Compliance with treatment regimen in women with gestational diabetes: Living with fear

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ABSTRACT
Background: Gestational diabetes mellitus is a prevalent pregnancy complication that seriously endangers mothers' and babies' health. The aim of this study was to explore factors affecting treatment compliance among women with gestational diabetes mellitus.

Materials and Methods: A qualitative content analysis approach was employed. Twenty-five semi-structured interviews were conducted with hospitalized pregnant women with gestational diabetes mellitus. The research was conducted in four teaching hospitals in Tehran, Iran; purposive sampling was used.

Results: Participants' experiences regarding factors that influence treatment compliance fell into six categories: Unexpected diagnosis, the need for urgent change, temptation to consume inappropriate foods, life in the shadow of the illness, risk avoidance, and seeking adjustment.

Conclusions: Holistic education of families on gestational diabetes, training specialist diabetes nurses, and referral to public health centers and diabetes clinics could increase treatment compliance. These findings could serve patients and the healthcare system in general, if considered by healthcare officials and policy makers. Furthermore, providing outpatient services, considering cultural dietary conventions when recommending diets, and alleviating the stigma associated with diabetes through mass media could also promote treatment compliance.

Key words: Compliance with treatment regimen, gestational diabetes, pregnancy, qualitative study

INTRODUCTION

Diabetes mellitus (DM) is prevalent in many parts of the world, affecting 143 million people worldwide; this number is expected to double by 2030.¹ One of the major DM classifications is the type associated with pregnancy, which in turn has two classifications: Pre-gestational and gestational DM (pre-GDM and GDM).²

GDM is defined as any degree of glucose intolerance that first appears or is diagnosed during pregnancy.³ With an incidence of 1 in every 25 pregnancies,³ GDM is one of the most common complications associated with pregnancy.⁴

Complications related to diabetes are less common in pregnant women with GDM than in those with pre-GDM.⁵⁻⁷ Babies of pregnant women with GDM are at risk of developing life-threatening complications such as macrosomia, birth trauma, stillbirth, prematurity, respiratory distress syndrome, hypoglycemia, jaundice,⁸⁻⁹ and DM.¹⁰⁻¹¹ Women with GDM are at risk of developing pre-diabetes, type II DM, and recurrent episodes of GDM.¹⁰⁻¹² Effective management of GDM during pregnancy and proper follow-up care can prevent these complications.¹³

One of the most important factors affecting GDM management is patients’ compliance with the prescribed treatment regimen. Despite this, little is known about factors affecting treatment compliance; exploring these could help nurses and other healthcare professionals provide better medical care and more appropriate patient education, thereby considerably improving the lives of the affected women and their children. The aim of this study was to explore factors that affect women’s compliance with GDM treatment.

MATERIALS AND METHODS

Design
A qualitative content analysis approach was used to explore factors affecting women’s compliance with GDM treatment. This method is used to enable in-depth understanding of individuals’ experiences.¹⁴
Setting, sample, and procedures
The study was conducted in 2013. Purposive sampling was used to select 25 women who, at the time, were 28–38 weeks pregnant and had been hospitalized in one of four teaching hospitals in Tehran, Iran. The criteria for participation in the study included having GDM, type I, or type II diabetes first diagnosed during pregnancy.

Data collection and interviews
Data were collected through in-depth face-to-face interviews comprising semi-structured questions and field notes. Interviews were conducted in a quiet environment (the head nurse’s office) selected by the participants. In total, 25 interviews were conducted with pregnant women with GDM; each interview took 40–50 min.

Analysis
The data were analyzed using conventional content analysis in accordance with the Graneheim and Lundman method.¹⁵ The contents of the interview were immediately transcribed. After transcription, interview texts were reviewed several times in order to facilitate full understanding of the participants’ statements, in line with the objectives of the study. Then, meaning units or initial codes were derived from the data. Finally, codes were merged and categorized according to similarities and differences.

Quality assurance of data analysis and interpretation
Four Lincoln–Guba criteria were used to verify the data.¹⁴ To confirm the study results, the following methods were used: Prolonged field presence (11 months), field notes and interviews, the experience of the researcher in working with pregnant women with GDM, approval of results by member check, and peer check. Maximum diversity in terms of age, education, pregnancy, family history of diabetes, and the type of treatment regimen followed by participants was observed during data collection. In this study, performing in-depth descriptions and analysis, clearly describing the obstacles and limitations helped transfer of data. Moreover, all the stages of the study, particularly data analysis, were recorded in detail.

Ethical approval
This study adhered to standard ethical considerations including obtaining permission to conduct the study from the ethics committee at Tehran University of Medical Sciences, explaining the study objectives to the participants and subsequently obtaining their written informed consent to participate, ensuring the confidentiality of the data, maintaining participants’ anonymity in all study documents, giving them the option to withdraw at any stage during the study, and ensuring their access to the study results.

Results
Participant characteristics
The mean age of women with GDM was 26 ± 8 years. Additional demographic details are presented in Table 1.

Qualitative results
The factors affecting participants’ compliance with treatment were divided into six themes: Unexpected diagnosis, the need for urgent change, temptation to consume unsuitable food, living in the shadow of the illness, risk avoidance, and seeking adjustment. The themes are described below.

Theme 1: Unexpected diagnosis
Comprising two sub-themes, the diagnosis of GDM is the first step toward treatment compliance. These include feelings of ambiguity or participants’ challenges regarding diagnosis, stigma, and shock.

Diagnosis challenges
Participants believed that as long as one was unaware of the reasons for undergoing GDM screening, one could not properly understand GDM or attempt to control it. Yet, for many, their doctors had not clarified the reasons for the GDM screening. The participants reported not having interpreted the results upon receiving them and not taking any action to obtain the relevant information. They attributed this to not taking their situation seriously and delayed following up on their test results. Some women who could, to some extent, interpret the test results and immediately went to the doctor for confirmation of the results.

“I didn’t know why my doctor had requested such a test for me, and thought it was a routine check-up.” (PW, 6).

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<th>Table 1: Participants’ characteristics</th>
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GDM: Gestational diabetes mellitus
**Feelings of shock**
For all participants, final confirmation of their GDM was made by the doctor. They did not expect such a diagnosis. Disbelief, denial, guilt, sadness, fear, and fright were their first reactions following diagnosis. Their first reaction was to search family history and GDM risk factors.

“When the doctor told me about my diabetes, I felt sick, I couldn’t believe it, I kept asking myself, why me? It’s impossible, since we have no history of the disease in my family.” (PW, 7).

For women with a family history of the disease, the diagnosis was expected. For this group, the reaction to diagnosis was not denial; however, the duration of sadness, fear, and fright was longer. Following diagnosis, almost all of the participants experienced confusion. Each sought to determine what the consequences of this disease would be for her and her child, how she could prevent the complications associated with the disease, and whether diabetes was going to be temporary or not. Although the women’s reactions to the diagnosis differed, they all experienced fear regarding the possible consequences of the disease for themselves and their offspring. Some considered this primal fear and anxiety to be a factor that led them to seek more information about the disease, also ensuring compliance with treatment. In their opinion, obtaining clear and comprehensive information regarding the causes of the disease, its complications, and management considerably reduced the fear associated with diagnosis and facilitated treatment compliance throughout pregnancy. Participants also considered the support received from a spouse or family member upon hearing the diagnosis as a factor that enabled them to cope.

“I really didn’t know what to do. I was confused, and kept asking my doctor, what should I do now?” (PW, 22).

**Theme 2: The urgent need for change**
Most participants understood the urgent need for major, restrictive lifestyle changes including diet modification, blood glucose monitoring, exercise, return visits, and drug therapy with metformin and insulin. Participants’ reactions to the recommended treatment differed according to their compliance with the treatment, perceived crisis of hospitalization, and change in perceived health.

**Compliance with treatment regimen**
For many participants, the first stage of treatment was diet, followed by monitoring blood glucose levels and physical activity. In their opinion, although implementing dietary changes had been very difficult and tiresome, requiring strong motivation, an understanding of the values assigned to food ingredients, and knowledge of food substitutes, participants were able to accept the treatment regimen and reported feeling less threatened by their condition. Insulin shots were administered to some of the women immediately after diagnosis. They reported feeling more concerned about their condition, considering that it was critical and posed extreme danger to the survival of their offspring. Although they had received information about the treatment from healthcare providers, most had difficulty accepting the disease and did not feel equipped to manage it. Participants’ failure to accept insulin treatment was considered to stem from their lack of autonomy during drug administration, its invasive nature, and the maintenance, cost, and training required to use the necessary specialized equipment.

“The thought that I have to inject insulin for the rest of my life worries me. I detest insulin. I am frightened of injecting insulin—I do not think I will be able to handle this treatment (insulin injection). I don’t feel good about it.” (PW, 3).

**Hospitalization crisis**
Women with prescriptions for insulin were hospitalized for a limited period to monitor their blood sugar levels and regulate their insulin dosage. Most considered hospitalization effective in treatment compliance. However, encountering or talking to sick patients, women with type I or II diabetes, other patients in the obstetrics ward, and healthcare providers (HCPs) informed the participants about the consequences of the disease, resulting in excessive fear among most participants; this was sometimes followed by non-compliance with the recommended diet. Some other consequences of hospitalization included lack of sleep due to irregular visits of doctors, responding to questions from people such as medical and nursing students, and reduced food intake due to a lack of preference for the recommended diet and fear and anxiety relating to diagnostic procedures such as daily blood samples, ultrasounds, or amniocentesis. Some participants identified being away from one’s family, nostalgia, and a lack of whole-hearted family support as other problems related to hospitalization.

“When I say I’m pregnant and also have diabetes, other patients quickly tell me that I should comply with my treatment regimen, the foetus might be too big, my child will have problems, I’ll have preterm labour, I’ll go blind. All these are stressful for me.” (PW, 20).

**Changes in perceived health**
According to the participants, the need for early lifestyle changes, especially hospitalization, has changed their perception of health; they equate GDM with being unhealthy and at risk, and leading a life of fear and anxiety.
“Having gestational diabetes is a disaster. If you have diabetes, you are not well, and there is a huge difference between you and a pregnant woman with no diabetes. Her pregnancy risk is zero, but me?” (PW, 2).

**Theme 3: Temptation to consume inappropriate food**
Participants believed that acceptance and compliance with the recommended diet highly depended on the compatibility between the recommended diet and one’s cultural habits, as well as the will to meet one’s nutritional needs during pregnancy.

*Cultural mores*
Most of our studies on our study mainly shows that the typical regimen of pregnant women include rice, pasta, carbonated drinks and variety of snack which contain carbohydrates mostly. The temptation to consume these foods was considered a major obstacle to adherence. Participants felt that one of the duties of an Iranian woman is to procure and prepare food. Therefore, they are faced with foods they like at every meal that may be prohibited. In their view, dealing with the urge to consume tempting and available food is extremely difficult. Consuming prohibited foods following such craving has been associated with reactions such as anger, fear of harming the fetus, guilt, loss of appetite, and low dietary intake.

Participants’ reasons for consuming prohibited foods included that their typical diet according to cultural conventions was excluded from the recommended food. Most participants also argued that the list of food items obtained from the nutritionist did not contain accurate instructions about consumption, nutritional information, or alternative foods incorporating cultural dietary conventions. Further, some participants did not consider compliance with scheduled meal times and consuming snacks as compatible with their dietary conventions.

“The list that I received from the nutritionists did not include any of the foods that I used to have during childhood. The nutritionist left this list on my desk when I was asleep, I cannot come to terms with this list.” (PW, 4).

*Nutritional needs during pregnancy*
Participants believed that their nutritional needs during pregnancy differed from those during other times. Besides providing for her own nutritional, physical, and psychological needs, a pregnant woman must also nurture fetal development. Many women crave certain foods during pregnancy which are not necessarily on the nutritional list.

“I crave fast foods. It’s very hard for me to hold back.” (PW, 12).

**Theme 4: Life overshadowed by illness**
For most participants, daily thoughts and activities were taken over by the GDM diagnosis; their lives were “overshadowed by the illness.” This theme comprised the three sub-themes as shown below.

*Anxiously waiting*
Participants believed that test results motivated them to engage in self-care, and that self-care evaluation could occur only after interpretation of the results. Yet, most admitted experiencing constant fear and anxiety when monitoring and recording their blood glucose levels before reporting them to the doctor.

“My life has become dependent on my sugar level. I have lost the nerve to eat; I’m often hungry as I fear my blood sugar may go up. I’m fine before the blood sugar test, but as soon as I want to monitor my blood sugar, I’m overtaken by fear and anxiety.” (PW, 3).

*A life of numbers and measurements*
Frequent blood sugar monitoring, insulin injections, and exercise consumed participants’ time. They had to adjust to treatment and adopt lifestyle changes in order to manage their GDM. Further, learning disease-control techniques such as injecting insulin, monitoring blood sugar levels, understanding nutritional information, and food preparation all require time. Most participants believed that visiting the doctor was quite time consuming; for them, spending long periods in a doctor’s office could result in fatigue and non-adherence to treatment.

“Most of my time is spent weighing food items for fear of using more than the recommended amount—it took me hours to learn how to inject insulin.” (PW, 5).

*Social isolation*
Participants experienced the social stigma attached to diabetes, which discouraged them from disclosing their condition, reduced their beliefs in their self-care abilities, and instilled shame about being ill. Participants also believed the stigma played an important role in their self-social isolation.

“When my husband’s family found out that I had diabetes, they kept telling me how unlucky I was to have diabetes. At mealtimes, they say, ‘You have diabetes, you should not eat this food,’ or ‘You poor thing! You cannot eat this food.’ It really annoys me; it makes me feel more ill.” (PW, 10).

Eating with family and friends is also challenging.

“What would I say if they asked me why I don’t eat the food I cooked myself? It bothers me to keep saying I have diabetes.” (PW, 7).
Some participants pointed out treatment limitations, also considered a contributing factor in social isolation. Some treatment procedures (e.g. insulin therapy) require specific equipment, such as coolers or cold storage for insulin. Some of the factors that compelled participants to forego social activities included preparing and carrying insulin injections and blood sugar monitoring equipment, or the preoccupation with remembering to bring all their equipments when leaving home. Participants believed that this restricted not only their own but also their family members’ activities.

“Most of the time I stay at home because my whole life is structured around my disease. Wherever I want to go or whatever I want to do, I have to think about my illness first.” (PW, 11).

**Theme 5: Avoiding danger**

When participants sensed danger to themselves and the fetus, they adopted escape strategies. This category includes the challenges of knowing and the predicament of not knowing, misconceptions, and seeking help.

**Challenges of knowing and not knowing**

Participants repeatedly expressed a need to receive information about the disease. They considered this the most important factor in facilitating their compliance with treatment and autonomy in managing the disease. Healthcare providers were considered the best source of clear, correct, and comprehensive information regarding disease management. Most participants stated that the training they had received on disease management was brief and limited. They also believed that their consultations with doctors and nurses were limited, and that their requests for information were often negatively received. Some participants were reluctant to ask any questions due to shyness. However, this lack of openness was attributed to insufficient interaction and rapport between patients and the treatment team.

“I’m too shy to ask nurses about my illness, and think I’d be wasting their time. Sometimes I cannot even express my problems.” (PW, 22).

Participants believed that education should cover a wide range of topics including the recommended diet, alternative foods, exercise, and the use of insulin and blood sugar monitoring equipment. The participants’ family members should also be educated on providing emotional and psychological support, the needs associated with GDM, and general pregnancy care. The knowledge of the family can be a positive point in the process of the treatment.

“I have a problem with injecting insulin; if my husband could be taught, it’d be a great help. If my husband knows my needs, surely he can better support me.” (PW, 25).

Most participants’ health literacy was low. They could hardly understand the information relating to treatment procedures which was provided by healthcare providers. The majority admittedly knew little about blood glucose monitoring, and the return visits required led to failure to comply with this important stage of the treatment process. For some participants, limited knowledge regarding dietary issues and disease management resulted in fear of eating, constant hunger, and the possibility of malnutrition for both the mother and the fetus. Some women who had earnestly tried to obtain information about disease control felt intimidated and helpless as their requests were ignored by doctors and nurses, their condition not monitored, their educational needs neglected, and they received incorrect or conflicting information.

“Since I was hospitalised, everyone has had something to say. For example, the nutritionist says I can have these foods, but my doctor says I can’t. I don’t know what I’m supposed to do. I feel my baby and I are at risk ....” (PW, 4).

Participants believed that the health risks posed by not having received appropriate, comprehensive information about GDM led to non-compliance with treatment. Out of fear of high blood glucose levels, they turned to consuming foods that do not provide the necessary calories for fetal development or their own nutritional needs. Other participants had consulted non-professionals on strategies for disease management, sometimes without consulting the treatment team; this might have resulted in participants implementing misguided strategies.

“I know which activities or foods are good for me. I try not to use sugar; or when my blood sugar is high, I use blood sugar lowering tablets.” (PW, 6).

**Misconceptions**

Adopting mistaken beliefs was another strategy used to avoid the danger threatening their fetus and them. Some participants believed that using substances such as opium could counter diabetes, or that consuming fruit, dates, or honey was suitable.

“One of our neighbours, who has diabetes, told me that if I used a small amount of opium daily, it would lower my blood sugar and I wouldn’t need insulin injections anymore. Well, since my husband procured some for me, I take some each day.” (PW, 8).
Seeking help

Most participants understood the importance of antenatal care, and that GDM management required a holistic support system. Therefore, all the participants consulted healthcare professionals for antenatal services. The participants deemed the support systems within healthcare services inadequate. For example, admission in public hospitals is time consuming and, sometimes impossible, due to staff shortages and high patient numbers which is possibly due to the lower treatment costs in these facilities as compared to private centers.

The fact that no services are provided after hours has resulted in some women not using public health centers. In these instances, the only alternative is private health care. However, many pregnant women considered the high financial burden imposed by private centers to be a barrier to consultation with the doctor and seeking antenatal care. Although most participants had health insurance, insurance companies did not cover expenses associated with the purchase of equipments such as glucometers and related supplies. Furthermore, insurance companies only covered a small portion of treatment expenses. Accordingly, families without health insurance ultimately carry the full financial burden of treatment.

“Where I live, there are no public health centres. Even if there is one, I don’t know about it. It’s been a few months since I was diagnosed with gestational diabetes, but I have been unable to visit the doctor, with my low income.” (PW, 5).

Theme 5: Adjustment seeking

Most participants experienced various challenges that threatened their compliance with treatment. They had to develop strategies to avoid potential risks to the unborn child and garner family support, while hoping that the disease was temporary. In an attempt to adjust to the condition, participants accepted the treatment regimen and attempted to ensure their own survival and that of their children.

Protecting the child

Responsibility, maternal affection, and fear of diabetes complications were the main contributors toward participants’ acceptance of the treatment regimen and higher tolerance of problems resulting from diabetes and pregnancy. Traditional therapies, minimizing stress, and turning to religious beliefs are examples of participants’ strategies for protecting their children. As described by a pregnant woman who had experienced two miscarriages,

“When I notice that my blood sugar is high, I have some nettle tea, or, sometimes, grated zucchini in yoghurt.” (PW, 3).

Family support

Participants believed that family support (emotional, psychological, or financial) played a significant role in their acceptance and compliance with the treatment regimen while they tried to cope with the disease. However, for some participants, family members’ excessive concern and obsessive behavior relating to GDM made them feel enslaved by the family. These individuals reported challenges such as losing self-confidence, feeling ill, relying excessively on the family, and being unable to perform daily activities.

“I’m constantly watched, whatever I want to do or eat, I’m controlled by the family. They don’t allow me to do my own chores. Honestly, I’m tired of their behaviour.” (PW, 25).

Hoping the disease is temporary

For most participants, believing that the disease was temporary minimized their stress levels and helped them adjust. However, for some participants, the hope that the disease was temporary hindered any personal effort to control the disease or prevent its complications. This was also implicated in their failure to attend antenatal check-ups.

“Most doctors tell me my illness will last until the end of the pregnancy, so it is not necessary to suffer much for treatment.” (PW, 17).

Discussion

In this study, most participants were shocked and confused at the time of diagnosis. For many, an urgent and dire need to change their diet and lifestyle led to confusion and feelings of being lost. This sudden change in circumstances and uncertainty regarding the future for the affected women and their fetuses brought on feelings of fear and fright. This fear influenced important aspects of the participants’ lives during pregnancy. This result was similar to the findings of other studies.[16,17] Notably, in this study, fear of complications as a result of the disease led to better treatment compliance in some women. In a study by Albright, stress was one of the four factors associated with patients’ self-care behaviors.[18] The initial anxiety experienced by the patient at the time of diagnosis is an appropriate time to stimulate behavioral change and establish patient incentives. Moreover, primary educational interventions for patients with diabetes lead to better outcomes, particularly with regard to treatment compliance.[19]

The women in this study believed that the type of treatment facilitated compliance. Participants viewed diet as a relatively easy option that was less threatening and
Iranians generally hold a negative fear, self-medication, and the adoption of mistaken cultural disease and its management was associated with intense contributor to compliance. Lack of education regarding the knowledge about the disease to be the most important consequences of the disease, and disease management.

In this study, treatment compliance depended on participants identifying insulin as an easier means of controlling GDM compared to diet alone. This preference was apparently informed by the women’s concern with further complications such as hyperglycemia due to dietary restrictions and behavioral changes.

Another factor that hampered treatment compliance in this study was the cultural aspect, including social stigma and misconceptions about diabetes management. Stigma can lead to high-risk behaviors among pregnant women such as consuming prohibited foods, concealing their disease, not seeking health services, social isolation, failure to accept that one has diabetes, and possible non-adherence to treatment. Iranians generally hold a negative attitude toward diabetes due to the high prevalence of its accompanying complications. In this study, stigma stemmed from the notion that the affected women would be unable to have children in future or partake in daily activities, and fear regarding the transmission of the disease to the child. As further demonstration of the stigmatization of diabetes, many refer to individuals with diabetes as “diabetic patients,” instead of “persons with diabetes.”

In this study, treatment compliance depended on participants receiving etiological counseling, education regarding the consequences of the disease, and disease management. Consequently, most participants considered greater knowledge about the disease to be the most important contributor to compliance. Lack of education regarding the disease and its management was associated with intense concern about one’s health and the future of one’s children, fear, self-medication, and the adoption of mistaken cultural beliefs in an effort to manage the condition. Since diagnosis, participants understood the need for education. They also considered obtaining information as a major preventative factor. Although some participants were somewhat knowledgeable about GDM, they were extremely eager to learn more about the condition.

In relation to this, Carolan also believes that education is an important factor in the self-management of blood sugar levels. Limited education is associated with poor dietary adherence, hyperglycemia, and non-acceptance of treatment. It can also reduce self-care and family involvement in patient care, and result in less autonomy in disease management. Increased knowledge of diabetes and its control strategies is associated with changes in patients’ health perceptions. Conflicting information can also confuse patients about the self-management of the disease, and possibly reduce their confidence in the treatment. Pregnant women with insufficient knowledge of GDM may also not attend antenatal and postpartum check-ups, thus increasing their risk of developing type II diabetes.

In Iran, interventions relating to the care of women with GDM have yet to be planned and implemented due to nursing staff shortages and the limited number of specialized diabetes nurses. In the absence of diabetes nursing staff beside the staff shortage, inadequate attention from healthcare providers can seriously endanger patient safety, ultimately compromising community health and the efficiency of the health system in general. Support from family and healthcare providers is important in ensuring treatment compliance. In this study, participants identified family members as important sources of psychological support. Other studies have also noted the important role of psychological support from these sources, both in changing the affected women’s negative views regarding GDM and encouraging diabetes self-management.

**Conclusion and Clinical Implications**

The results of this study suggest that holistic education of families about GDM is the most important and effective strategy in increasing treatment compliance. This should be especially noted by healthcare providers.

Treatment compliance could also be enhanced by establishing public health centers and outpatient services for women with GDM, educating specialist diabetes nurses and effectively utilizing their services in healthcare centers, considering patients’ cultural backgrounds when recommending diets, and de-stigmatizing diabetes through mass media campaigns. Creating an environment in which
women with GDM can feel safe and enjoy the support of family and healthcare providers would enhance quality of life for both women and their unborn children.

As the perspectives of healthcare providers and family members seem to play a role in treatment compliance, it is recommended that their perspectives be directly examined through qualitative studies in future research. This study was conducted in Iran; thus, future studies in other cultures and contexts are necessary in order to determine the transferability of findings in the current study.

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