Title: Juggling Type 1 diabetes and pregnancy in rural Australia

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Abstract

Background: Women with type 1 diabetes and their babies are at higher risk of morbidity and mortality during pregnancy and birth. The focus of management is medical, with an emphasis on control of blood glucose levels prior to conception, and during pregnancy. Management is further complicated for women living in rural settings where there is limited access to diabetes specific specialist services. This study explored rural Australian women's experiences of pre-gestational pregnancy, including interactions with health professionals.

Methods: Using a collective case study design seven women with pre-gestational diabetes who had given birth within the previous twelve months participated in in-depth interviews about their experiences of pregnancy and birth. Data were analysed thematically.

Findings: Rigid narrow control of blood glucose levels both preconception and during pregnancy created unfamiliar body responses for women, with their diabetes presenting an unfamiliar bodily experience. Women needed information and support to differentiate between what might be normal or abnormal bodily processes. Women's preparation for conception and pregnancy was reliant on the level of available expertise and advice. Participants' experiences were coloured by their limited access and interactions with expert health professionals.

Conclusion: Women with type 1 diabetes experienced significant hardship during their pregnancy, compounded by a scarcity of available information to support their management of their pregnancy. Building confidence in professional care requires increased access to specialist services, and increased levels of demonstrated knowledge and expertise.

Key words: Type 1 Diabetes Mellitus, pregnancy, interview, case study, rural health

Background

Type 1 Diabetes is the most common chronic illness that complicates pregnancy (1) and presents significant risks for women with pre-gestational diabetes. These include higher rates of congenital malformations and still birth compared to non-diabetic women (2, 3). Additionally, women with pre-gestational diabetes experience progression in the diabetes-related complications of nephropathy, retinopathy and hypertension, with increased incidence of pre-eclampsia and pre term deliveries (4). These risks can be markedly reduced with optimal glycaemic control (2).

While there is a large body of literature related to pre-gestational diabetes and pregnancy, it is biomedical in focus, emphasising medical management, with current research and guidelines for practice to optimise clinical outcomes for women and their foetus (5, 6). Success of medical interventions is measured in terms of maternal and neonatal mortality and morbidity outcomes. However, the impact of a high risk pregnancy and the concomitant medical management for women with type 1 diabetes has received less attention.

Care for women with diabetes once pregnant involves earlier monitoring often resulting in time away from work, more likelihood of hospitalization during the pregnancy, and juggling leave and other family commitments (6, 7). Women who carry a 'high risk pregnancy' require frequent consultations with specialist obstetricians and physicians in addition to specialist diabetic nurses, and dieticians (8). However, the level of specialist maternity services available for women with

diabetes is limited in spite of international agreements of the need and goals of this care (9).

Living in rural communities is well accepted as leading to poorer health outcomes and having reduced access to health services (10, 11). Globally there is a clearly documented imbalance in the geographical distribution of health care specialists, with greater access to specialist care in urban settings (12). Therefore, conception and pregnancy for women with pre-gestational diabetes living in rural communities are likely to face additional challenges. However, we were unable to locate any published work exploring this. This project investigated the pregnancy and maternity care experiences of women with pre-gestational diabetes who live in regional and rural communities in Australia. The aims of the study were to explore and describe rural dwelling women's experience of pregnancy and birth in the context of pre-gestational diabetes. Additionally, we aimed to describe women's engagement with, and expectations of health care providers during this period, subsequently, highlight potential service and informational gaps.

Study design and method

Using a "collective case study" design (13) a series of in-depth interviews (14) were conducted over a three month period. Seven women with Type 1 diabetes agreed to be interviewed by one of the authors (RK), either face to face or by telephone, at a place and time convenient to them. Women were asked to describe their experiences and expectations of their pregnancy, birth and their experiences of health care provision during this period. No specific questions were asked; rather a number of pre determined topics were included in a conversational style interview with each

participant. Unstructured interviews allowed a focus on particular aspects of the study whilst allowing for freedom of participants' expression of their views (15). Rapport was established through empathetic listening. During the interview, the interviewer verified participant's responses by regularly re framing and feeding back the responses (16).

Prior to commencement of the study ethical approval was obtained from the relevant university Human Research Ethics Committee. All potential participants were provided with a plain language information sheet explaining the study and what their participation would involve.

Study Sample

A convenience sample was recruited between October and December 2005. Women were contacted through advertisement in local diabetes services and via a website providing information to young people with diabetes, 'Reality Check' (<http://www.realitycheck.org.au/>). The women who agreed to join the study were aged between 26 and 35 years, with a mean age of 30.42 years. They were all married; three women had one child each and the remaining four had 2 children each. All the women had attempted to breastfeed and most maintained breastfeeding for at least 3 months.

Analysis

All interviews were audio recorded and transcribed verbatim by a professional transcriber, with accuracy of transcripts checked by the researcher. Thematic analysis through repeated reading of transcriptions and listening to tapes allowed categorizing and grouping of themes. Regularities and irregularities were identified and discussed by the team (16).

Findings

During the interviews the women talked about the discipline, stress and sheer hard work involved in reducing and maintaining blood glucose levels to a level which signified minimal risk to both their foetus and themselves. Blood glucose management was a dominant feature in their conversations. It was linked to their preparation for pregnancy, their experience of pregnancy and the quality of and access to specialist health services.

Preparing for conception and pregnancy

Each woman had approached pregnancy with their own personal experiences, concerns and memories influencing their emotional and physical preparation. Some women reported retaining powerful messages given by doctors at the time they were first diagnosed with type 1 diabetes. These messages advised them, when they were young girls, that because they had diabetes they may never be able to have children, that they should have them early or that they would have to go to the major city in their state for care. As one participant recounted:

As a child when I was diagnosed, at that time I was told that I may never have children and that if I was to have children that perhaps the last three months of pregnancy would be spent in Melbourne [major city], in bed and restricted and things like that, so having children was always a scary, scary thing for me.

Another participant stated:

There are some very high profile Drs here in [local community] that discouraged or said you shouldn't have children. Told not to [get pregnant] and told I wouldn't be supported here if I fell pregnant

However, women reported their decision to have a baby and have a family was very affirming and empowering.

This is the course I'm taking this is what I have done. I was told I would never have kids, I've got two beautiful children so don't tell me I can't do this because I know I can.

The women reported being motivated to be as healthy as possible and ensure the best outcomes for their baby. The focus was on having a healthy baby. Many commented that although they may not always have been as strict with their diet and lifestyle as recommended, once the decision was made, their preparation for pregnancy had been carefully considered. The women talked about some of the strategies they had adopted with the help of health professionals; these included changing to a different kind of insulin and two participants had enquired into purchasing insulin pumps with limited success.

I approached a GP about a pump and I was basically told no, we can't support that here and it's too dangerous and you can die...

The length of time of preparation varied, with some women reporting conceiving relatively quickly with minimal preparation, and others taking up to several years.

A key aspect of the women's preparation for the pregnancy was getting better control over the blood glucose levels, which meant doing more exercise, and eating more healthily. The women reported a need for getting control over their blood glucose because of the potential risks to their foetus. The potential risks caused them considerable stress and anxiety. In particular, the women worried about their baby being born with an abnormality, dying in utero, or being sick and needing medical care following birth.

The main indicator of glucose control was their monitoring a reduction of their blood glucose levels, or HbA1c, which they reported as taking enormous amounts of self discipline. Participants monitored blood glucose levels many times daily and at night, often taking more than a year to be ready to conceive. One participant said:

It took two years of planning and preparation before my HbA1c level was satisfactory. The specialist said after a year that I could go ahead but just from my own research, I didn't like the margins that I had. It was too close for me.

Women changed jobs and some stopped employment to achieve the required level control over their blood glucose levels.

I decided to give up work before I had children, because of the immense amounts of pressure to try and keep everything controlled and everything so tight.

The increased vigilance and successful maintenance of their blood glucose in a narrow range resulted in changes to their usual recognition to changes in blood glucose. One woman reported losing all recognition of hypoglycaemia when she was trying to conceive:

I could be walking around on 1.5mmol and then just pass out, my whole life structure pretty much changed

While acknowledging the effort and hard work, all participants relayed that it was worthwhile. Although they commented that there were times when they would have appreciated more acknowledgment of their hard work by health professionals.

Limited access to information

The women in this study understood that their pregnancy would present complexity and many sought additional resources to assist them in their planning and

subsequent management of their pregnancy. They also reported a need to understand what the worst case scenarios might be, as well as information about what to expect in the labour, birth and postnatal periods. A number of participants commented that their health professionals, particularly the midwives, were also in need of information about diabetes and pregnancy. All participants commented on a scarcity of information and much of their knowledge was gained from international websites. Participant comments included:

... there definitely needs to be more information out there ... I was really surprised at first because there was just nothing there, you really had to dig deep to get anything ...

My basic support was a website based in America that was for diabetic pregnant mothers and Type 1 diabetics and it was a sole lifeline. There were a lot of people I bounced things off, they were the people that I said well this is how things are or have these things happened to you and they used to do the same so it was a great support group both ways.

The experience of pregnancy

Generally there was recognition amongst the women that the pregnancy posed significant strain upon them over and above that experienced by women without diabetes. Their pregnancy experience was dominated by blood glucose management and its consequent effects, including a loss of recognition of 'hypo' (hypoglycaemic episodes) symptoms, increased incidence of hypoglycaemic episodes (some resulting in loss of consciousness), and weight gain.

Managing hypoglycaemia in pregnancy was reported as difficult because the episodes were unpredictable and most women experienced a loss of recognition and/or altered symptoms of lowered blood glucose levels. A loss in their ability to recognise 'hypo' symptoms undermined the women's confidence in their ability to manage their diabetes, to safely go about their daily life and to look after other children in their care.

The first thing I noticed was I was getting like tunnel vision and then my reading was like 1.1 [mmol] and like I had never been that low with no other symptoms ...

Many women reported experiencing a lot of hypoglycaemic episodes which they attributed to the rigid narrow range of control of their blood glucose. These hypoglycaemic episodes posed potential health threats; one woman reported numerous collapses requiring assistance and two women reported experiencing a 'hypo' while driving. As one woman reported:

... my blood sugar was fine during the day but it went low ... I was driving home from a friends place and that's why I had the car accident ...

In the second and third trimester of pregnancy, insulin demands became greater and more erratic leading to some women needing to monitor blood glucose levels frequently through out the day and night. Some women reported that health professionals had high expectations of how blood glucose levels should be monitored and maintained which in turn imposed considerable costs to women's mental and physical well being

For my first pregnancy my HbA1c was never above 6. It was always 5.3 that's where the obstetrician insisted it be ... I was hypoing day and night...

It was the endocrinologist who said to me you will have to do readings every two hours, [to] set your alarm clock

The women used insulin to maintain low blood glucose. This often resulted in them eating more food to stabilise the blood sugars when they overestimated their insulin requirements, one woman commented on her significant weight gain:

By 38 weeks I weighed 96 kilos and I was miserable and could barely walk, my insulin requirements were through the roof. After K was born I went from 96 to 56 kilos in thirty days.

Engaging with health care providers and services

Pregnancy is a time of physical and emotional transition and for the women in this study it was particularly challenging because they perceived a volatility and untrustworthiness in their body. They lost confidence in their capacity to manage these new situations where they could no longer safely interpret the signs and symptoms of hypoglycaemia, where insulin demands were erratic and they had the added onerous responsibility of a developing foetus.

Access to diabetes specialist care was variable for women in this study. There was limited choice of provider and it was good fortune if there was an experienced local practitioner who had some expertise in diabetes and pregnancy who was prepared to provide care to them. Women reported high levels of satisfaction when they were able to see experienced professionals who treated them as adults, acknowledged that the women were highly motivated, and that it was hard work to keep their blood glucose in control. The professionals who were prepared to work with these women, support them and liaise with other professionals as necessary, gave the women

confidence. Strategies that improved communication included regular email and phone calls.

Interactions with health professionals were not always useful. The women related that they were often confronted with professionals who were authoritarian in their approach, who could only lecture women about the need to control glucose:

'just don't get pregnancy now because if something happens to the baby you will never forgive yourself' .

Women found these messages depressing; undermining their confidence , and making them fearful for their baby. One woman reported being bullied by her obstetrician who demanded very strict control of the blood glucose levels:

With my first obstetrician my pregnancy was made into a side show....he went completely overboardI would be doing thirteen tests a day and if I missed one. he'd have me in tears, [saying] don't you care about this child? ... Awful, it was an awful, awful pregnancy ... it was just a medical circus type thing

Women also found significant gaps and discrepancies in the information health professionals provided, which possibly reflects the limited levels of experience and expertise rural health professionals had with diabetes and pregnancy. The women received very different messages from various health professionals about their progress and/or potential outcomes of their pregnancy. One woman said:

The specialist there in the hospital he was great.. really good, really laid back, said '5.9 fabulous, you know your stuff if you need anything come and see me' ... but when we had a relieving doctor it was really difficult because I

would always be confronted with a doctor saying oh you can expect to have a still birth,your going to have a handicapped child.... oh lovely things...

A number of women reported that some health team members could only give them limited support; because the women were motivated and reasonably well informed these health professionals were simply unable to tell them anything more than what they already knew. It was problematic for the women to realise that they were relying on health professionals who frequently did not know as much as they did about diabetes and pregnancy. Many health professionals seemingly felt unequipped to provide services to the women. Several participants reported that they were refused services in their local communities, which seemed to be related to concerns about the level of risk these women and their babies posed and the capability of the health services to respond.

There was a lot of fear and I guess that's because of a combination of a lack of knowledge, lack of resources, lack of networks and fear of litigation.

I met this couple from [town XX], he was a vicar, they were only in their late twenties and he said the GP's there had refused to support them, had told them she would be writing her own dispenses [the last sacraments] if she fell pregnant, so they moved to [major city]. They shifted everything and their careers just to get access to resources.

Those participants able to receive services locally perceived that the level of service was not as comprehensive as that available in metropolitan centres. Consequently

women reported that they had to take more responsibility in the management of their diabetes during the pregnancy in lieu of the lack of expertise from their caregivers.

I think you have to drive a lot of it, I felt that with this obstetrician knew babies

... diabetes stuff they didn't know, so I had to become a bit of the driver ...

Most women had no access to an endocrinologist in their local area. Some of the women chose to travel long distances to larger centres where specialist services were offered.

Basically he's about the only endocrinologist on the Coast, you just don't have any choice here ... I've actually only seen him twice ... I would like to have someone to be talking to more regularly about the diabetes.

But some were able to access support from local experienced medical specialists with an interest in diabetes and pregnancy.

Discussion

Some of these findings are consistent with previous studies and women's stories.

Women with pre-existing diabetes understand that they will experience a different trajectory of obstetric care to other women (7, 17). The normal feelings of anticipation, concern and adjustment to pregnancy and birth are compounded by additional worries about the well being of both baby and mother. The transition to motherhood has been identified as a particularly difficult and complex period for young women with type 1 diabetes (18). Transition periods are times when the self management of diabetes becomes particularly problematic for young women (19). Women appreciate acknowledgement from health professionals of the extra stress and strain they must bear in the context of diabetes and are frustrated when their hard work was not acknowledged by health professionals (7).

A lack of available information for women about various aspects of diabetes management in relation to pre pregnancy and counselling, planning pregnancy and parenting has also been reported in other recent studies (18, 19). Australian women speaking in a small anthology of diabetic women's voices commented that they would have appreciated more information about diabetes and pregnancy from both libraries and hospitals (17). In the UK, research supports the notion that women are unsatisfied with the level of information and support they receive (20).

Hypoglycaemia was a significant issue for women in this study and they communicated a need for better access and quality of information to assist their management of this. In particular, their loss of recognition of hypoglycaemic events, together with changing symptoms produced physical and psychological risks that at times were potentially life threatening. These findings were reflected in Rasmussen's (19) recent work with women with Type 1 diabetes who reported the physical and emotional impact of hypoglycaemia, in particular the impact of unpredictable 'hypos', producing feelings of fear and emotional vulnerability. Hypoglycaemic episodes were physically exhausting, often taking some days to recover (19).

Many women had difficulties in accessing appropriately skilled medical and nurse diabetes specialists. Medical and consumer discourses about Type 1 diabetes and pregnancy unanimously advocate the importance of women receiving pre pregnancy counselling and stabilisation of optimum blood glucose levels prior to conception. Women are recommended to speak to their 'team' of specialists prior to conceiving and during the pregnancy (21, 22, 23). Yet for many women who live in rural settings

this ideal of a health professional 'team' is problematic. Women in this study did not have access to teams of skilled diabetes clinicians to provide care in their communities. Service providers were not always well informed, or helpful, and the women often received contradictory information. Contradictory information undermined their trust and confidence in the expertise of health professionals and consequently contributed to them feeling insecure and anxious about their pregnancy. Other studies have reported women experiencing difficulties in accessing professionals with appropriate expertise or who were prepared to work with them and to share information at the level they expected (18, 19).

For women living in rural communities the level of risk their pregnancy presented additional difficulties. Services were often not available locally due to the levels of risk the pregnancies presented and the limited staff expertise in the health care service organisations. Government policy and funding limitations placed on rural health services in Australia stipulate the level of infrastructure and staffing to support high risk pregnancies and births which results in few rural centres being able to support these women (24). This means relocation or considerable travel for many women with pre-gestational diabetes. For many women this is not a practical option. However, if women drive themselves considerable distances, there are increased risks for the, particularly with the unpredictable, and often hard to recognise, hypoglycaemic events. In addition they must contemplate the costs of separation from their family and temporary relocation in order to access a distant service.

Internationally the management of pregnancy amongst women with pre-gestational diabetes remains less than optimal (21, 22, 23, 25) despite evidence that better

outcomes are achievable. The recognised benefits of professionals working in partnership with women (22) were absent in many of the stories of women in this study. One clear strategy that could support improved partnerships is improved quality and access of information about type 1 diabetes and pregnancy for health professionals and consumers. This is a consistent theme throughout the literature (7, 17, 18, 19, 20). There is a clear need for high level information that is readily available. More work is required to identify optimal means for conveying this information, and web based information clearing houses may provide access to a widely distributed audience. The scope of further work should include the identification of the particular information needs and priorities for both health professionals and women to assist in relevant and appropriate targeting of information.

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