




BMJ Open Current practice, attitude and views of providing pregnancy care for women with type 1 diabetes in China: a qualitative study

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ABSTRACT

Objective Data are sparse on healthcare needs related to pregnancy among Chinese women with type 1 diabetes (T1D) or the gap between the needs and healthcare provision in China. We aimed to identify their needs and the gaps in pregnancy care provision.

Design This is a qualitative, face-to-face, one-to-one in-depth interview study. We recruited our participants using a purposive sampling strategy. Semistructured outlines were used to guide the interviews. The interviews were digitally recorded, transcribed and analysed using a thematic framework method with NVivo V.10.0.

Setting Guangdong Province in China.

Participants This study involved three key stakeholders of pregnancy care for women with T1D: 29 women with T1D of childbearing age (aged 18–50 years), 16 family members (husbands, parents and parents-in-law of women with T1D) and 35 relevant healthcare providers (HCPs).

Results We found that women with T1D and the family members had a more pessimistic attitude towards pregnancy outcomes, which was different from the more positive view of HCPs. However, all three stakeholders shared the following perspectives regarding pregnancy-related care for women with T1D: (1) lack of knowledge and access to education, (2) lack of multidisciplinary cooperation, (3) education should be started earlier in adulthood, (3) positive role of peer support, and (4) hope for future training of HCPs for relevant knowledge and skills specified for T1D and pregnancy with T1D.

Conclusions An immense gap was identified between the needs of women with T1D regarding pregnancy-related care and current care provision in China. These findings suggest that education be provided to patients and HCPs, and the role of professional and multidisciplinary support should be enhanced to optimise pregnancy care for women with T1D in China.

INTRODUCTION

Pregnancy complicated with type 1 diabetes (T1D) is associated with an elevated risk of various adverse pregnancy outcomes.¹ Emerging evidence has proven that comprehensive pregnancy care, including planned pregnancy, intensive glycaemic treatment

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A main strength of this study is that we applied multidimensional in-depth interviews of three key stakeholders of pregnancy decision making, patients, family members and healthcare professionals, to fully depict the needs and the gaps in healthcare provision for pregnancy complicated with type 1 diabetes (T1D) in China.
- ⇒ A combination of sampling strategies was adopted to recruit participants of diverse backgrounds and enabled us to approach those 'hidden' populations of women with T1D and to obtain as much information as possible.
- ⇒ The non-probability sampling strategies and the limited sample size could not rule out selection bias. Further investigations on a larger scale are warranted.

and blood pressure control, can reduce the risk of adverse pregnancy outcomes among women with T1D.^{1–3} However, the pregnancy outcomes of women with T1D are not reduced to the level of the general population globally.^{4–6} The cause is multifactorial. The suboptimal implementation and uptake of comprehensive care, as evidence suggests, plays an important role.^{7–10} The National Institute for Health and Care Excellence guidelines suggest that key information on potential barriers should be uncovered to reflect diverse unmet needs and to bridge the gap between needs and provision.¹¹ Unmet needs of biomedical nature could be addressed by carefully designed studies and trials, while needs of sociopsychological nature would require further reliable qualitative investigation to uncover.

Although the T1D incidence rate is low,¹² the Chinese T1D population is still estimated to rank fourth globally.¹³ However, the population with T1D usually remains covert due to social stigmatisation.¹⁴ Previously, data were

absent regarding pregnancy outcomes among Chinese women with T1D. To understand the current status of pregnancy complicated with T1D in China, we conducted a nationwide retrospective study as the first step of a series study (the CARNATION Study series). Our findings in this retrospective study revealed that the pregnancy outcomes of women with T1D were astonishingly poor during 2004–2014, worse than those of the UK and Denmark during the same period.¹⁵ The results also indicated that such poor pregnancy outcomes may be attributed to low preconception care uptake, as reflected by a low preconceptional haemoglobin A1c testing rate and inadequate diabetes management during pregnancy. Reducing the adverse outcomes among women with T1D requires enhancement of pregnancy-related care designated to their needs. Previous studies in other countries find that the uptake of pregnancy-related care in diabetes among patients with pregestational or gestational diabetes is associated with several sociopsychological risk factors, including patient knowledge levels, patients' and healthcare professionals' awareness of the disease, health service accessibility, and communication between patients and healthcare professionals.^{16–21} However, studies addressing the unmet sociopsychological needs of pregnant women with T1D are imperative in China. Therefore, we conducted this qualitative study to investigate the attitude, views, needs and current practice of pregnancy care for women with T1D.

METHODS

This is a qualitative study. We conducted multidimensional in-depth interviews, which allowed us to identify unmet needs and barriers in current pregnancy-related care provision for women with T1D in China. The findings of this study aimed to provide guidance for the enhancement of a comprehensive management plan for pregnant women with T1D in China.²²

Participants and sampling

The intended interviewees included key stakeholders in pregnancy care practice for women with T1D: the patient, the family members and relevant healthcare professionals. We chose to interview these three parties because the establishment of a well-uptaken healthcare strategy requires a patient-centred view, and the core element of patient-centred care is the coproduction of care through the collaboration of patients, their families and caregivers, and healthcare providers (HCPs).²³

We recruited women with T1D of childbearing age (aged between 18 years and 50 years), their close family members (parents, husbands or parents-in-law) and HCPs relevant to diabetes care or pregnancy care in Guangdong Province, where the largest cohort of T1D in China has been established.²⁴

We used purposive sampling, a non-probability sampling strategy aiming to identify and select the participants who are information-rich in the studied topic.²⁵ This strategy allows us to obtain as much information as possible with

a relatively small sample size.²⁶ To facilitate the flexibility to meet the needs of the three stakeholders in our study, a combination of different purposive forms was applied sequentially.²⁷

For the interviewees of women with T1D, we adopted stratified purposive sampling and then snowball sampling.²⁵ We first recruited women from the Guangdong Translational Study of Type 1 Diabetes (GTT).²⁴ The GTT cohort is a multicentre registry study of patients with T1D, consisting of 3173 patients, making it the largest cohort of T1D reported in China. We defined our strata and number allocated to each of the strata according to the development of their residential places, age, diabetes duration, marital/childbearing status, income levels and educational levels. The development level of the residential places was defined according to the population census of Guangdong in 2014²⁸; the proportion of the residential population in the Pearl River Delta (southern area, high income) was 53.74%; that in Eastern Guangdong (low-income area) was 16.12%, that in Northern Guangdong (low-income area) was 15.44%, and that in West Guangdong (low-income area) was 14.70%. We recruited eligible women with T1D complying with these proportions. We approached the patients at their regular follow-up visits. Snowball sampling was then adopted to reach those patients who were hard to approach or hidden to obtain as much information as possible.

Likewise, we adopted a combination of stratified purposive and snowball sampling to recruit HCP interviewees. We admit that HCPs relevant to pregnancy-related care for women with T1D would include physicians and nurses from endocrinology, gynaecology, obstetrics, ophthalmology departments, nutritionists, diabetes educators and midwives. However, in practice, the most relevant ones were physicians and nurses from endocrinology, gynaecology and obstetrics departments, as our pilot study suggests. Therefore, we focused on HCPs from these staff. We approached the HCPs in meetings of local associations of doctors and nurses. We ensured that the included HCPs covered high-income and low-income areas and were from general medical centres and primary care facilities and with different lengths of practice. Snowball sampling was used to recruit HCPs showing interest.

For close family members, we used convenient sampling and snowball sampling. We initially approached those who were relatives of the recruited women with T1D or registered as a relative of women with T1D in diabetes communities via ads and emails. We included parents who had a daughter/daughters with T1D, men who were married to a woman with T1D and women who had a daughter-in-law with T1D. These relatives were the most relevant regarding family planning and decision making in pregnancy.

Semistructural interview outlines

The interviews were conducted based on semistructural outlines for women with T1D, family members and HCPs, including questions mainly on knowledge, current

practice, attitude, concern and worries of pregnancy and related care (online supplemental tables 1–3, respectively) The semistructured outlines were developed via discussion among the research team (SL, SX, CW, DY and XZ), with consultation from YG. The outlines were pilot tested on a woman with T1D, an endocrinologist and a nurse for the clarity of the questions and the time needed for an interview.

Interview

The interviewers were SX and CW, who were physicians undergoing training for in-depth interviews prior to the conduction of interviews. They did not know the interviewees nor were known to the interviewees in advance. The interviews were conducted in a one-to-one and face-to-face manner with the participants at a time of their convenience. The place of the interview was a private room where the participants felt comfortable, such as the doctor's office. Written informed consent was obtained from all the participants before the interview. During the interviews, the participants were encouraged to share their perspectives freely. The interview was digitally recorded and transcribed by two part-time students. All identifiable personal information was kept confidential and was removed before transcription.

Data analysis

Transcripts of the interviews were coded into themes by three investigators (SL, SX and CW) via a thematic framework method in a deductive approach²⁹ using NVivo V.10 (QSR International, Australia). The interviews ended when saturation was achieved; that is, no new themes were obtained from further recruiting participants. Rendered themes from the three parties were compared by thorough discussion within the whole study team.

Patient and public involvement

Patients or the public were not involved in the design, conduct, reporting or dissemination of our research.

RESULTS

Participant recruitment was conducted between April 2015 and June 2016. We interviewed 29 women with T1D (30 agreed to be interviewed; 1 withdrew for personal reasons), 16 family members (10 husbands, 5 parents and 1 mother-in-law) and 35 HCPs (17 physicians and 18 nurses, 24 from general hospitals and 11 from primary care facilities). The interview time of these participants was approximately 60–90 min. Details of the participants are described in [table 1](#).

Perspectives of women with T1D and their family members

Eight themes were rendered from the perspectives of interviewed women with T1D ([box 1](#)), and nine themes were obtained from those of the family members ([box 2](#)). They shared most of the points.

Knowledge of pregnancy with T1D

Although some of the interviewed women and family members knew the possibility of having healthy babies if T1D was well controlled, more of them said they suffered from a lack of knowledge or even false information.

"There is no barrier to me. I just don't know where to find the tutorial or counseling (on pregnancy complicated with diabetes)." Patient 21

Worries and concern

Both the women's and the family members' greatest worries lay in the babies' adverse outcomes, such as malformations, inherited diabetes or over birth weight, while relatively, they cared less about the pregnant women. They expressed that they were not able to access relevant information from the HCPs about planned pregnancy or pregnancy with T1D, nor were they provided enough time for such education during clinical visits. The cost was yet another repeated concern for the patients and their families.

"(Pregnancy with T1D means) higher risk of abortion, macrosomia or malformation? I am also worried that the baby's blood glucose was abnormal when it is born." Patient 15

"Will it (pregnancy with T1D and related care) cost a lot?" Patient 9

Timing and contents of prepregnancy education for T1D

Most of them thought that prepregnancy education should be given around marriageable age (approximately 20 years). They would like to obtain various information, such as the impact of pregnancy on diabetes and their mental status, and guidance on diabetes management and things needing attention before, during and after pregnancy.

"(Pregnancy-related education should be given) at 23 or 24 years...I wish it should be provided before marriage. ... (so that) you won't worry about how to control your glucose and then won't be afraid of getting married and pregnant." Patient 3, unmarried

Opinions about HCPs

Participants from high-income areas were mostly satisfied with the service from HCPs, but some thought HCPs in low-income areas needed more training on T1D management. Some mentioned that they had received false information from HCPs.

"No one mentioned it (preconception care). ... when I found that I got the disease in Shanghai in 2008, the doctor ... said very affirmatively, that I could not get married or have a baby in the future." Patient 12

Most of them did not think HCPs had paid enough attention to their psychological problems regarding pregnancy.

"I was very upset at that doctor...I don't like to see a doctor that makes me feel upset... Actually I think for a patient

Table 1 Profiles of interviewees of the multidimensional in-depth interviews

Women with T1D*		n (%)	Family members of women with T1D†		n (%)
Location	Pearl River Delta	14 (48.3)	Relationship to the patient	Husband	10 (62.5)
	Eastern Guangdong	7 (24.1)		Mother	4 (25)
	Western Guangdong	4 (13.8)		Father	1 (6.25)
	Northern Guangdong	4 (13.8)		Mother-in-law	1 (6.25)
Age (years)	18~20	3 (10.3)	Monthly income (CNY)	0~3000	3 (18.75)
	20~25	8 (27.6)		3000~4000	2 (12.5)
	25~30	8 (27.6)		4000~5000	2 (12.5)
	30 or higher	10 (34.5)		5000 or higher	7 (43.75)
Monthly income (CNY)	0~3000	8 (27.6)	Education	Not willing to provide	2 (12.5)
	3000~4000	9 (31)		Junior middle school or lower	4 (25)
	4000~5000	3 (10.3)		Senior middle school	4 (25)
	5000 or higher	9 (31)		College	2 (12.5)
Education	Junior middle school or lower	8 (27.6)	Total	University or higher	5 (31.25)
	Senior middle school	7 (24.1)		Not willing to provide	1 (6.25)
	College	4 (13.8)			
	University or higher	10 (34.5)			
Marital status	Married	17 (58.6)	Relevant HCPs		N (%)
	Unmarried	12 (41.4)	Location	Low-income area	25 (71.4)
	Never	14 (48.3)		High-income area	10 (28.6)
			Class of healthcare facility	Primary care centre	11 (31.4)
Childbearing status	Pregnant now	10 (34.5)		General hospital	24 (68.6)
	Yes	5 (17.2)	Position	Nurse	16 (45.7)
History of miscarriage	Yes	8 (27.6)		Physician	19 (54.3)
	No	21 (72.4)	Discipline	Endocrinology	26 (74.3)
Duration of diabetes (years)	0~1	6 (20.7)		OB/Gyn	9 (25.7)
	1~5	5 (17.2)	Experience of practice (years)	≤10	21 (60)
	5~10	9 (31)		>10	14 (40)
	10 or longer	9 (31)	Total		35 (100)
Latest HbA1c (%)	<7	18 (62.1)			
	7 or higher	11 (37.9)			
Complications of T1D	Yes	4 (13.8)			
	No	25 (86.2)			
Treatment	CSII	15 (51.7)			
	MDI	14 (48.3)			
Total		29 (100)			

*Thirty women with T1D agreed to be interviewed, and one of them withdrew due to personal reasons afterwards. The interviews of 29 women were included in the analysis.

†All the interviewed family members were recruited from the families of the interviewed women with T1D.

CSII, continuous subcutaneous insulin infusion; HbA1c, haemoglobin A1c; HCP, healthcare provider; MDI, multiple daily injection of insulin; OB/Gyn, obstetrics or gynecology; T1D, type 1 diabetes.

with diabetes, psychological counseling should be provided more." Patient 1

Multidisciplinary cooperation

They strongly expressed that there was a lack of multidisciplinary cooperation in pregnancy care delivery.

"I don't think there is much communication (between disciplines). They (the doctors) were not motivated to do this unless we asked for it." Patient 22

Peer support

All the interviewees agreed that peer support was meaningful but lacked the chance of sharing.

“Friends with diabetes pass on positive energy to each other. Some of us may feel distressed, and others will come to give comfort. We share our experiences on diet, exercises ... and go outing together...I gain a lot from the group.” Patient 8

Box 1 Themes obtained from the in-depth interviews of women with T1D with regard to pregnancy-related care.

Theme 1: knowledge level of pregnancy with T1D

- ⇒ Positive attitude: possible to have healthy babies if T1D is under good control.
- ⇒ Negative attitude/false information: higher risk of infertility due to T1D; T1D is inheritable; and lack of relevant knowledge.

Theme 2: worries and concerns

- ⇒ Worries were mainly about the child and were less about themselves.
- ⇒ Higher risk of adverse outcomes in the babies.
- ⇒ Increased difficulty in glycaemic control.
- ⇒ Increased cost of disease control due to pregnancy.

Theme 3: education of planned pregnancy

- ⇒ Unable to access any information from HCPs about pregnancy complicated with T1D.
- ⇒ Not enough time for such education.
- ⇒ Proper timing of such education: around legally marriageable age.

Theme 4: information wanted for pregnancy-related care

- ⇒ Before pregnancy: diet, exercise, adjustment of medication, diabetes-related and pregnancy-related medical tests, glycaemic targets and mental preparation.
- ⇒ During pregnancy: diet, exercise, adjustment of medication, handling of emergency, glycaemic targets, and impacts of pregnancy on their bodies and the babies.
- ⇒ Others: choice of delivery mode (vaginal delivery or caesarean section), sharing of successful cases of pregnancy with T1D and medical check-ups of their babies after birth.

Theme 5: opinions about HCPs

- ⇒ HCPs provided positive messages on T1D with pregnancy and were helpful most of the time.
- ⇒ Dissatisfaction: HCPs in low-income areas needs more training on T1D management; not enough information provided by HCPs; not enough attention given to the psychological issues of women with T1D; lack of multidisciplinary cooperation during pregnancy.

Theme 6: attitude of family members towards pregnancy

- ⇒ Parents and their parents: diverged.
- ⇒ Husbands: mainly concerned about the health of their wives (women with T1D).
- ⇒ Parents-in-law: most of them wanted healthy grandchildren; the health of the women with T1D was usually the second priority.

Theme 7: communication with other patients with T1D

- ⇒ Peer communication is meaningful.
- ⇒ Lack of experience sharing of T1D with pregnancy.

Theme 8: dilemma caused by T1D itself.

- ⇒ Patients were under immense pressure due to social ignorance.
- ⇒ Some unmarried patients were even afraid of getting married and/or pregnant.

HCP, healthcare provider; T1D, type 1 diabetes.

Box 2 Themes obtained from the in-depth interviews with close family members of women with T1D

Theme 1: knowledge of T1D and pregnancy-related care

Most family members demonstrated little knowledge of both due to a lack of education.

Theme 2: the content of pregnancy-related care

Knowledge of dietary guidance, glycaemic control and daily care for the patient was most inquired.

Theme 3: timing of starting preconception care

Reaching adulthood (18 years) was most recommended, while the rest were suggested during adolescence.

Theme 4: the approach of pregnancy-related care

Internet and face-to-face consultation were well recognised by family members, while tutorials and educational materials were suggested as supplements.

Theme 5: multidisciplinary cooperation

Most considered that endocrinology professionals should take the primary responsibility of pregnancy-related care in collaboration with obstetrics and gynaecology professionals.

Theme 6: the attitude towards pregnancy complicated with T1D

Most family members wanted the women with T1D in their stem family to have child(ren); nearly a quarter of them considered it as an obligation, while the rest showed respect to the women's own decision.

Theme 7: family members' concern

Family members expressed worries on the complications occurring or progressing during pregnancy, the inheritance of T1D, social discrimination and economic cost.

Theme 8: HCP-patient communication

Family members thought the information and consultation time provided by doctors were inadequate.

Theme 9: peer support

Most family members supported peer communication because it enabled patients to convey experience and confidence, while the minority opposed it, fearing the spread of negative information.

HCP, healthcare provider; T1D, type 1 diabetes.

“I never met other patients with type 1 diabetes, in clinics or in real life...I would like to communicate with them.”
Patient 17

Family attitude towards pregnancy complicated with T1D

Although most of the interviewed family members showed respect to the women's own decision on pregnancy, a quarter of them thought that the women had an obligation to have a child. The patients' parents expressed both optimistic and pessimistic attitudes towards pregnancy outcomes. The husbands expressed more concern about the impact of pregnancy on their wives' health, while the mothers-in-law laid their concern mainly on the infant's health. These attitudes were also reflected in the perspectives of the patients. The interviewed women expressed that they were under immense pressure due to social ignorance and obligation to have a child, and some

unmarried patients were even afraid of getting married and/or pregnant.

“My parents-in-law don’t know I have diabetes, even now. I am not going to tell them. It’s unnecessary. In addition, I couldn’t have got married if they knew it. I have a friend with diabetes. Her parents-in-law knew about her disease, and she got divorced after she failed to get pregnant.” Patient 17

“...Of course, I would love to have a child. (Is this an obligation?) For me? No, not for me. But... in the Chinese society, this is the culture. I like children, but I care for my wife. If she does not want one, we are still happy. However, we are not a family of two...we have many concerns (on having a baby).” Family member 4, a husband

Perspectives from relevant HCPs

Ten themes were rendered from the perspectives of the interviewed HCPs (box 3).

Attitudes towards pregnancy complicated with T1D and related care

All interviewed HCPs agreed that if T1D was well managed, women with T1D deserved the same perspectives to become mothers as healthy women. However, the interviewed HCPs admitted that basically no proper type 1 diabetes-specific pregnancy care for the women with type 1 diabetes was implemented. They speculated that potential causes included the rareness of the disease, lack of resources and unawareness of the disease among the patients.

“We did not see many patients with type 1 diabetes, perhaps one or two every three months, and thus even fewer patients with new onset T1D would consult us.” HCP 12, endocrinologist

“The women with T1D wouldn’t consider that issue (T1D specific pregnancy care) unless they were going to get pregnant or had been pregnant. Before they got pregnant, they thought pregnancy was a natural thing with no need of worrying about other problems.” HCP 11, endocrinologist

“The doctors were too busy to provide preconception care (for T1D). ... When the patients got pregnant, the nurses were unable to provide preconception care. (Interviewer: What factors restricted it?) The limited number of patients with T1D. In addition, HCP may not have enough knowledge.” HCP 26, diabetic educator

“I think more education on the facts of T1D should be given to the public (by health administrations) because here is... suburban area but surrounded by rural area. Without enough advertisement, the local people would have a poor understanding of it.” HCP 8, diabetic nurse

Contents and approaches of pregnancy-related care for T1D

They listed contents that should be included in pregnancy care education for women with type 1 diabetes, mainly guidance of diabetes control, the impact of pregnancy on women with type 1 diabetes and their infants, and psychological support. They agreed that prepregnancy education

Box 3 The themes obtained from the in-depth interviews of relevant HCPs

Theme 1: current status of pregnancy-related care for women with T1D
Potential underlying reasons for poor implementation preconception and pregnancy care specialised for T1D:

- ⇒ The rareness of the disease.
- ⇒ Lack of both resources and educational material.
- ⇒ Unawareness of women with T1D themselves preventing them from showing up or requesting such care.

Theme 2: content of preconception care and pregnancy-related care for women with T1D: what should be included

- ⇒ Preconception care: mental/psychological support, basic knowledge on pregnancy and preconceptional preparation (adjustment of diet and diabetes treatment and the necessity of receiving routine check-ups for pregnancy).
- ⇒ Pregnancy-related care: guidance for glucose control, diet, physical exercise, weight management, monitoring the development of the embryo/fetus and emergencies during pregnancy; necessity of receiving additional tests specified for pregnancy complicated with T1D (eg, routine follow-up of microalbuminuria, fundus examination, etc).
- ⇒ Impact of pregnancy on the mother with T1D and the impact of T1D on the baby.

Theme 3: timing of starting preconceptional care—when it should be brought on

- ⇒ After the age of maturity (≥ 18 years old) (32 of 35).
- ⇒ During puberty (age not specified) (3 of 35).

Theme 4: approach of preconception care: where it should be available.

- ⇒ Online: Video clips or articles available on smartphone SNS apps and hospital websites.
- ⇒ Face to face: lectures, home visits, one-to-one education, booklets and propaganda materials.

Theme 5: preconception care and pregnancy-related care provider: who should do it.

- ⇒ A collaboration of staff from the endocrinology department, obstetrics department, nutrition department and even paediatrics department (21 of 35).
- ⇒ Staff from endocrinology department (12 of 35).
- ⇒ Staff from obstetrics department (2 of 35).

Theme 6: insufficiency of HCP–patient communication.

- ⇒ Insufficiency of mental/psychological support from the HCPs (1 of 35).
- ⇒ HCPs should pay more attention to lifestyle education for the patient (2 of 35).

Theme 7: peer support in preconception and pregnancy-related care

- ⇒ All interviewed HCPs agreed that peer support should be encouraged.

Theme 8: attitude towards pregnancy complicated with T1D

- ⇒ All interviewed HCPs agreed that if diabetes was well controlled, women with T1D would have the same opportunity to a mother as other healthy women.

Theme 9: awareness of difficulties women with T1D are facing regarding pregnancy

Continued

Box 3 Continued

⇒ Some HCPs shared the cases that some patients felt difficult to accept the fact of illness and were reluctant to tell others about their disease and worried about marriage. Antagonism towards disease came with unsatisfactory treatment.

Theme 10: needs for future training on preconception and pregnancy-related care for women with T1D

- ⇒ Further training on preconception and pregnancy-related care for women with T1D is needed.
- ⇒ Strengthening the training on the psychological role of mental support was necessary.
- ⇒ Training should be conducted by experts from higher-level hospitals and experts on T1D via on-site courses.

HCP, healthcare provider; T1D, type 1 diabetes.

should be given at 18 years of age or even at the beginning of puberty. They thought that both online and face-to-face approaches should be adopted to increase the time and quality of care. Most of them felt that pregnancy care should be provided in multidisciplinary collaboration of endocrinologists, obstetricians, nutritionists and even paediatricians. However, they also noted that such multidisciplinary cooperation was lacking. Most expressed that HCP–patient communication was insufficient. Only a few HCPs showed understanding of the difficulties faced by women with T1D regarding pregnancy.

Needs from HCPs for implementation of pregnancy-related care for T1D

Most HCPs expressed their desire for further training on pregnancy care for women with T1D due to their lack of relevant knowledge and skills. Only some mentioned the necessity of strengthening the training on psychological support. All of them agreed that peer support would be helpful.

Shared perspectives among patients, family members and HCPs

We summarised the shared and diverged perspectives among the patients, family members and HCPs (figure 1). Despite their different attitudes on the outcome of pregnancy, we found that the patients, family members and HCPs shared the following perspectives: (1) lack

of knowledge and educational resources for pregnancy complicated with T1D, (2) need for earlier education, (3) lack of multidisciplinary cooperation in care implementation, (4) positive role of peer support and (5) need for further training for the relevant HCPs.

DISCUSSION

In this study, we investigated and compared the experiences, views and needs of three crucial parties participating in pregnancy-related care practice for women with T1D. To the best of our knowledge, this is the first report on the attitudes and barriers to pregnancy care for women with T1D in China. Our findings identify significant challenges in providing adequate care for Chinese women with T1D throughout pregnancy. Patients, family members, and even HCPs lacked awareness and knowledge of pregnancy care specified for T1D.

We conducted this study, succeeding a retrospective study on pregnancy outcomes.¹⁵ As such, the interviews allow us to construct a comprehensive view of potential problems influencing pregnancy care among diverse clinical settings and cultural values in a concurrent period. This comprehensive view provides insights into the unmet needs of the different parties, revealing potential barriers and outlining possible directions to establish and implement proper pregnancy care for women with type 1 diabetes in China. The central question would be meeting the needs shared by all three stakeholders, as shown in figure 1.

First, we found that women with T1D and their family members were unaware of pregnancy diabetes care, as studies in other populations have suggested.^{16–18 30} Unawareness was also seen among HCPs. Previously, an Australian study indicated that HCPs in remote areas may be less skilful.³¹ Our results showed that HCPs could lack awareness or even provide false information, which has rarely been reported. This phenomenon tended to happen among non-endocrinologists, HCPs in low-income regions and HCPs from primary healthcare facilities. A possible explanation for the unawareness of pregnancy-related care for T1D is the low incidence of T1D in China (1.01 per 100 000 person-years)¹² and hence the lack of opportunity to treat a patient with T1D,

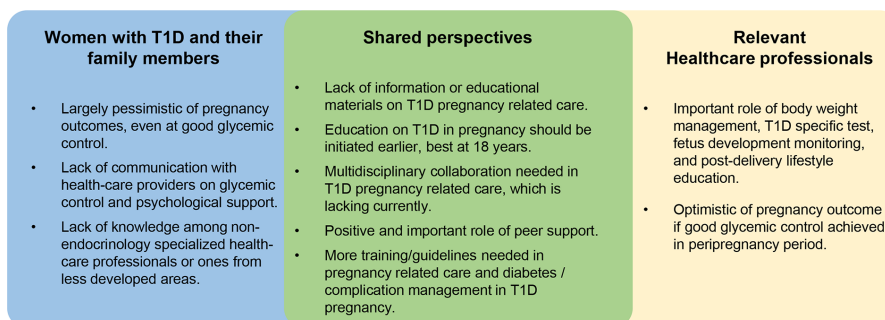


Figure 1 Shared and different perspectives of women with T1D, their family members and relevant healthcare providers in the multidimensional in-depth interviews. T1D, type 1 diabetes.

not to mention women with T1D pregnant or planning pregnancy, as mentioned by the interviewed HCPs.

Second, healthcare resources were limited, and pregnancy care for women with T1D was inaccessible. Limited clinical resources and inaccessibility are common restrictions in many countries.^{31 32} What is worse, in our interviews, we found that extra out-of-pocket payment for pregnancy care was a particular repeated concern for patients, especially under the circumstances that in China, insulin and blood glucose monitoring were already consuming a sizeable portion of their income.³³

Third, multidisciplinary cooperation essential for pregnancy care for type 1 diabetes was lacking. Patients and their family members expressed insufficiency of smooth multidisciplinary cooperation during pregnancy. HCPs noted that they were short of a practical guide to facilitate multidisciplinary cooperation. A similar situation was reported in Sweden,³⁴ indicating that this is also a common barrier.

Finally, peer support was viewed as important and valuable by all the stakeholders in our study. However, in reality, peer support in pregnancy-related care for T1D is lacking. It is generally accepted that peer support is valuable, especially for women with T1D who have complex needs.³⁵ However, most studies on peer support for patients with T1D focus on patients in childhood/adolescence or in early adulthood.^{36 37} As far as we are concerned, there is a dearth of research on peer support in pregnancy for women with T1D. The dearth of research may reflect the lack of peer support of such kind. Additionally, patients with T1D are suffering from systemic stigmatisation in China,¹⁴ which has made them tend to conceal their condition, even from close family members, as mentioned by the interviewed women in our study. These issues may also hinder them from finding peer patients and hence from gaining peer support. Together, the needs for peer support regarding pregnancy issues for women with T1D should be considered.

Study strength, limitations and recommendations

The strength of this study is that we constructed a multi-dimensional and contemporaneous view of the current practice of pregnancy care for Chinese women with T1D. Although the findings from in-depth interviews tend to be subjective, we enhanced the reliability by analysing and comparing perspectives from different angles of the patient, their family members and HCPs. Additionally, the combination of various forms of purposive sampling strategy we adopted enabled us to recruit participants of diverse backgrounds and to approach those 'hidden' populations of women with T1D. We acknowledge that there were limitations to our study. First, the sample size is limited. Second, due to the non-probability nature of our sampling strategy, we could not rule out selection bias. Especially for the family members, for whom we used convenient sampling, we did this out of protection of the patients' privacy of the disease. Therefore, investigations covering a larger population are warranted. In addition,

given the differences in culture and clinical settings, these findings may have limited generalisability in other parts of the world. However, as we have discussed previously, many of the potential barriers are commonly shared.

The issues raised earlier suggest that effort be directed to the following aspects. First, more resources distributed to improve the education for both the patients and the HCPs may help. For the patients, both patients and HCPs mentioned that online materials could improve the accessibility of education while being less time-consuming and labor-consuming. The effectiveness of an online smartphone app has been tested in enhancing the uptake of diabetes-specific pregnancy care in Denmark.¹ Peer support, which all participants have positively viewed, is accessible via smartphone social media apps.³⁸ Additionally, given that family members, especially parents-in-law, play a vital role in family planning in Chinese families, as our results showed, future interventions should involve them. For the training of HCPs, a practical guideline for T1D-specific pregnancy care is favoured. However, with multiple guidelines available now, the implementation of care remains suboptimal. Therefore, the effect of the guidelines themselves may be limited. Second, considering limited resources and extra out-of-the-pocket costs for pregnancy care, it is urged to configure strategies integrating diabetes-specific care into the country's universal antenatal care framework. In other chronic manageable diseases, there is evidence that such integration is beneficial while feasible.^{39 40} Third, multidisciplinary cooperation has been proven essential in improving the quality of pregnancy care for women with T1D.⁴¹ Regarding the lack of multidisciplinary cooperation, apart from lack of knowledge of T1D and pregnancy in pre-existing diabetes, another potential barrier would be the obscurity of responsibility of each discipline.⁴² For future direction, a quick decision-making tool may be a solution to clarify relevant disciplines' responsibility.

Collectively, we identified an immense gap between the needs of women with T1D regarding pregnancy-related care and current care practice in China. Under resource-limited circumstances, a feasible way of implementing comprehensive care should be found. Additionally, the findings suggest that education be provided to patients and HCPs, and the role of professional and multidisciplinary support should be enhanced to optimise pregnancy care for women with T1D in China.

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Supplementary Materials

Table S1. The outline of the in-depth interview on pregnancy-related care for women with type 1 diabetes: patients' version.

A. Basic information		
Name:	Occupation:	Obstetrical histories:
Date of birth:	Monthly income:	Marital Status:
Residential area:	Time of T1D diagnosis:	Treatment:
Education:	Complications of T1D:	Latest HbA1c:
B. T1D patients' perspective on pregnancy-related care		
1. What information related to pregnancy with T1D do you know?		
2. By what means have you got the information?		
3. Have the health care providers provided you with the information related to pregnancy?		
4. What more information you would like to know but hasn't been provided by health care providers?		
5. Do you think you can deliver a healthy baby?		
6. Do you have worries on pregnancy?		
7. Have you attended preconception counseling or relevant training? If yes, where and by whom is preconception counseling or training provided? Has it really helped you? If you haven't attended any, what are the reasons?		
8. What kind of information on preconception education and pregnancy-related care do you want to obtain? By what means?		
9. Do you think it necessary for family members to take part in preconception training or to involve in pregnancy-related care?		
10. When do you think is appropriate to start the preconception education?		
C. Communication with health care providers		
1. How about your communication with doctors or nurses?		
2. Will you get more negative or positive information after your communication with them?		
3. In your opinion, which discipline(s) should be responsible of preconception care? And care during pregnancy? What about the communication between different disciplines related to peri-pregnancy care?		
4. Do you have any advice for the health care providers?		
D. Social support		
1. Have your family members talked about pregnancy with you? What are their attitudes? What are the impacts on you?		
2. Do you always communicate with other T1D patients? Do you talk about pregnancy? Do you think it necessary to communicate with other T1D patients?		

Abbreviations: T1D, type 1 diabetes; HbA1c, hemoglobin A1c.

Table S2. The outlines of the in-depth interview on pregnancy-related care for women with type 1 diabetes: family members' version.

A. Basic information		
Name:	Education:	Time of T1D diagnosis of the patient (if known):
Date of birth:	Occupation:	Glycemic status of the patient (if known):
Residential Area:	Monthly income:	Treatment regimen (if known):
Relation to the patient:		
B. Family members' of perspective on pregnancy-related care		
1. Have you known information related to pregnancy complicated with T1D? By what means?		
2. Have health care providers provided you with information related to pregnancy?		
3. What information you would like to know but hasn't been provided by health care providers?		
4. Do you have any concerns or worries for her (the women with T1D) pregnancy? If so, what are they?		
5. Have you attended preconception counseling or relevant training? If yes, where and by whom is preconception counseling or training provided? Has it really helped you? If you haven't attended any, what are the reasons?		
6. What kind of information on preconception education and pregnancy care complicated with T1D do you want to get? By what means?		
7. Do you think it necessary for family members to take part in preconception training?		
8. When do you think is appropriate to start the preconception education for the women with T1D?		
C. Communication with health care providers		
1. How about your communication with doctors or nurses?		
2. Will you get more negative or positive information after your communication with them?		
3. In your opinion, which discipline(s) should be responsible of preconception care? And care during pregnancy? What about the communication between different disciplines related to peri-pregnancy care?		
4. Do you have any advice for the health care providers?		
D. Social support		
1. What is your attitude towards her pregnancy?		
2. Do you think T1D has affected your relationship with the patient?		
3. Is it necessary to communicate with other T1D patients? Why?		

Abbreviations: T1D, type 1 diabetes.

Table S3. The outlines of the in-depth interview on pregnancy-related care for women with type 1 diabetes: healthcare providers’ version.

A. Basic information		
Name:	Professional degree(s):	Position:
Date of birth:	Working place/hospital:	Experience of practice (years):
Working Area:	Discipline:	
B. Major points on pregnancy-related care for women with T1D		
1.	Does the medical institution you are currently working in provide any preconception education for women with T1D?	
2.	Any pregnancy care specialized for them?	
3.	What factors restrict the implementation of preconception education and care during pregnancy for women with T1D?	
4.	What kind of information on preconception care and care during pregnancy do you think should be taken by women with T1D? By what means?	
5.	Do you think it necessary for family members to take part in preconception training?	
6.	When do you think is appropriate to start the preconception education for women with T1D?	
7.	In your opinion, which discipline(s) should be responsible for preconception care for women with T1D? And care during pregnancy?	
8.	What about the collaboration among different disciplines? Are there any policies/system to improve collaboration?	
9.	What is your attitude towards pregnancy complicated with T1D?	
10.	Do you think you have mastered enough knowledge of T1D? And pregnancy complicated with T1D? If not, what factors restrict your from learning more? Are there any solutions?	
11.	Is it necessary for a T1D patient to communicate with other T1D patients? Or just let the patient get knowledge from healthcare providers?	

Abbreviations: T1D, type 1 diabetes.