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Diabetic women's perspectives and experiences of collecting colostrum in pregnancy: a semi-structured interview study.

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TITLE PAGE: BMJ OPEN**Diabetic women's perspectives and experiences of collecting colostrum in pregnancy: a semi-structured interview study**

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ABSTRACT

Objectives: To explore and describe the experiences and perspectives of collecting and storing colostrum in the antenatal period in women who have had diabetes in pregnancy.

Design: Face-to-face, semi-structured interviews analysed with purposive sampling and thematic analysis.

Setting: A regional hospital in North Queensland with a high prevalence of diabetes in pregnancy.

Participants: Six women with a previous pregnancy complicated by diabetes who were advised to collect and store colostrum in pregnancy.

Results: Six themes were identified: wariness of medicalisation (adjusting to an 'abnormal' pregnancy, seeking continuity of care, determination to reduce formula, fear of invasive intervention); underlying altruism (providing the best for baby, preparing for complications, eager for milk donation); internal pressure to succeed (coping with confronting information, disheartened by failures, constant fear of insufficient supply, overwhelming guilt, concern for future breastfeeding success); self-management and ownership (adapting to awkwardness, developing strategies for success, actively seeking education, gaining confidence to request help, accepting personal limitations); frustrated by waste (encroaching on time, squandering a precious resource, ambiguous about necessity); and building fortitude for motherhood (physically preparing for breastfeeding, symbolic of the imminent infant, establishing early relationships with supports, approaching challenges with realistic optimism).

1
2
3 **Conclusion:** Women with diabetes in pregnancy experience guilt and stress about the
4 added risk of hypoglycaemia to their babies and strive to provide the best for their
5 babies by collecting and storing colostrum; even if this leads to distress to themselves.
6
7 It is crucial that these women be provided accurate, realistic advice about the benefits
8 and disadvantages of collecting colostrum in the antenatal period.
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10
11
12

13 14 15 16 **STRENGTHS AND LIMITATIONS OF THIS STUDY**

- 17
18
19 • In-depth, face-to-face interviewing allowed for a detailed understanding of
20 women's experiences of collecting and storing colostrum.
- 21
22 • Participants were recruited until theoretical saturation was achieved.
- 23
24 • Researcher triangulation was used to ensure the themes reflected the range and
25 depth of data collected.
- 26
27 • A limitation of this study was that only Caucasian women were represented in the
28 sample
- 29
30 • The study was only conducted in one centre so transferability to other settings is
31 uncertain.
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40

41 **FUNDING STATEMENT**

42
43
44 This work was supported by the College of Medicine and Dentistry, James Cook
45 University grant number JCU-QLD-578961.
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BACKGROUND

Diabetes mellitus is a common problem that affects more than 13% of pregnant women in Australia.[1] Diabetes in pregnancy includes both gestational diabetes mellitus (GDM) and pre-existing diabetes (Type I diabetes mellitus or Type II diabetes mellitus). Diabetes has short-term and long-term implications for the health of the mother and her newborn, including neonatal hypoglycaemia.[2] Hypoglycaemia is a significant problem as it is associated with cardiorespiratory disturbances, damage to the central nervous system and developmental delay.[3,4] Approximately 6% of Australian neonates experience hypoglycaemia, however this rate is greatly increased in maternal diabetes with 25-50% of newborns affected.[5]

Women with diabetes in pregnancy are referred to a lactation consultant and encouraged to begin expressing and storing colostrum in the late antenatal period. After delivery, breastfeeding is encouraged and postnatal lactational performance may be improved because of the prior antenatal expressing. The collected colostrum may also be used to supplement breastfeeding and stabilise the BGL in place of formula feeding, especially if the newborn requires separation from the mother for admission to the special care nursery (SCN).[6] Because of these perceived benefits to the neonate, women with diabetes in pregnancy are encouraged to collect and store colostrum by midwives, diabetes educators and obstetricians.[7] However, the experiences of women with diabetes who are encouraged to engage in this practice have not been well explored.

The Diabetes and Antenatal Milk Expressing (DAME) study, a multi-centre randomised control trial in Melbourne, found that expressing from 36 weeks gestation

1
2
3 was safe in low risk women with diabetes and may have some benefits to the newborn
4 including increased rates of exclusive breastfeeding.[8] In non-diabetic pregnant
5
6
7 populations, antenatal expressing has also been shown to be associated with reduced
8
9
10 time to initiation of full establishment of lactation, which suggests expressing in the
11
12 antenatal period may improve postnatal lactational performance.[9] However, a
13
14 qualitative study of antenatal expressing in a non-diabetic population of women found
15
16 that though collecting colostrum antenatally may increase confidence and breast
17
18 familiarity, it can also evoke embarrassment and can be difficult and painful to engage
19
20 in.[10]
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24

25 This study aims to explore the perspectives and experiences of women who have had
26
27 diabetes in pregnancy and were encouraged to collect and store colostrum in the
28
29 antenatal period, which may elucidate motivating factors, challenges, benefits and
30
31 stress factors in this population.
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34

35 **METHODS**

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38 The Consolidated Criteria for Reporting Qualitative Health Research (COREQ) was
39
40 followed.[11]
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43

44 **Patient selection and setting**

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47 Women were eligible to participate in this study if they were English speaking, had
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49 experienced diabetes in pregnancy which resulted in a live, singleton birth and were at
50
51 least six weeks post-partum. Purposive sampling was used to capture a range of
52
53 clinical characteristics including type of diabetes (GDM or pre-existing) and neonatal
54
55 complications. Selected women who had been registered on the 2014 and 2015
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57
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1
2
3 diabetes antenatal register at the study hospital were identified by the Diabetes
4 Educator midwife, contacted by mail and invited to participate. Participants who
5 returned the signed consent form were contacted by the primary author (JRC) to
6
7 arrange an interview. Ethics approval was obtained from The Townsville Hospital
8
9 and Health Service (HREC/16/QTHS/66).
10
11
12

13 14 **Data collection**

15
16
17 A semi-structured face-to-face interview was conducted with each participant in the
18 women's choice of their home, meeting room at the hospital or local café between
19
20 May 2017 and July 2017. The average length of interview was 28 minutes. All
21
22 interviews were conducted by one author, who is a female medical student,
23
24 experienced in qualitative research (JRC). No participants were known to the
25
26 interviewer. Participants were alone or accompanied by their infant. The interview
27
28 guide included questions about experiencing and coping with diabetes in pregnancy,
29
30 expressing and storing colostrum, post-partum adjustment and breastfeeding. This
31
32 guide was developed after a review of the literature and discussion among the
33
34 investigators, which consisted of an obstetric clinician and research officers
35
36 experienced in qualitative research. Interviews were digitally recorded with
37
38 participants' consent and transcribed. Field notes were also written during the
39
40 interviews. Interviews were conducted until theoretical saturation was achieved.
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45

46 47 **Data analysis**

48
49 Transcripts were entered in software for qualitative data management
50
51 (HyperRESEARCH; V.3.5.2 ResearchWare Inc.) for analysis. Drawing on the
52
53 principles of grounded theory and thematic analysis, one author (JRC) performed line-
54
55 by-line coding of each transcript to inductively identify themes in the data (i.e.,
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themes were not established a priori).[12] New codes were created to capture new concepts. The preliminary themes and codes were reviewed by three other authors (ELM, JB, CH) and iterated to ensure codes and themes reflected the data collected (investigator triangulation). Conceptual patterns and links between themes were identified to develop a thematic schema.

RESULTS

Participant characteristics

Thirty participants were contacted by mail. Six participants consented to be interviewed. Participant characteristics are provided in Table 1. The age of participants ranged from 27 to 45 years. Of the six participants, five had had GDM and one had Type I diabetes mellitus. Though all attempted to collect antenatal colostrum, five of the participants were successful. Four of the participants had babies who experienced neonatal hypoglycaemia.

Table 1: Participant characteristics.

Characteristics	Total n
Age Group (years)	
25 - 30	2
31 - 35	3
>35	1
Ethnicity	
Caucasian	6
Marital status	
Married	5
De facto	1
Education level	
Grade 12 or equivalent	1
Diploma	2
Bachelor's degree	2

Post-graduate degree	1
Diabetes type	
GDM	5
T1DM	1
Primiparous	
Yes	4
No	2
Person who advised woman to collect antenatal colostrum*	
Midwife	5
Lactation consultant	5
Diabetic educator	3
Obstetrician	2
Other**	3
Woman collected antenatal colostrum successfully	
Yes	5
No	1
Baby became hypoglycaemic	
Yes	4
No	2
Treatment of hypoglycaemia*	
EBM	4
Formula	4
IV dextrose	1

(*), more than one answer given; (**), other included Breastfeeding Australia, friends and general practitioners; GDM, gestational diabetes mellitus; T1DM, type I diabetes mellitus; EBM, expressed breast milk; IV, intravenous.

Themes

Six major themes emerged: wary of medicalization, underlying altruism, internal pressure to succeed, self-management and ownership, frustration with waste, and building fortitude for motherhood. Each theme and corresponding subthemes are outlined below. Illustrative quotes are provided in Table 2. Figure 1 depicts a thematic schema which maps conceptual links between themes.

Table 2: Themes and illustrative quotes.

THEME	ILLUSTRATIVE QUOTE
Wary of medicalization	
Adjusting to an 'abnormal pregnancy'	"When you're pregnant, you're trying to figure it out anyway and then you've got the added complication of diabetes." (GDM, 20s)

	"I cried on the phone...I was like, "I don't know what I'm doing, I don't know what's going on!" (T1DM, 20s)
Seeking continuity of care	"The continuity of care is so important!" (GDM, 20s)
Determination to reduce formula	"We managed to avoid a few top up feeds from the formula." (GDM, 20s)
	"Get as much as you can! Because it is better than formula!" (T1DM, 20s)
Fear of invasive intervention	"It heartbreaking actually because they ended up having to put in drips and things to stabilise it [BGL]" (GDM, 40s)
Underlying altruism	
Providing the best for baby	"It was an important thing to do for the baby so you just do it." (GDM, 40s)
	"The milk beforehand was so good for the baby." (GDM, 30s)
Preparing for inevitable complications	"I knew very early that I'd be having a [caesarean section]. So should've anything happen there was that [colostrum] there." (GDM, 30s)
Eager for milk donation	"There was a mother struggling and she didn't have any and I couldn't have been happier to give her some of mine." (GDM, 30s)
	"Even if your baby doesn't need it, there's possibilities that other babies would be able to use it as well" (GDM, 40s)
Internal pressure to succeed	
Coping with confronting information	"It's just an overwhelming lot of information." (GDM, 20s)
Disheartened by failures	"I was just one of those women that didn't get a colostrum. I tried so hard!" (GDM, 20s)
	"I tried a bit earlier on and I was unsuccessful to get anything." (GDM, 30s)
Constant fear of insufficient supply	"I just kept looking at all the packets of stuff that I hadn't filled and thought 'I've just got to get these filled'." (GDM, 30s)
	"I remember him [obstetrician] going 'Calm down he'll be fine' I'm like, 'I'm freaking out, I don't have any colostrum!'" (GDM, 20s)
Overwhelming guilt	"If I didn't do it and she needed it, I'd only have myself to blame if it wasn't there." (GDM, 30s)
	"I just felt that my body could give more. I just didn't put the time in." (T1DM, 20s)
Concern for future breastfeeding success	"I was beginning to actually get scared I would never make milk." (GDM, 20s)
Frustrated by waste	
Encroaching on time	"It [expressing] was taking me probably a couple of hours to do a night." (GDM, 30s)

	"So yeah it [expressing] was just time consuming." (GDM, 30s)
Squandering a precious resource	"I showed up with 20mls of colostrum thinking I'm sweet and disappeared in three feeds!" (GDM, 20s)
	"It seemed like a waste that it [colostrum] eventually went in the bin." (GDM, 30s)
Ambiguous about necessity	"I didn't end up using the milk. My daughter didn't need it." (GDM, 30s)
	"It was just quite ambiguous... Why am I really doing this?" (T1DM, 20s)
Self-management and ownership	
Adapting to awkwardness	"I felt like it [expressing] was a bit weird. Then when I started to collect I was like 'Okay I get it'." (T1DM, 20s)
	"It didn't seem odd or unusual, just natural." (GDM, 40s)
Developing strategies for success	"I had specimen cups that I collected in and I had all the syringes and had caps and all the labels already printed." (GDM, 30s)
	"I used warm compresses and made sure that I was nice and warm as well. And I would heat up a flannel and pop that over my breast before I tried to express." (GDM, 40s)
Actively seeking education	"I <i>YouTubed</i> , the best way to actually collect." (GDM, 30s)
	"I did some research on it and I saw the benefits." (T1DM, 20s)
Gaining confidence to request help	"I went over and she [lactation consultant] helped me out on her own personal time because it was something I was worried about." (GDM, 20s)
	"Go to lactation consultant and make sure you know how to do it properly." (GDM, 30s)
Accepting personal limitations	"Just knowing that the little that you have is better than nothing." (GDM, 30s)
	"You are disappointed with yourself that you couldn't get it but next time you got heaps...swings and roundabouts." (GDM, 40s)
Building fortitude for motherhood	
Physically preparing for breastfeeding	"It [expressing] made breastfeeding this time really a lot easier. I didn't really breastfeed my first baby." (GDM, 30s)
	"I felt like that [breastfeeding] was quite easy for me to do. Whereas other women, they'd have to learn that technique." (T1DM, 20s)
Symbolic for an imminent infant	"It was all part of what you do to prepare for a baby." (GDM, 40s)
Establishing early relationships with supports	"If I hadn't [expressed] I wouldn't have known where to go and probably wouldn't have felt comfortable reaching out but I'd already made those relationships." (GDM, 30s)
	"I had confidence knowing [I could] walk to [lactation consultant's]

with baby and she'll help me." (GDM, 20s)

Approaching challenges with realistic optimism "I guess looking at the bigger picture and just thinking about the baby." (GDM, 30s)

GDM, gestational diabetes mellitus; T1DM, type I diabetes mellitus; BGL, blood glucose level.

Wary of medicalization

Adjusting to an 'abnormal pregnancy'

Participants reflected that having diabetes was an "added complication" that made their pregnancy unnatural. They felt "shocked" and "terrified" when they were diagnosed with diabetes and were especially concerned about the added risks to their baby. Some felt distressed to be labelled a "high risk pregnancy", especially when they had been "fit and well" prior to diagnosis.

Seeking continuity of care

Participants emphasised the importance of having continuity of care throughout their pregnancy. They were disappointed when they were moved from a low-risk midwife clinic to the diabetes clinic where every week they'd "see someone new". They strove to maintain control of their diabetes to avoid changes to their care – "If I didn't manage the diabetes I wasn't going to be able to give birth at the birth centre."

Determination to reduce formula

Participants actively sought to avoid formula, iterating the benefits of breastfeeding over formula use – "It is better than formula". They felt that by collecting and storing colostrum, they were able to ensure that formula consumption could be reduced.

Women whose babies experienced hypoglycaemia were "overwhelmed" by how

1
2
3 much formula was used, which they considered was unnatural and invasive as it was
4
5 “pouring down the tube”.
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7

8 Fear of invasive intervention 9

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11 Throughout pregnancy, participants experienced relentless fear that their babies and
12
13 they might be subjected to invasive interventions. They feared missing out on a
14
15 “natural, empowered birth” and were particularly frightened by the idea that their
16
17 baby might require nasogastric tubing or intravenous cannulation. They described
18
19 feeling “heartbroken” when their babies were taken away from them to the SCN.
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22 Underlying altruism 23

24 Providing the best for baby 25

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29 Participants were motivated to collect and store colostrum by their ingrained desire to
30
31 provide “the best” for their babies. They described that colostrum could provide
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33 “extra nutrients” and “immunity” and that it had immeasurable benefits in the first
34
35 hours and days. Some participants stated that collecting colostrum had no benefits to
36
37 themselves but emphasized that “you don’t go into motherhood to think about
38
39 yourself”. Ultimately, they believed that by having collected colostrum available, they
40
41 were ensuring their baby had the best possible start – “If it’s the best start for a baby,
42
43 let alone a gestational diabetic baby, I wanted to do anything that I could do to help
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45 him!”
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49 Preparing for complications 50

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53 Participants perceived that complications, especially neonatal hypoglycaemia, were
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55 inevitable, a “sure thing” and that the threat of these complications made collecting
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3 colostrum so important. They felt more secure knowing that the colostrum was
4 available as a “safety net or a backup” and described a sense of pride and confidence
5 at seeing the syringe in the freezer “ready to go” in case the baby experienced low
6 blood sugars or need to be taken to SCN. Collecting was a tangible strategy to “be
7 prepared for the worst, if it should happen.”
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13 14 **Eager for milk donation** 15

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17 For many participants, altruism extended beyond their own babies, as they expressed
18 strong desire for opportunities to donate their collected colostrum. Women who had a
19 plentiful supply of collected colostrum were saddened that there was no milk bank
20 they could donate it to, especially when they saw other mothers struggling. Similarly,
21 women who had been unable to collect were devastated that they were “not allowed to
22 bring in donated breastmilk”. Some women even thought they would have been
23 motivated to collect more colostrum if a milk bank or similar capability was available
24 because of the possibilities that other babies could use it as well.
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36 **Internal pressure to succeed** 37

38 39 **Coping with confronting information** 40

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42 The amount and content of information provided during pregnancy was
43 overwhelming for many participants. Some “never realised” that it was possible to
44 express breast milk prior to birth and that they would have to do it. Women recounted
45 being asked how they would feel if their babies required interventions to correct their
46 blood sugars and found these questions confronting – “I was even told that diabetics
47 have issues with milk supply. They said to me ‘How are you going to feel if he has to
48 go on formula?’”
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Disheartened by failures

Participants described a sense of failure when they have difficulties collecting colostrum and were “devastated” when they were unsuccessful. They experienced ongoing worry that they were using an incorrect technique and found that the process continued to be frustrating and stressful even after they had success with collecting. Some women questioned whether the process was so difficult because they were “forcing it to come out when it’s not fully ready”. Women who had ongoing difficulties collecting colostrum became particularly distressed by their perceived failure – “I went down there just balling!”

Constant fear of insufficient supply

Many participants experienced ongoing and often relentless anxiety that they would have insufficient colostrum collected for their baby. Some described looking at the empty syringes and feeling pressured and panicked to “get these filled!”. Though many women were able to successfully collect multiple syringes of colostrum, they remained absorbed by the idea that they were not getting enough and that the amount they had was “nothing compared” to what they perceived they needed. Some participants compared their supply of colostrum to other expressing women and were uneasy that they had not collected as much as others. For some women, the lack of colostrum supply led them to approach the birth of their baby with extreme apprehension – “They were talking about induction and I said ‘But I don’t have any colostrum yet!’”

Overwhelming guilt

1
2
3 Having diabetes in pregnancy evoked a sense of guilt for many participants,
4 especially because of its implications for their babies and the “many extra risks” it
5 added. This guilt extended to collecting colostrum as women experienced
6 disappointment and self-blame when they struggled with the process. Some women
7 worried that their technique could make the collected colostrum harmful to their baby
8 such as difficulties with sterilisation. Women felt remorseful that they hadn’t started
9 collecting earlier in their pregnancy and some lamented that they did not dedicate
10 more time and effort to the process.
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21 Concern for future breastfeeding success

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24 For some participants, difficulties with collecting colostrum in the antenatal period led
25 them to question whether they would have success with breastfeeding postnatally.
26 They became stressed that their lack of colostrum was a reflection of their future
27 postnatal lactational performance – “I was beginning to actually get scared that I was
28 never going to make milk!”
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36 Self-management and ownership

37 Adapting to awkwardness

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40 To achieve success with collecting colostrum, participants were required to adapt to a
41 process that many found “weird” and “funny” and associated with underlying
42 embarrassment. However, participants explained that once they began to express they
43 gained more confidence and experienced pride and excitement when they saw how
44 much they were collecting. Ultimately they were able to accept that the process was
45 “not odd or unusual, just natural.”
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56 Developing strategies for success

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3 Many participants were empowered to develop personal strategies to be successful
4 with collecting and storing colostrum. They described using methods such warm
5 compresses, showers and relaxation techniques to help initiate colostrum expression
6 and experimented with collecting instruments including syringes, teaspoons,
7 collection cups and mechanical breast-pumps. Ultimately, many women perceived
8 that the key to successful colostrum expressing was organisation and relaxation –
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15
16 “When you got a routine down it became quite easy.”
17

18 Actively seeking education

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21
22 Participants sought to become more educated about collecting colostrum antenatally
23 by utilising social media groups, watching YouTube videos and seeking written
24 material from their midwives and lactation consultants. Some women thought the
25 amount of education provided could be improved for example, by using case studies
26 to emphasise why collecting colostrum might be important for the mother and baby.
27
28
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33 One woman with Type I diabetes was concerned that most education readily available
34 was targeted at women with GDM and wished for more specific education for women
35 with pre-existing diabetes in pregnancy.
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39

40 Gaining confidence to request help

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42
43 Participants enthusiastically communicated the role that supports such as midwives
44 and lactation consultants played in providing advice and encouragement to help them
45 achieve success with collecting. Some women also relied on family such as their
46 mother or spouse to provide support and one woman contacted Breastfeeding
47 Australia to gain further reassurance. Women who had difficulties collecting
48 colostrum felt confident after gaining professional help from a lactation consultant –
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50
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55
56 “I didn’t get any colostrum but it felt good because someone else had tried to do it.”
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59

Accepting personal limitations

Participants were able to overcome their personal limitation with collecting colostrum and begin to take pride in small successes. They acknowledged that the process could be “luck of the draw” and they need to celebrate the “little wins”. For many, positive thinking was the mainstay of adjusting to diabetes in pregnancy and collecting colostrum – “Some” days you’ve just got to chalk it up to a bad day and try again tomorrow.”

Frustration with waste

Encroaching on time

Collecting colostrum was pronounced a tedious and time consuming process that participants reported could take hours to complete. Some participants also felt that appointments associated with collecting colostrum, such as visiting the lactation consultant, took up excessive time, especially given the many appointments they were required to attend because of their diabetes. One woman thought it would be particularly difficult for working women – “I was lucky because I didn’t work, so I could come to the hospital a lot more.”

Squandering a precious resource

Participants found it was easy to waste colostrum and were frustrated when they missed drops when expressing or left colostrum on the teaspoon. They were also extremely disappointed when their supply of collected colostrum was wasted if they didn’t need to use it, especially when it “eventually went in the bin.” Women with both ample and insufficient supply of colostrum reiterated their disappointment that

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3 there are no opportunities for milk donation, to prevent the expressed colostrum from
4
5 merely being “dumped”.

6 7 8 **Ambiguous about necessity**

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11 Some participants questioned whether having colostrum available was really worth
12
13 the effort required to collect it. They found themselves asking – “Why am I really
14
15 doing this?”

16 17 18 **Building fortitude for motherhood**

19 20 21 **Preparing for breastfeeding**

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23
24 Participants emphasised that collecting colostrum antenatally helped them prepare for
25
26 breastfeeding postnatally. Some participants noticed that their milk “came on a lot
27
28 quicker” than with previous pregnancies. Others felt the skills they had learnt to hand
29
30 express were useful when their baby needed tops-up to supplement breastfeeding.

31
32
33 Expressing in the antenatal period also provided mental fortitude for breastfeeding –
34
35
36 “I know I can make milk, it’s in my head.”

37 38 39 **Symbolic of the imminent infant**

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41
42 Collecting colostrum was a tangible symbol of the coming baby for many
43
44 participants, a reminder that they would soon be mothers and a practical way to
45
46 “prepare” for a baby – “Expressing was the first time that it was like, you’re having a
47
48 baby!”

49 50 51 **Establishing early relationships with breastfeeding supports**

1
2
3 By seeking advice as they negotiated the challenges of collecting antenatal colostrum,
4 participants were able to build relationships with professionals and organisations that
5 could provide support throughout breastfeeding. They perceived that expressing
6 helped them know who to ask for help and gave them the confidence to admit when
7 they were having difficulties postnatally.
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13 14 Approaching challenges with realistic optimism 15

16
17 Participants felt that the psychological strategies they developed to cope with the
18 frustrations of diabetes in pregnancy, and especially collecting colostrum, ultimately
19 aided them to approach the inevitable challenges of motherhood with similar
20 positivity – “I felt like it [collecting colostrum] prepared me, hardened everything
21 up.”
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29 30 **DISCUSSION** 31

32
33 In this analysis of the experiences of women with diabetes in pregnancy, women were
34 motivated to collect and store colostrum by wariness of medicalization and an
35 underlying desire to provide the best start for their babies and avoid unnecessary
36 interventions such as formula. These motivating factors, however, also contributed to
37 an ongoing and often overwhelming pressure to be successful with collecting
38 colostrum, associated with considerable guilt and distress when they had difficulties
39 with the process. This pressure also drove women to develop personal strategies to
40 regain control in the context of their pregnancy complicated by diabetes. Women
41 were able to adjust to frustrations associated with expressing and ultimately develop
42 bio-psychosocial fortitude for motherhood.
43
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3 One major finding that emerged in this study was participants' eagerness for the
4 availability of milk banks, as a strategy to reduce wastage of unused colostrum and as
5 an outlet of altruism to support other mothers with an insufficient supply. A recent
6 qualitative study of mother's opinions of human milk banking found that women
7 perceived donor milk as healthier than formula and that it allowed smoother transition
8 to exclusive breastfeeding.[13] Donor breast milk has been shown to offer health
9 benefits compared to formula including reduction in complications such as necrotising
10 enterocolitis and an improvement in feeding tolerance.[14,15] Given that women
11 dedicate considerable time and effort to collecting colostrum, which often goes
12 unused, protocols should be in place to minimise waste, such as though donation, if
13 this practice continues to be promoted.
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29 Women in this study who were able to collect colostrum in the antenatal period
30 perceived that they were more physically and psychosocially prepared for
31 breastfeeding postnatally. Similarly, previous qualitative analysis of non-diabetic
32 women's experiences with expressing revealed that antenatal expressing can bolster
33 women's confidence in breastfeeding by facilitating a sense of mastery and breast
34 familiarity.[10] Breastfeeding is particularly beneficial for mothers with diabetes and
35 their newborns because it can reduce the development of Type II diabetes in mothers
36 with GDM, and can reduce the development of diabetes in the child in the long-term
37 and hypoglycaemia in the short-term.[16-18] However, diabetes in pregnancy has
38 been associated with delayed lactogenesis, which paradoxically makes breastfeeding
39 more difficult for these mothers.[19] A recent prospective study in a non-diabetic
40 population found that expressing antenatally can significantly improve postnatal
41 lactational performance by early establishment of plentiful milk secretion.[9] Further
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3 investigation of the effects of collecting colostrum antenatally on time to full lactation
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5 in the diabetic population appears warranted.
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9 We performed in-depth, face-to-face interviewing which allowed for a detailed
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11 understanding of women's experiences of collecting and storing colostrum.
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13 Participants were interviewed until no new concepts emerged (i.e. theoretical
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15 saturation was achieved). Researcher triangulation was used to ensure the themes
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17 reflected the range and depth of data collected. However, this study had some
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19 limitations. Non-English speaking participants were excluded from the study and only
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21 women of Caucasian ethnicity were represented in the study sample. Participants were
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23 only recruited from one site so the transferability to other settings is uncertain.
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29 **CONCLUSION**

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32 Women who have diabetes in pregnancy experience stress and guilt due to the added
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34 risks to their babies, especially neonatal hypoglycaemia, and experience internal
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36 pressure to provide the best for their babies by collecting colostrum, even though this
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38 process can cause further distress and frustration. Though the DAME trial found that
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40 expressing antenatally is safe for low risk diabetic women, the specific benefits to the
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42 newborn remain less clear.[7,8] Care must be taken to present accurate and realistic
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44 advice to women with diabetes in pregnancy about the benefits and challenges of
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46 collecting antenatal colostrum to facilitate informed decision-making.
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52 **ACKNOWLEDGEMENTS**

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4 participant recruitment. We would like to particularly acknowledge the women who
5 gave up their time to participate in this study.
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10 11 **CONTRIBUTOR STATEMENT**

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14 JRC designed the study, conducted the interviews, coded and analysed the data,
15 carried out the thematic analysis and drafted the manuscript. ELM coded and analysed
16 the data, participated in the thematic analysis and critical review of the first and
17 subsequent manuscript drafts. JB assisted with study design and interview tool
18 development, provided intellectual input into first and subsequent manuscript drafts
19 and assisted with thematic analysis. KB conceived the study, assisted with study
20 design and interview tool development and provided intellectual input into subsequent
21 manuscript drafts. CH assisted with study design and interview tool development,
22 provided intellectual input into first and subsequent manuscript drafts, assisted with
23 thematic analysis and is the guarantor. All authors had full access to all of the data in
24 the study and can take responsibility for the integrity of the data and the accuracy of
25 the data analysis.
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42 **COMPETING INTERESTS**

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44 The authors have no competing interests to declare.
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52 Dentistry, grant number JCU-QLD-578961.
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STATEMENT OF ETHICS APPROVAL

Ethics approval was obtained for this study from The Townsville Hospital and Health Service (HREC/16/QTHS/66). All participants gave informed written consent before taking part in this study.

DATA SHARING STATEMENT

No additional data are available.

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3 **Figure 1:** Thematic schema of diabetic women's experiences of collecting colostrum
4 in pregnancy.
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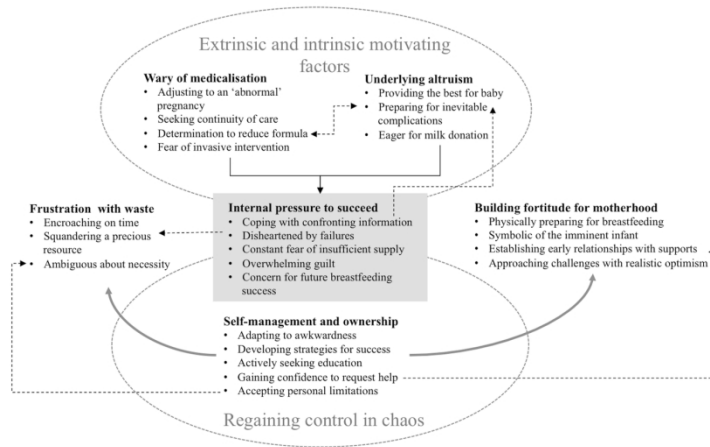


Figure 1: Thematic schema of diabetic women's experiences of collecting colostrum in pregnancy.

84x47mm (600 x 600 DPI)

BMJ Open

Perspectives and experiences of collecting antenatal colostrum in women who have had diabetes during pregnancy: a North Queensland semi-structured interview study

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Secondary Subject Heading:	Qualitative research
Keywords:	Diabetes in pregnancy < DIABETES & ENDOCRINOLOGY, QUALITATIVE RESEARCH, Colostrum, Breastfeeding

SCHOLARONE™
Manuscripts

TITLE PAGE: BMJ OPEN**Perspectives and experiences of collecting antenatal colostrum in women who have had diabetes during pregnancy: a North Queensland semi-structured interview study**

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Word count: 3429

ABSTRACT

Objectives: To explore and describe the experiences and perspectives of collecting and storing colostrum in the antenatal period in women who have had diabetes in pregnancy.

Design: Face-to-face, semi-structured interviews analysed with purposive sampling and thematic analysis.

Setting: A regional hospital in North Queensland with a high prevalence of diabetes in pregnancy.

Participants: Six women with a previous pregnancy complicated by diabetes who were advised to collect and store colostrum in pregnancy.

Results: Six themes were identified: wariness of medicalisation (adjusting to an 'abnormal' pregnancy, seeking continuity of care, determination to reduce formula, fear of invasive intervention); underlying altruism (providing the best for baby, preparing for complications, eager for milk donation); internal pressure to succeed (coping with confronting information, disheartened by failures, constant fear of insufficient supply, overwhelming guilt, concern for future breastfeeding success); self-management and ownership (adapting to awkwardness, developing strategies for success, actively seeking education, gaining confidence to request help, accepting personal limitations); frustrated by waste (encroaching on time, squandering a precious resource, ambiguous about necessity); and building fortitude for motherhood (physically preparing for breastfeeding, symbolic of the imminent infant, establishing early relationships with supports, approaching challenges with realistic optimism).

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3 **Conclusion:** Women with diabetes in pregnancy experience guilt and stress about the
4 added risk of hypoglycaemia to their babies and strive to provide the best for their
5 babies by collecting and storing colostrum; even if this leads to distress to themselves.
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7 It is crucial that these women be provided accurate, realistic advice about the benefits
8 and disadvantages of collecting colostrum in the antenatal period.
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13 14 15 16 **STRENGTHS AND LIMITATIONS OF THIS STUDY** 17

- 18
19 • In-depth, face-to-face interviewing allowed for a detailed understanding of
20 women's experiences of collecting and storing colostrum.
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- 22
23 • Participants were recruited until theoretical saturation was achieved.
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26 • Researcher triangulation was used to ensure the themes reflected the range and
27 depth of data collected.
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30 • A limitation of this study was that only Caucasian women were represented in the
31 sample
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34 • The study was only conducted in one centre so transferability to other settings is
35 uncertain.
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41 **FUNDING STATEMENT** 42

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44 This work was supported by the College of Medicine and Dentistry, James Cook
45 University grant number JCU-QLD-578961.
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BACKGROUND

Diabetes mellitus is a common problem that affects more than 13% of pregnant women in Australia.[1] Diabetes in pregnancy includes both gestational diabetes mellitus (GDM) and pre-existing diabetes (Type I diabetes mellitus or Type II diabetes mellitus). Diabetes in pregnancy is associated with multiple risks to the newborn including macrosomia, shoulder dystocia, polycythaemia, hyperbilirubinemia and neonatal hypoglycaemia.[2] Hypoglycaemia is a significant problem as it is associated with cardiorespiratory disturbances, damage to the central nervous system and developmental delay.[3,4] Approximately 6% of Australian neonates experience hypoglycaemia, however this rate is greatly increased in infants born to mothers with diabetes with 25-50% of newborns affected.[5] The mainstay of management of infants at risk of hypoglycaemia is early breastfeeding and top up feeding with colostrum or formula.[6]

Some women with diabetes in pregnancy are referred to a lactation consultant and encouraged to begin expressing and storing colostrum in the late antenatal period.[7] This practice has been thought to promote earlier onset of lactogenesis and facilitate early breastfeeding; as well as provide a supply of colostrum that may be used to supplement breastfeeding and reduce reliance on formula feeding to treat hypoglycaemia.[7,8] Because of these perceived benefits to the neonate, women with diabetes in pregnancy are encouraged to collect and store colostrum by midwives, diabetes educators and obstetricians in many settings.[9] However, the experiences of women with diabetes who are encouraged to engage in this practice have not been well explored.

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3 The Diabetes and Antenatal Milk Expressing (DAME) study, a multi-centre
4 randomised control trial in Melbourne, found that expressing from 36 weeks gestation
5 was safe in low risk women with diabetes and may have some benefits to the neonate
6 including increased rates of exclusive breastfeeding in the first twenty-four hours of
7 life.[10] In women without diabetes in pregnancy, antenatal expressing has also been
8 shown to be associated with reduced time to initiation of full establishment of
9 lactation, which suggests expressing in the antenatal period may improve postnatal
10 lactational performance.[8] However, a qualitative study of antenatal expressing in
11 women without diabetes in pregnancy found that though collecting colostrum
12 antenatally may increase confidence and breast familiarity, it can also evoke
13 embarrassment and can be difficult and painful to engage in.[11]

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29 Women with diabetes in our centre routinely attend an education session with the
30 diabetes educator midwife, where they are advised to collect antenatal colostrum and
31 are referred to a lactation consultant. Women are provided with syringes and labels
32 and are encouraged to begin expressing colostrum daily from 34-36 weeks gestation
33 and continue until birth.

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42 This study aims to explore the perspectives and experiences of women who have had
43 diabetes in pregnancy and were encouraged to collect and store colostrum in the
44 antenatal period, which may elucidate motivating factors, challenges, benefits and
45 stress factors in this population.
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53 **METHODS**

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3 The Consolidated Criteria for Reporting Qualitative Health Research (COREQ) was
4 followed.[12]
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8 **Patient selection and setting**

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11 Women were eligible to participate in this study if they were English speaking, had
12 experienced diabetes in pregnancy, had attended an education session with the
13 diabetes educator midwife about collecting antenatal colostrum, had had a live,
14 singleton birth and were at least six weeks postpartum. Purposive sampling was used
15 to capture a range of clinical characteristics including type of diabetes (GDM or
16 diabetes unrelated to pregnancy) and neonatal complications. Selected women who
17 had been registered on the 2014 and 2015 diabetes antenatal register at the study
18 hospital were identified by the diabetes educator midwife, contacted by mail and
19 invited to participate. Participants who returned the signed consent form were
20 contacted by the primary author (JRC) to arrange an interview. Ethics approval was
21 obtained from The Townsville Hospital and Health Service (HREC/16/QTHS/66).
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36 **Data collection**

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39 A semi-structured face-to-face interview was conducted with each participant in the
40 women's choice of their home, meeting room at the hospital or local café between
41 May 2017 and July 2017. The average length of interview was 28 minutes. All
42 interviews were conducted by one author, who is a female medical student,
43 experienced in qualitative research (JRC). No participants were known to the
44 interviewer. Participants were alone or accompanied by their infant. The interview
45 guide included questions about experiencing and coping with diabetes in pregnancy,
46 expressing and storing colostrum, postpartum adjustment and breastfeeding. This
47 guide was developed after a review of the literature [7-11] and discussion among the
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3 investigators, which consisted of an obstetric clinician and research officers
4 experienced in qualitative research. Interviews were digitally recorded with
5 participants' consent and transcribed. Field notes were also written during the
6 interviews. Interviews were conducted until theoretical saturation was achieved.
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11 **Patient and public involvement**

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15 No patients were directly involved in the development of the research question,
16 selection of the outcome measures, design of the study or interpretation of the results.
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20 **Data analysis**

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24 Transcripts were entered in software for qualitative data management
25 (HyperRESEARCH; V.3.5.2 ResearchWare Inc.) for analysis. Drawing on the
26 principles of grounded theory and thematic analysis, one author (JRC) performed line-
27 by-line coding of each transcript to inductively identify themes in the data (i.e.,
28 themes were not established a priori).[13] New codes were created to capture new
29 concepts. The preliminary themes and codes were reviewed by three other authors
30 (ELM, JB, CH) and iterated to ensure codes and themes reflected the data collected
31 (investigator triangulation). Conceptual patterns and links between themes were
32 identified to develop a thematic schema.
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46 **RESULTS**

47 **Participant characteristics**

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50 Thirty participants were contacted by mail. Six participants consented to be
51 interviewed. Participant characteristics are provided in Table 1. The age of
52 participants ranged from 27 to 45 years. Of the six participants, five had had GDM
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and one had Type I diabetes mellitus. All six women were diagnosed with diabetes during pregnancy. Though all attempted to collect antenatal colostrum, five of the participants were able to obtain colostrum. Four of the participants had babies who experienced neonatal hypoglycaemia.

Table 1: Participant characteristics.

Characteristics	Total n
Age Group (years)	
25 - 30	2
31 - 35	3
>35	1
Ethnicity	
Caucasian	6
Marital status	
Married	5
De facto	1
Education level	
Grade 12 or equivalent	1
Diploma	2
Bachelor's degree	2
Post-graduate degree	1
Diabetes type	
GDM	5
T1DM	1
Primiparous	
Yes	4
Person who advised woman to collect antenatal colostrum*	
Midwife	5
Lactation consultant	5
Diabetic educator	3
Obstetrician	2
Other**	3
Woman obtained antenatal colostrum	
Yes	5
Baby became hypoglycaemic	
Yes	4
Treatment of hypoglycaemia*	
EBM	4
Formula	4

IV dextrose

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(*), more than one answer given; (**), other included Breastfeeding Australia, friends and general practitioners; GDM, gestational diabetes mellitus; T1DM, type I diabetes mellitus; EBM, expressed breast milk; IV, intravenous.

Themes

Six major themes emerged: wary of medicalization, underlying altruism, internal pressure to succeed, self-management and ownership, frustration with waste, and building fortitude for motherhood. Each theme and corresponding subthemes are outlined below. Illustrative quotes are provided in Table 2. Figure 1 depicts a thematic schema which maps conceptual links between themes.

Table 2: Themes and illustrative quotes.

THEME	ILLUSTRATIVE QUOTE
Wary of medicalization	
Adjusting to an 'abnormal pregnancy'	"When you're pregnant, you're trying to figure it out anyway and then you've got the added complication of diabetes." (GDM, 20s)
	"I cried on the phone...I was like, "I don't know what I'm doing, I don't know what's going on!" (T1DM, 20s)
Seeking continuity of care	"The continuity of care is so important!" (GDM, 20s)
Determination to reduce formula	"We managed to avoid a few top up feeds from the formula." (GDM, 20s)
	"Get as much as you can! Because it is better than formula!" (T1DM, 20s)
Fear of invasive intervention	"It heartbreaking actually because they ended up having to put in drips and things to stabilise it [BGL]" (GDM, 40s)
Underlying altruism	
Providing the best for baby	"It was an important thing to do for the baby so you just do it." (GDM, 40s)
	"The milk beforehand was so good for the baby." (GDM, 30s)
Preparing for inevitable complications	"I knew very early that I'd be having a [caesarean section]. So should've anything happen there was that [colostrum] there." (GDM, 30s)
Eager for milk donation	"There was a mother struggling and she didn't have any and I couldn't have been happier to give her some of mine." (GDM, 30s)
	"Even if your baby doesn't need it, there's possibilities that other babies would be able to use it as well" (GDM, 40s)
Internal pressure to	

succeed	
Coping with confronting information	"It's just an overwhelming lot of information." (GDM, 20s)
Disheartened by failures	"I was just one of those women that didn't get a colostrum. I tried so hard!" (GDM, 20s) "I tried a bit earlier on and I was unsuccessful to get anything." (GDM, 30s)
Constant fear of insufficient supply	"I just kept looking at all the packets of stuff that I hadn't filled and thought 'I've just got to get these filled'." (GDM, 30s) "I remember him [obstetrician] going 'Calm down he'll be fine' I'm like, 'I'm freaking out, I don't have any colostrum!'" (GDM, 20s)
Overwhelming guilt	"If I didn't do it and she needed it, I'd only have myself to blame if it wasn't there." (GDM, 30s) "I just felt that my body could give more. I just didn't put the time in." (T1DM, 20s)
Concern for future breastfeeding success	"I was beginning to actually get scared I would never make milk." (GDM, 20s)
Frustrated by waste	
Encroaching on time	"It [expressing] was taking me probably a couple of hours to do a night." (GDM, 30s) "So yeah it [expressing] was just time consuming." (GDM, 30s)
Squandering a precious resource	"I showed up with 20mls of colostrum thinking I'm sweet and disappeared in three feeds!" (GDM, 20s) "It seemed like a waste that it [colostrum] eventually went in the bin." (GDM, 30s)
Ambiguous about necessity	"I didn't end up using the milk. My daughter didn't need it." (GDM, 30s) "It was just quite ambiguous... Why am I really doing this?" (T1DM, 20s)
Self-management and ownership	
Adapting to awkwardness	"I felt like it [expressing] was a bit weird. Then when I started to collect I was like 'Okay I get it.'" (T1DM, 20s) "It didn't seem odd or unusual, just natural." (GDM, 40s)
Developing strategies for success	"I had specimen cups that I collected in and I had all the syringes and had caps and all the labels already printed." (GDM, 30s) "I used warm compresses and made sure that I was nice and warm as well. And I would heat up a flannel and pop that over my breast before I tried to express." (GDM, 40s)
Actively seeking education	"I <i>YouTubed</i> , the best way to actually collect." (GDM, 30s)

	"I did some research on it and I saw the benefits." (T1DM, 20s)
Gaining confidence to request help	"I went over and she [lactation consultant] helped me out on her own personal time because it was something I was worried about." (GDM, 20s)
	"Go to lactation consultant and make sure you know how to do it properly." (GDM, 30s)
Accepting personal limitations	"Just knowing that the little that you have is better than nothing." (GDM, 30s)
	"You are disappointed with yourself that you couldn't get it but next time you got heaps...swings and roundabouts." (GDM, 40s)

Building fortitude for motherhood

Physically preparing for breastfeeding	"It [expressing] made breastfeeding this time really a lot easier. I didn't really breastfeed my first baby." (GDM, 30s)
	"I felt like that [breastfeeding] was quite easy for me to do. Whereas other women, they'd have to learn that technique." (T1DM, 20s)
Symbolic for an imminent infant	"It was all part of what you do to prepare for a baby." (GDM, 40s)
Establishing early relationships with supports	"If I hadn't [expressed] I wouldn't have known where to go and probably wouldn't have felt comfortable reaching out but I'd already made those relationships." (GDM, 30s)
	"I had confidence knowing [I could] walk to [lactation consultant's] with baby and she'll help me." (GDM, 20s)
Approaching challenges with realistic optimism	"I guess looking at the bigger picture and just thinking about the baby." (GDM, 30s)

GDM, gestational diabetes mellitus; T1DM, type I diabetes mellitus; BGL, blood glucose level.

Wary of medicalization

Adjusting to an 'abnormal pregnancy'

Participants reflected that having diabetes was an "added complication" that made their pregnancy unnatural. They felt "shocked" and "terrified" when they were diagnosed with diabetes and were especially concerned about the added risks to their baby. Some felt distressed to be labelled a "high risk pregnancy", especially when they had been "fit and well" prior to diagnosis.

Seeking continuity of care

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3 Participants emphasised the importance of having continuity of care throughout their
4 pregnancy. They were disappointed when they were moved from a low-risk midwife
5 clinic to the diabetes clinic where every week they'd "see someone new". They strove
6 to maintain control of their diabetes to avoid changes to their care – "If I didn't
7 manage the diabetes I wasn't going to be able to give birth at the birth centre."
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13 14 Determination to reduce formula

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17 Participants actively sought to avoid formula, iterating the benefits of breastfeeding
18 over formula use – "It is better than formula". They felt that by collecting and storing
19 colostrum, they were able to ensure that formula consumption could be reduced.
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24 Women whose babies experienced hypoglycaemia were "overwhelmed" by how
25 much formula was used, which they considered was unnatural and invasive as it was
26 "pouring down the tube".
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31 32 Fear of invasive intervention

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34 Throughout pregnancy, participants experienced relentless fear that their babies and
35 they might be subjected to invasive interventions. They feared missing out on a
36 "natural, empowered birth" and were particularly frightened by the idea that their
37 baby might require nasogastric tubing or intravenous cannulation. They described
38 feeling "heartbroken" when their babies were taken away from them to the SCN.
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46 47 Underlying altruism

48 49 Providing the best for baby

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52 Participants were motivated to collect and store colostrum by their ingrained desire to
53 provide "the best" for their babies. They described that colostrum could provide
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3 “extra nutrients” and “immunity” and that it had immeasurable benefits in the first
4 hours and days. Some participants stated that collecting colostrum had no benefits to
5 themselves but emphasized that “you don’t go into motherhood to think about
6 yourself”. Ultimately, they believed that by having collected colostrum available, they
7 were ensuring their baby had the best possible start – “If it’s the best start for a baby,
8 let alone a gestational diabetic baby, I wanted to do anything that I could do to help
9 him!”

18 Preparing for complications

21
22 Participants perceived that complications, especially neonatal hypoglycaemia, were
23 inevitable, a “sure thing” and that the threat of these complications made collecting
24 colostrum so important. They felt more secure knowing that the colostrum was
25 available as a “safety net or a backup” and described a sense of pride and confidence
26 at seeing the syringe in the freezer “ready to go” in case the baby experienced low
27 blood sugars or need to be taken to SCN. Collecting was a tangible strategy to “be
28 prepared for the worst, if it should happen.”

38 Eager for milk donation

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42 For many participants, altruism extended beyond their own babies, as they expressed
43 strong desire for opportunities to donate their collected colostrum. Women who had a
44 plentiful supply of collected colostrum were saddened that there was no milk bank
45 they could donate it to, especially when they saw other mothers struggling. Similarly,
46 women who had been unable to obtain colostrum were devastated that they were “not
47 allowed to bring in donated breastmilk”. Some women even thought they would have
48 been motivated to collect more colostrum if a milk bank or similar capability was
49 available because of the possibilities that other babies could use it as well.

Internal pressure to succeed

Coping with confronting information

The amount and content of information provided during pregnancy was overwhelming for many participants. Some “never realised” that it was possible to express breast milk prior to birth and that they would have to do it. Women recounted being asked how they would feel if their babies required interventions to correct their blood sugars and found these questions confronting – “I was even told that diabetics have issues with milk supply. They said to me ‘How are you going to feel if he has to go on formula?’”

Disheartened by failures

Participants described a sense of failure when they have difficulties collecting colostrum and were “devastated” when they were unable to obtain colostrum. They experienced ongoing worry that they were using an incorrect technique and found that the process continued to be frustrating and stressful even after they had successfully managed to collect some colostrum. Some women questioned whether the process was so difficult because they were “forcing it to come out when it’s not fully ready”. Women who had ongoing difficulties collecting colostrum became particularly distressed by their perceived failure – “I went down there just balling!”

Constant fear of insufficient supply

Many participants experienced ongoing and often relentless anxiety that they would have insufficient colostrum collected for their baby. Some described looking at the empty syringes and feeling pressured and panicked to “get these filled!”. Though

1
2
3 many women were able to successfully collect multiple syringes of colostrum, they
4 remained absorbed by the idea that they were not getting enough and that the amount
5 they had was “nothing compared” to what they perceived they needed. Some
6
7 participants compared their supply of colostrum to other expressing women and were
8
9 uneasy that they had not collected as much as others. For some women, the lack of
10
11 colostrum supply led them to approach the birth of their baby with extreme
12
13 apprehension – “They were talking about induction and I said ‘But I don’t have any
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15 colostrum yet!’”
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21 Overwhelming guilt

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24 Having diabetes in pregnancy evoked a sense of guilt for many participants,
25 especially because of its implications for their babies and the “many extra risks” it
26
27 added. This guilt extended to collecting colostrum as women experienced
28
29 disappointment and self-blame when they struggled with the process. Some women
30
31 worried that their technique could make the collected colostrum harmful to their baby
32
33 such as difficulties with sterilisation. Women felt remorseful that they hadn’t started
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35 collecting earlier in their pregnancy and some lamented that they did not dedicate
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37 more time and effort to the process.
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42 Concern for future breastfeeding success

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45 For some participants, difficulties with collecting colostrum in the antenatal period led
46
47 them to question whether they would have success with breastfeeding postnatally.
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49 They became stressed that their lack of colostrum was a reflection of their future
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51 postnatal lactational performance – “I was beginning to actually get scared that I was
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53 never going to make milk!”
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Self-management and ownership

Adapting to awkwardness

To enable the collection of colostrum, participants were required to adapt to a process that many found “weird” and “funny” and associated with underlying embarrassment. However, participants explained that once they began to express they gained more confidence, and experienced pride and excitement when they saw how much they were collecting. Ultimately they were able to accept that the process was “not odd or unusual, just natural.”

Developing strategies for success

Many participants were empowered to develop personal strategies to enable them to collect and store more colostrum. They described using methods such warm compresses, showers and relaxation techniques to help initiate colostrum expression and experimented with collecting instruments including syringes, teaspoons, collection cups and mechanical breast-pumps. Ultimately, many women perceived that the key to obtaining colostrum was organisation and relaxation – “When you got a routine down it became quite easy.”

Actively seeking education

Participants sought to become more educated about collecting colostrum antenatally by utilising social media groups, watching YouTube videos and seeking written material from their midwives and lactation consultants. Some women thought the amount of education provided could be improved for example, by using case studies to emphasise why collecting colostrum might be important for the mother and baby.

Gaining confidence to request help

Participants enthusiastically communicated the role that supports such as midwives and lactation consultants played in providing advice and encouragement to help them with collecting. Some women also relied on family such as their mother or spouse to provide support and one woman contacted Breastfeeding Australia to gain further reassurance. Women who had difficulties collecting colostrum felt confident after gaining professional help from a lactation consultant – “I didn’t get any colostrum but it felt good because someone else had tried to do it.”

Accepting personal limitations

Participants were able to overcome their personal limitation with collecting colostrum and begin to take pride in small successes. They acknowledged that the process could be “luck of the draw” and they need to celebrate the “little wins”. For many, positive thinking was the mainstay of adjusting to diabetes in pregnancy and collecting colostrum – “Some” days you’ve just got to chalk it up to a bad day and try again tomorrow.”

Frustration with waste

Encroaching on time

Collecting colostrum was pronounced a tedious and time consuming process that participants reported could take hours to complete. Some participants also felt that appointments associated with collecting colostrum, such as visiting the lactation consultant, took up excessive time, especially given the many appointments they were required to attend because of their diabetes. One woman thought it would be

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3 particularly difficult for working women – “I was lucky because I didn’t work, so I
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5 could come to the hospital a lot more.”
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8 Squandering a precious resource 9

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11 Participants found it was easy to waste colostrum and were frustrated when they
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13 missed drops when expressing or left colostrum on the teaspoon. They were also
14
15 extremely disappointed when their supply of collected colostrum was wasted if they
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17 didn’t need to use it, especially when it “eventually went in the bin.” Women with
18
19 both ample and insufficient supply of colostrum reiterated their disappointment that
20
21 there are no opportunities for milk donation, to prevent the expressed colostrum from
22
23 merely being “dumped”.
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26 27 Ambiguous about necessity 28

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30 Some participants questioned whether having colostrum available was really worth
31
32 the effort required to collect it. They found themselves asking – “Why am I really
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34 doing this?”
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37 38 **Building fortitude for motherhood** 39

40 41 Preparing for breastfeeding 42

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44 Participants emphasised that collecting colostrum antenatally helped them prepare for
45
46 breastfeeding postnatally. Some participants noticed that their milk “came on a lot
47
48 quicker” than with previous pregnancies. Others felt the skills they had learnt to hand
49
50 express were useful when their baby needed tops-up to supplement breastfeeding.
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52 Expressing in the antenatal period also provided mental fortitude for breastfeeding –
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54 “I know I can make milk, it’s in my head.”
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Symbolic of the imminent infant

Collecting colostrum was a tangible symbol of the coming baby for many participants, a reminder that they would soon be mothers and a practical way to “prepare” for a baby – “Expressing was the first time that it was like, you’re having a baby!”

Establishing early relationships with breastfeeding supports

By seeking advice as they negotiated the challenges of collecting antenatal colostrum, participants were able to build relationships with professionals and organisations that could provide support throughout breastfeeding. They perceived that expressing helped them know who to ask for help and gave them the confidence to admit when they were having difficulties postnatally.

Approaching challenges with realistic optimism

Participants felt that the psychological strategies they developed to cope with the frustrations of diabetes in pregnancy, and especially collecting colostrum, ultimately aided them to approach the inevitable challenges of motherhood with similar positivity – “I felt like it [collecting colostrum] prepared me, hardened everything up.”

DISCUSSION

In this analysis of the experiences of women with diabetes in pregnancy, women were motivated to collect and store colostrum by wariness of medicalization and an underlying desire to provide the best start for their babies and avoid unnecessary interventions such as formula. These motivating factors, however, also contributed to

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3 an ongoing and often overwhelming pressure to obtain colostrum, associated with
4 considerable guilt and distress when they had difficulties with the process. This
5 pressure also drove women to develop personal strategies to regain control in the
6 context of their pregnancy complicated by diabetes. Women were able to adjust to
7 frustrations associated with expressing and ultimately develop bio-psychosocial
8 fortitude for motherhood.
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18 One major finding that emerged in this study was participants' eagerness for the
19 availability of milk banks, as a strategy to reduce wastage of unused colostrum and as
20 an outlet of altruism to support other mothers with an insufficient supply. A recent
21 qualitative study of mother's opinions of human milk banking found that women
22 perceived donor milk as healthier than formula and that it allowed smoother transition
23 to exclusive breastfeeding.[14] Donor breast milk has been shown to offer health
24 benefits compared to formula including reduction in complications such as necrotising
25 enterocolitis and an improvement in feeding tolerance.[15,16] Given that women
26 dedicate considerable time and effort to collecting colostrum, which often goes
27 unused, protocols should be in place to minimise waste, such as though donation, if
28 this practice continues to be promoted.
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44 Women in this study who were able to collect colostrum in the antenatal period
45 perceived that they were more physically and psychosocially prepared for
46 breastfeeding postnatally. Similarly, previous qualitative analysis of women without
47 diabetes in pregnancy revealed that antenatal expressing can bolster women's
48 confidence in breastfeeding by facilitating a sense of mastery and breast
49 familiarity.[11] Breastfeeding is particularly beneficial for mothers with diabetes and
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3 their newborns because it can reduce the development of Type II diabetes in mothers
4 with GDM, and can reduce the development of diabetes in the child in the long-term
5 and hypoglycaemia in the short-term.[17-19] However, diabetes in pregnancy has
6 been associated with delayed lactogenesis, which paradoxically makes breastfeeding
7 more difficult for these mothers.[20] A recent prospective study in a non-diabetic
8 population found that expressing antenatally can significantly improve postnatal
9 lactational performance by early establishment of plentiful milk secretion.[10] Further
10 investigation of the effects of collecting colostrum antenatally on time to full lactation
11 in the diabetic population appears warranted.
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24 We performed in-depth, face-to-face interviewing which allowed for a detailed
25 understanding of women's experiences of collecting and storing colostrum.
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27 Participants were interviewed until no new concepts emerged (i.e. theoretical
28 saturation was achieved). Researcher triangulation was used to ensure the themes
29 reflected the range and depth of data collected. However, this study had some
30 limitations. Non-English speaking participants were excluded from the study and only
31 women of Caucasian ethnicity were represented in the study sample. Participants were
32 only recruited from one site so the transferability to other settings is uncertain.
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44 **CONCLUSION**

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47 Women who have diabetes in pregnancy experience stress and guilt due to the added
48 risks to their babies, especially neonatal hypoglycaemia, and experience internal
49 pressure to provide the best for their babies by collecting colostrum, even though this
50 process can cause further distress and frustration. Though the DAME trial found that
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3 expressing antenatally is safe for low risk diabetic women, no specific benefits to the
4 newborn have been demonstrated. Continuing to place undue emphasis on the benefits
5 of collecting and storing colostrum to the neonate may have the potential to cause
6 unnecessary stress, guilt and ultimately harm to women already coping with the stress
7 of diabetes in pregnancy. Care must be taken to present accurate and realistic
8 recommendations to women with diabetes in pregnancy about collecting antenatal
9 colostrum to facilitate informed decision-making.
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23 participant recruitment. We would like to particularly acknowledge the women who
24 gave up their time to participate in this study.
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31 **CONTRIBUTOR STATEMENT**

32
33 JRC designed the study, conducted the interviews, coded and analysed the data,
34 carried out the thematic analysis and drafted the manuscript. ELM coded and analysed
35 the data, participated in the thematic analysis and critical review of the first and
36 subsequent manuscript drafts. JB assisted with study design and interview tool
37 development, provided intellectual input into first and subsequent manuscript drafts
38 and assisted with thematic analysis. KB conceived the study, assisted with study
39 design and interview tool development and provided intellectual input into subsequent
40 manuscript drafts. CH assisted with study design and interview tool development,
41 provided intellectual input into first and subsequent manuscript drafts, assisted with
42 thematic analysis and is the guarantor. All authors had full access to all of the data in
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3 the study and can take responsibility for the integrity of the data and the accuracy of
4
5 the data analysis.
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9 **COMPETING INTERESTS**

10
11 The authors have no competing interests to declare.
12
13

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17
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19
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23 **STATEMENT OF ETHICS APPROVAL**

24
25 Ethics approval was obtained for this study from The Townsville Hospital and Health
26
27 Service (HREC/16/QTHS/66). All participants gave informed written consent before
28
29 taking part in this study.
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34 **DATA SHARING STATEMENT**

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36 No additional data are available.
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Figure 1: Thematic schema of diabetic women's experiences of collecting colostrum in pregnancy.

For peer review only

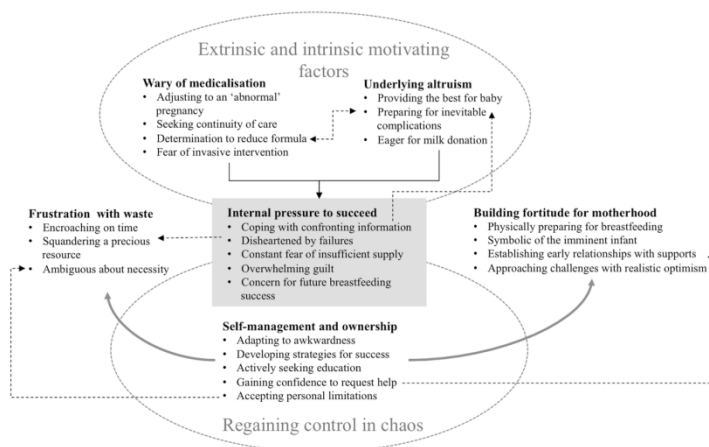


Figure 1: Thematic schema of diabetic women's experiences of collecting colostrum in pregnancy.

84x47mm (600 x 600 DPI)

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	1/1-4
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	2/3-23 3/1-5

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	4/2-24 5/1-11
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	5/18-21

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	7/5-8
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	6/16-19
<p>Context - Setting/site and salient contextual factors; rationale**</p>	6/2-5
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	6/5-11 7/2
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	6/11-12
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	6/4-12

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7/19-27
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7/16-23
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	7/4-12
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	7/5-12
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	7/9-11

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8-19/41-17
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pg 9-10 Table 2

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	19-22/19-7
Limitations - Trustworthiness and limitations of findings	21/11-18

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	23/5
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	23/8-9

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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