideas and construct higher order themes at further analysis. Thematic analysis was used to explore salient topics that emerged from the interviews. Our thematic analysis involved initial independent coding by three researchers. The codes were then clustered and used to form sub-themes that integrated from the original main themes. Further analyses led to the emergence of four overarching themes that illustrated the most significant and broad similarities or differences of experiences among women after diagnosis of GDM.

3. RESULTS

The sample consisted of 20 refugee women diagnosed with GDM who live in Gaza Strip. The mean of participants' age was 34.1 (± 6.56) years, mean height was 162.4 (± 5.4), and mean weight was 81.1kg (± 13.1). The majority of participants had completed their high school (n=15), one did not complete her high school and 4 participants had a graduate degree. Thirteen participants were housewives and 10 have a family size that ranged from 4 to 6. Moreover, 16 women had the experience of being pregnant and parity ranged between 4 and 6. Most of the participants have the experience of GDM for the first time (n=16). To protect the confidentiality of the participants, the researcher used pseudonyms to identify their quotes. Three main themes had emerged in this study. These themes were: lack of awareness, coping with the situation and keep sustainability.

3.1 Theme 1: “Lack of Awareness”

The current research revealed that refugee women living in Gaza Strip who were diagnosed with GDM had lack of awareness and knowledge about GDM, how to adjust to a new lifestyle that requires challenges and in behavioral modification imposed by GDM. Several participants demonstrated having vague ideas about GDM. ‘Lack of awareness’ theme represents the reality of the participants’ illustration when they first heard about gestational diabetes or when the participants have been told that they have GDM. This theme represents the initial state of unconsciousness and denial of the diagnosis. For example, Huda remarked about the moment when she was told by her healthcare provider about having GDM:

“I’ve been told by the nurse that have this ‘pregnancy diabetes’ but I don’t understand what is that? I’ve no idea about diabetes in pregnancy before. I thank God this only happen during pregnancy”.

Although knowledge is important, participants' feelings of lack of awareness depicted how these women felt. Their lack of awareness was clearly depicted in the three sub-themes below:

3.1.1 Definition of GDM

Some women had no idea about the definition and the meaning of GDM. They tried to define the condition by using some phrases related to GDM medical disorder such as 'high blood glucose level in the blood.' The majority of women were surprised when they first heard this question “What is your own definition of GDM?” They even did not know how to find the words. This was reflected by Azza, Naramin, and Farah's answers:

“This concept never came to my mind”

“Allah only knows what GDM is”

“I do not know anything about this condition before”

3.1.2 Knowledge of GDM

Most of the participants described their poor knowledge and information about GDM which encouraged them to seek information from several sources such as staff in the clinic, friends, family members, internet, their private doctors and others. Shifa narrated how she tried to gain necessary information:

“I try to ask the people that I already know and who have this disease and how I can face it; I want to learn from them how I can deal or adapt with this condition”.

3.1.3 Being at Risk

Besides this, the majority of participants think that stress and heredity are the most common risk factors for having GDM. However, only a few number of participating women claimed that the risk factors include nutrition, obesity, and having a large baby. This is well reflected in Shehada's and Adwan's anecdote below:

“Stress that we have her in Gaza Strip and the war situation could be some of the causes. Living in a country that have a war almost every two years is a stressful experience during my pregnancy. I missed a lot of close persons who died during the war. All our life is grieving and panic”.

“I heard it's a heredity disease. It seems that I got it from my mother who has diabetes”

3.2 Theme 2: “Coping With the Situation”

Participants of this study reported that it was very difficult to accept the diagnosis of GDM, especially at the first few weeks after the diagnosis was confirmed. Moreover, most of these women faced a lot of challenges and they struggled to cope with the new situation and adapting to a new lifestyle and behaviors such as emotional changes and diet modifications. Lila described how she tried to cope with the situation after a long time:

“I try to avoid all types of sweet food that increase the glucose level in the blood. I did not take any insulin injection. All of my treatment was using diet only. I told myself I’ve to accept the condition and I try to find anything to distract me from thinking about it. I avoided sitting alone. I prefer to go out of home most of the time. I go to my friends and relative; just to talk and relieve my tensions”.

Dealing with GDM diagnosis has been coupled with anxiety about the condition of the fetus and the pregnancy outcome. Some participants were concerned about complications related to the new situation of being diagnosed with GDM such as fear of maternal mortality and adverse perinatal outcomes. This was well reflected in the following sub-themes:

3.2.1 Emotional Changes

Emotional changes means that the participants expressed different emotions when they were first informed about GDM diagnosis during their pregnancy. These emotional changes varied from one participant to another. The most common emotional feelings reported by participants were feeling sad, worry, grief, anxious, depressed, isolated and frustrated. This was well reflected in the transcript of fifteen participants. Some of the participants felt that they reacted negatively toward the illness condition and expressed sadness and depression when they were first told by the doctor that they had GDM. Aameera recalled how she felt when the doctor communicated the diagnosis to her:

“This is the real fear to me. I hate to be called a diabetic patient. I am very worry if this condition will continue after delivery... a lot of questions comes to my mind ... I am worry about my baby, the pain I will have during and after delivery. I am worried too that my baby will be admitted to the hospital”.

3.2.2 Adaptation Behavior

The theme of adaptation behavior depicted how the participants during their pregnancy endured the fear of GDM complications and its impact on perinatal outcomes. In the endeavor to challenge GDM, they are subject to behavioral adaptations, an overall coordination and change in their behavior to accommodate with the new situation. The experience of having GDM had profound effects on the participants' adaptation behavior. Their adaptation, therefore, served as a valuable change for them and it would influence how they would change from previous behavioral habits to new positive habits such as nutritional, physical, and psychological adaptation. This is clearly illuminated in the anecdote of the majority of the participants of this study. Manal remarked:

“When I’ve been told that I’ve diabetes, I tried to follow the instructions and control my diet. I decreased my weight and I always tried to visit my doctor and listen to his advice about how to adapt with the condition”.

3.2.3 Facing Challenges

The theme ‘facing challenges’ depicted cutting point or turning point that the GDM women faced before adjusting to new lifestyle. The participants described facing challenges as the ability to overcome all the obstacles that interfere with coping with the current situation and adapting to healthier lifestyles and adjustment with the new condition. Eight participants out of twenty reported that the first challenge for them was how to accept the illness condition and to accept the reality of having GDM. A second challenge was the commitment to changes that should be adopted such as avoiding eating several types of food that they liked to eat prior to their diagnosis with GDM. A third challenge was dealing with the condition seriously and the fourth challenge was how to keep forward with the new behaviors. Tasneem pointed out how she tried to face these challenges:

“I control myself. I avoid taking the types of food that I liked to eat previously before being diagnosed with GDM. This is hard ... actually I was afraid to eat even any food. I tried to become so strict because I want to regulate my diet as much as possible. I stay away from cake and sweet food, This had a negative effect on my children and my family ... there is no cake or sweet food at home ... sometimes I feel guilty because I tried not to cook sweet food for my kids ... the foods my kids like ... I was afraid that I couldn’t control myself.”

3.3 Theme 3: “Keep Sustainability”

This theme refers to those attitudes and actions that were taken to help the GDM mothers to sustain their new health behaviors during their pregnancy and after delivery. Most participants believed that GDM is considered as an alarm sign for developing diabetes type II in the future. Several participants were afraid to develop diabetes. The participants claimed that they tried hard to exert control such as trying to practice certain measures to prevent future diabetes. Some participants acknowledged their recognition of GDM’s consequences. Recognition is a good sign that would motivate them to move forward and adopt a new life style to avoid developing diabetes mellitus type II. This is well-

reflected in the three sub-themes below:

3.3.1 Commitment

The participants held the belief that commitment is necessary. Hence, they strongly believed that it is important that they commit to changes in lifestyles and to continue in practicing these changes. Some participants strongly believed that chronic diabetes or type II diabetes could be prevented if they are committed to the new changes in their lifestyle. Some participants expressed that there is some evidence that if they have positive family history of diabetes, they would develop diabetes anytime in the future and being diagnosed with GDM will put them at a higher risk for developing diabetes. The participants felt that being committed to the new changes in life style is difficult. For example, their inability to adapt, lack of support, difficulties, and new responsibilities and roles to care for their newborns. Olfat remarked:

“This experience gave me the courage to face my future and keep my commitment for changing my life.”

3.3.2 Self-Empowerment and Management

Self-empowerment and management refers to participants' belief in their ability to accomplish a specific behavior. Additionally, self-empowerment refers to women's ability to be responsible for their own lives and behaviors. Some participants attempted to change certain behavioral patterns such as eating habits and daily activities. Most participants explained how their attempts were achieved successfully. The present findings showed that some of the participants had difficulties and barriers in adapting to new behaviors or sustain new behaviors. This was depicted in the words of Manal which reflected how she had the power to manage

“When I was told that I've diabetes, I tried to follow the instructions and control my diet. I visited my doctor frequently and listened to his advice about how to adapt with new situation. This experience helped me to continue. After delivery, I followed the same diet and accepted the changes that happened to my life. I consider my mother as a role model for me, she accepted her situation (with chronic diabetes) and adapted normally with her condition for many years”.

3.3.4 Being Supported

In the present study, most of the participants were looking for emotional support. Some talked about their internal support that comes from Allah (spiritual support). Others talk about the need for external support from families, peers, doctors, and other health care providers. Being supported by others was necessary for most of these GDM women to adapt to the illness condition and to move forward. Marwa described the need for support by others as:

“I felt that I need much support. My husband stood beside me during the entire period of pregnancy and gave me a lot of support. I think without my husband, I couldn't tolerate the situation ... even this was not enough, so I try to get support from my special doctor and staff in the clinic who gave me instructions”.

4. DISCUSSION

The finding of this study uncovered that women diagnosed with GDM are generally 'adjusting to new lifestyle' and keep lifestyle changes sustained during their journey of pregnancy to childbirth. This feeling was intensified when they faced challenges including the impact of GDM on perinatal outcomes and changes during their journey to full-term. The women with GDM found themselves in a situation where they were gradually adjusting to a new lifestyle as time passed. The significance of adjusting to a new lifestyle was also pointed out by other researchers (Evans & O'Brien, 2005; Persson et al., 2010). Our participants reported that their adaption to new behavioral and diet changes came after a great struggle. These findings were consistent with the results of other studies (Evans & O'Brien, 2005; Persson et al., 2010). Most of the participants believed that the diagnosis of GDM is an alarming sign for developing type II diabetes. Our findings further reflected that preventing type II diabetes in the future was the greatest motivator for sustaining the new lifestyle after childbirth. However, Persson et al. (2010) study illustrated that having a new baby and the fact of being responsible for the newborn child were the motivators for GDM mothers to adapt to GDM. In contrast to this study, Persson's et al. study showed that the mothers have different motivation when adjusting to a new lifestyle.

Moreover, our study confirmed that commitment, self-empowerment and management were needed in order to keep sustainability of new lifestyle behaviors. In a similar qualitative study, results revealed that women diagnosed with GDM reach the state of “adjustment to gestational diabetes self-management” after developing certain strategies to maintain their blood sugar within prescribed limits (Carolan-Olah, Gill, & Steel, 2013). According to Carolan-Olah et al. (2013), self-management requires awareness, motivation, knowledge, and facing challenges in order to change their behaviors.

The finding of this study revealed that assurance of being supported by others was an essential requirement before reaching the adjustment to a new lifestyle. They declared that support could be internal or external support. Internal support, such as spiritual support, gave them the internal power to cope and accept the new situation while external

support that was provided by family, friends, and health care providers helped them to sustain new changes to life style. Some GDM women explained their need for both types of support together to cope with the new life style. On the contrary, lack of support, encouragement, and facing challenges were definite barriers that prevented some mothers to adapt and adjust to a new lifestyle (Carolan-Olah et al., 2013). Instead, they regressed back to previous behaviors before the diagnosis of GDM. Results of this study revealed that women diagnosed with GDM might become used to their new emotion such as worry, fear, depression, and grief as time passes, and thus spiritual support is beneficial, as agreed by others (Carolan-Olah et al., 2013; Evans & O'Brien, 2005; Persson, 2009; Persson et al., 2010) who suggested that people usually adapt to the changes of their emotion as time goes on.

According to previous studies, support from family, husband and health care professionals was considered as the most important source of psychological support. The presence of psychological support definitely motivates GDM women to be more committed in their management of their diabetes and in sustaining required behavioral changes (Carolan-Olah et al., 2013; Downs & Ulbrecht, 2006; Kim, McEwen, Kieffer, Herman, & Piette, 2008). Furthermore, the support of health care professionals plays an important role in encouraging women to control their GDM within short time (Levy-Shiff et al., 2002). These women, who were well supported by health care providers, were less likely to report feeling of anxiety or depression (Levy-Shiff et al., 2002).

Our study also showed that some GDM women believe that being diagnosed with GDM was an alarm for them that they will be at higher risk for developing diabetes mellitus type II in the future. The findings revealed that they were committed to practice certain measures to prevent future diabetes. Hence, they described that in order to sustain commitment to new behavioral changes, other factors were required such as self-empowerment, and obtaining encouragement and support from others. Most of the participants stressed that without the internal power, support, and other facilities they could adapt to and sustain a new life style. The most behavioral changes that have been reported by most of the participants in this study were changing diet, decrease their weight, and not conceiving a future pregnancy.

5. CONCLUSIONS

This study has shown that refugee women living in Gaza Strip were engaged in a process of adjustment to a new lifestyle after delivery. Their lived experiences have created a deeper understanding of the meaning that GDM women ascribed to their lived experiences. The findings also pointed out that the process to adjust to a new lifestyle was not easy. Most GDM Gaza refugee women were in a position where they did what they thought being relevant to face the challenges to adjusting to new lifestyles. This situation implied that the experience of the illness condition increased their self-empowerment, commitment to keep this new lifestyle and sustain these changes after delivery for a long period of time. Furthermore, as their motivation increased, women diagnosed with GDM found it easier to manage and prevent or postpone developing type II diabetes. They perceived the diagnosis of GDM as a serious but a manageable condition; a view that contributes to their self-empowerment and taking responsibility and a sense of control in their success and achievement.

In terms of study implications, the findings point out the direction in developing the interventions that address Diabetes Prevention Program (DPP) and Medical Nutrition Therapy for GDM. It is advantageous in terms of making a strong support system for women diagnosed with GDM. This would benefit and improve the health care system, specifically services for antenatal care for women diagnosed with GDM. Health strategies should direct the Gaza Strip population with a specific pathway in order to facilitate their own effective healthcare. Evidence from this study could be a direction or a model for future research and health planning for a better health policy for the refugee Gaza women. However, some limitations exist in this study. The refugee Gaza women during pregnancy who participated in this study came from various backgrounds and their beliefs and attitudes towards GDM may be different. Thus, it might affect the narration of these mothers in describing their experiences through the trajectories of GDM. Moreover, the study targeted refugee women, which may affect the generalizability of the findings of this study to other women living in Gaza Strip.

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7. DISCLOSURE OF INTERESTS

The authors have no conflict of interests to declare.

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