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Pregnancy Experiences of Western Australian Women Attending a Specialist Childbirth and Mental Illness Antenatal Clinic

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Abstract

Our purpose was to explore the pregnancy experiences of Australian women attending a specialized Childbirth and Mental Illness (CAMI) antenatal clinic. A qualitative exploratory design was selected to give voice to women with a severe mental illness receiving antenatal care. Telephone interviews with 41 women, 24 primiparous and 17 multiparous, were analysed using thematic analysis. Three themes emerged: 'Building relationships', 'Acknowledged me as a person with special needs' and 'Respect and understanding without stigma'. Findings offer

insight into care experiences possible within a multidisciplinary model developed to addresses psychiatric and obstetric needs of pregnant women with severe mental illness.

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Women with a severe mental illness face added obstetric risks during their pregnancy and birth. A multidisciplinary team offering support from mental health and obstetric services is ideally suited to address these complex needs. We explored the pregnancy experiences of women attending a specialized Childbirth and Mental Illness antenatal clinic; an example of a multidisciplinary model within the Australian public health system.

Mental health services have generally not recognized the parenting needs of women with severe mental illness (Mowbray, Oyserman, & Bybee, 2000; Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001) however, deinstitutionalisation and community support programs have increased the likelihood these women will become parents (Oyserman, Mowbray, Meares, & Firminger, 2000). Nonetheless, becoming a parent is fraught with challenges for women with a severe mental illness as they face increased risks of complications across the

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childbearing period (Jablensky, Morgan, Zubrick, Bower, & Yellachich, 2005; MacCabe et al., 2007; Nilsson, Lichtenstein, Cnattingius, Murray, & Hultman, 2002; Schneid-Kofman, Sheiner, & Levy, 2008). In addition to obstetric risks, these women often face social disadvantage with an increased likelihood of being a single parent, having limited informal support, are more likely to have involvement from child welfare services, experience separation from their child and continue with negative lifestyle habits such as using tobacco, alcohol and other substances (Dipple, Smith, Andrews, & Evans, 2002; Howard, Shah, Salmon, & Appleby, 2003; Jablensky, et al., 2005). As well as presenting later during pregnancy for obstetric care (Goodman & Emory, 1992), attendance at antenatal clinics is less regular (Miller & Finnerty, 1996) at a time of need for complex psychiatric management due to risk of relapse (Viguera et al., 2000).

Motherhood is a reality for many women with severe mental illness. Researchers note these women are having babies at a similar rate to the general population (Miller & Finnerty, 1996; Nicholson & Biebel, 2002) for although women with schizophrenia have reduced fertility (Abel & Morgan, 2011), this is not the case for women with mood disorders (Howard, 2005). Historically, research has focused upon child outcomes (Mowbray, Oyserman, Zemencuk, & Ross, 1995) and management of mental illness during pregnancy (Sharma, 2009; Solari, Dickson, & Miller, 2009a) rather than exploring the meaning of pregnancy and childbearing for these mothers (Mowbray, et al., 1995). Limited evidence around the subjective experiences of mothers with an enduring mental illness (Montgomery, 2005), has confirmed that motherhood is seen to be challenging but rewarding and central to their lives (Diaz-Caneja & Johnson, 2004; Mowbray, et al., 2001; Oyserman, et al., 2000). In fact, these mothers strive for meaningful relationships with their children and research has provided insight into their efforts to protect

their children and fulfil their mothering role (Montgomery, Tompkins, Forchuk, & French, 2006).

Given the relationship between mental illness and obstetric complications for women as well as recognition that mental illness can adversely affect mothers and their infants, care of pregnant women with severe mental illness warrants special attention by mental health and obstetric services (Thornton, Guendelman, & Hosang, 2010). United Kingdom researchers have explored the needs of mothers with schizophrenia using a qualitative approach from the perspective of perinatal psychiatry and antenatal services workers but not from the perspective of the mothers (Wan, Moulton, & Abel, 2008). However, there is no evidence available around the experience of pregnancy for women with severe mental illness from the perspective of the women themselves.

Childbirth and Mental Illness Clinic: Western Australian context

Researchers from a project involving Western Australian (WA) mental health clinicians, consumers, general practitioners and midwives identified three concepts felt to be essential for engaging with women attending community mental health services: providing a holistic approach, promoting reproductive choice and encouraging continuity of care (Hauck, Rock, Jackiewicz, & Jablensky, 2008). Resulting recommendations for a specialist antenatal service incorporating a small known team approach were supported and the Childbirth and Mental Illness Clinic (CAMI) commenced in July 2007 with its first birth in December 2007 at King Edward Memorial Hospital (KEMH). This tertiary hospital is part of the public health system available to all WA citizens. Alternately, women with the financial means are able to attend private health services. Limited antenatal models of care in the WA public sector provide

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continuity of care. Women are exposed to different health care professionals (i.e. medical and midwifery staff) at each visit. Pregnant women attend their first visit at KEMH antenatal clinics at 20 weeks gestation after they are referred by a community general practitioner who confirms the pregnancy and provides care during the first trimester. For women with severe mental illness, this may not be optimal due to likely exposure of psychotropic medication in the first trimester and the need for early intervention around risk/benefit analysis of treatment as well as screening and monitoring. However, clinical practice is not always situated in an ideal context.

CAMI was developed within existing available resources and involved reorganisation of resources rather than additional resources. The CAMI clinicians collaborate with the Department of Psychological Medicine and the Obstetric Department targeting women with a history of psychotic disorders such as schizophrenia, bipolar affective disorders, and non-psychotic severe mental illness with serious impairment such as major depression, borderline personality disorder, anxiety disorder, post-traumatic stress disorder and bulimia. The antenatal clinic is staffed by a small known team of health professionals including a consultant psychiatrist, GP with obstetrics training supervised by an obstetrician, and clinical midwife. Additional support is available through obstetric and maternal fetal medicine, social work, dietetics and other allied health professionals as needed. The CAMI clinic has five aims: 1) providing state-wide preconception counselling for women 2) increasing access to antenatal care including early management of pregnancy 3) facilitating communication between obstetric and psychiatric services in addition to primary care providers 4) providing advocacy and specialist support for complex cases and 5) highlighting likely postnatal needs in order to organise support

services. Obstetric and neonatal outcomes of women attending the CAMI clinic have been reported elsewhere (Nguyen et al., 2012).

Our purpose in conducting this study was to explore the pregnancy experiences of Australian women attending a specialized Childbirth and Mental Illness (CAMI) antenatal clinic in Western Australia (WA). We focused upon process rather than outcomes to explore women's pregnancy experience, their satisfaction with the clinic and perception of the importance of continuity of care during pregnancy within a multidisciplinary model.

Method

Given the dearth of evidence around the subjective experience of pregnancy for women with severe mental illness a qualitative exploratory design was the most appropriate choice to give voice to these pregnant women receiving antenatal care within this innovative service (Grbich, 2004; Polit & Beck, 2010). Qualitative research is acknowledged for its ability to focus upon the social world by listening to participants stories (Liamputtong, 2010). Two process variables (satisfaction and continuity of care) were also chosen to complement the exploration of the pregnancy experience within this multidisciplinary continuity of care model. Satisfaction provides an indispensable reflection of client judgement on the quality of care in all its aspects, particularly interpersonal processes, the 'vehicle' by which care is implemented and quality of care facilitated (Donabedian, 1988). Ethical approval was obtained from the study hospital.

Data was collected through telephone interviews with postnatal women who were asked to reflect upon their recent pregnancy experience. Two independent research assistants (i.e. a psychologist and midwife) not involved with clinical care contacted the women and conducted the telephone interview. A minimum of three attempts were made to contact each woman

commencing 3 months post birth. Exclusion criteria for women who were not invited to participate in a telephone interview included women whose infant had out of home placements under statutory welfare orders, and women who were currently admitted to a psychiatric hospital or experienced an untoward outcome (i.e. stillbirth). While interviewing these women may have yielded useful data, it was felt that the process would be too stressful for the interviewees.

Following an explanation of the purpose of the telephone interview and obtaining verbal consent a consistent introductory statement was made to all women: 'we are interested in hearing about your experience with the CAMI clinic'. Following discussion of their experience two questions were asked around satisfaction and the importance of continuity of care. A 5 point Likert scale was provided as a guide for responses for the satisfaction and continuity of care. Each interview took between 10 and 15 minutes and although interviews were not digital recorded due to the potential sensitivity of making this request of these women, the research assistants noted all responses. The modified constant comparison method used in grounded theory methodology was performed to determine common themes around their pregnancy experiences (Maltby, Williams, McGarry, & Day, 2010; Norwood, 2010). Responses from all interviews were transcribed into word documents and three team members independently conducted an analysis to determine tentative themes (Maltby, et al., 2010). The team then came together to clarify and refine final themes and ensure no bias in interpretation had occurred. Data saturation was achieved for the qualitative analysis of women's pregnancy experience from the 41 responses received. Descriptive statistics (frequencies and percentages) were performed on the responses around satisfaction and continuity of care.

Findings

Demographic Profile of all CAMI women

There were 138 women who attended the CAMI clinic from October 2008 to May 2011. Mental illness diagnoses for the CAMI women were categorised into schizophrenia, bipolar affective disorders and other which included non-psychotic major depression, borderline personality disorder, anxiety disorder, post-traumatic stress disorder and bulimia. Seventeen women were not contacted for the following reasons: infant being apprehended (n=14), women being hospitalised in a psychiatric health service (n=2), and one woman experiencing a fetal death in utero. Forty eight women were able to be contacted with seven declining to participate resulting in 41 women participating in a telephone interview. Reasons for their declining to participate were not obtained.

A demographic profile the 41 participants revealed their mean age of 29.4 years (range 19 to 40), 58.5% (n=24) were primiparous women with 41.5% (n=17) being multiparous. Diagnoses included 56.1% (n=23) with a bipolar affective disorder, 17.1% (n=7) with schizophrenia and 26.8% (n=11) under the 'other' category. The seven women who declined to be interviewed were on average 29.1 years (range 22 to 38 years), primiparous (n=5 compared with 2 multiparous women) and had a diagnosis of schizophrenia (n=5 compared with 1 major depression and 1 bipolar).

Experience of Pregnancy in the CAMI Clinic

Three main themes emerged from analysis of the qualitative interview data focusing upon their experience of pregnancy in the CAMI clinic: 'Building relationships', 'Acknowledged me as a person with special needs' and 'Respect and understanding without stigma' (Table 1).

Supporting quotes to illustrate the themes are referenced according to each participant's contribution (P1 to P41).

Building relationships

Providing a small team approach at the CAMI clinic facilitated the woman's opportunity to see the same clinicians at each visit and build ongoing relationships. As one mother commented in comparison to antenatal care in a previous pregnancy, attending the CAMI clinic resulted in better relationships (P35). This approach to care ensured that women saw the same people who knew what was going on (P10). Two subthemes were included under 'Building relationships': 'Everyone knows everyone' and 'Trust and safety'.

'Everyone knows everyone' reflects a reciprocal process; recognising that clinicians are getting to know you as a patient; they remember me (P1) with another woman commenting upon how being known meant having someone to talk to (P4). At the same time, the women were getting to know the clinicians; nice seeing same staff and getting to know them (P15). Being in an environment with known people meant the women felt comfortable and understood. One participant's comment illustrates the impact of the relationships on her pregnancy care: more comfortable this time because we had a relationship and could talk about any problem (P4). Furthermore once an issue was discussed with the CAMI clinicians the woman felt secure in that you don't have to explain yourself over and over (P6), which is not the case in standard care models where women can be introduced to new health professionals at each antenatal visit.

'Trust and safety' were included as a subtheme under 'Building relationships' and were a consequence of these relationships. For example, women used words like *safety, security, backup* (P19) and *you could trust who you're seeing* (P11) when sharing their pregnancy experiences.

Women felt comfort knowing that *they kept an eye on everything* (P41) and importantly, *people followed up on things* (P26). This trust meant that women felt safe or as one woman said it gave her *peace of mind throughout the pregnancy* (P9). Finally, as women were known, clinicians were able to be sensitive and receptive to women's needs without women having to continually ask for information and explanations. Another woman noted how the CAMI clinicians *gave me a lot of options, explained anything I didn't understand* (P8).

Acknowledged me as a person with special needs

The second main theme around the pregnancy experiences of CAMI women focused upon having to a multidisciplinary team that could address all their needs in one clinic. Comments highlighting how women felt their needs were acknowledged included: everyone that you needed was there in the one spot (P25) and everything was there so didn't have to travel from A-B-C-D (P27). The small known team included a psychiatrist for mental health issues, a General Practitioner/Obstetrician for obstetric and medical issues, and a midwife for needs such as educational information for pregnancy, labour and birth, support for plans around infant feeding and to facilitate links with community child health nurses following the birth. In fact, one participant noted how she continued to have ongoing community support in the postnatal period due to her antenatal attendance at the clinic: I still have support now because of it [CAMI] (P6). The level of attention was valued in recognising their special needs: there is a constant level of attention (P33). Women noted how their access to the team was different compared to past pregnancies with other children as illustrated by the following quote: could touch base with them whenever I needed to (P7). Having a specialist team available to answer queries rather than one clinician was also seen as recognition of their needs. Being able to talk to a group of

professionals (P12) reinforced the benefits of decreasing delays for service or having needs overlooked: no delays and no slipping through the cracks (P19). Extended waiting times for antenatal appointments are a common concern for pregnant women (Novick, 2009) but this issue was not mentioned by many CAMI women despite the reality of having waiting times. In fact, one woman stated that: Not having to wait meant I didn't get anxious (P22). The quote that best captured the impact of the CAMI clinic in addressing the needs of these women with a severe mental illness was felt like the clinic was tailor made for me (P7).

Respect and understanding without stigma

The final theme that encompassed the pregnancy experience of women attending the CAMI clinic addressed perceptions of the quality of respect and understanding these women felt as a result of the empathy clinicians were able to demonstrate. They did their jobs and made me feel as comfortable as possible (P23). Participants acknowledged that clinicians did their job but excelled in their effort to create respect: [CAMI clinicians] really cared and were concerned about my health (P20). Experiencing stigma whilst living with a mental illness is widely recognised and the participants noted how they wanted to be treated: don't discriminate and don't put people in boxes (P40). In contract, their pregnancy experience within the CAMI clinic was appreciated as revealed in the following quotes: they didn't talk down to me (P24) and they were there – other people don't appreciate what you're going through (P1). These women acknowledged being challenged with their mental illness but one woman commented how the pregnancy experience, mental illness aside, was better than with [first baby] (P26). Even though CAMI is a specialist clinic for women with severe mental illness, one woman's comments highlight how this wasn't the focus and she did not feel set apart from other pregnant women: I

wasn't even aware that it was a special clinic and that was a good thing because I didn't feel any different (P7).

Satisfaction and Importance of Continuity of Care

In relation to women's perceptions of satisfaction and the importance of having continuity of care from a known team within the CAMI clinic, 97.6% (n=40) of women confirmed that they were either very satisfied or satisfied. The importance of having continuity of care during their pregnancy was also recognized. Women suggested it was very important / important to have the same GP obstetrician (90.2%, n=37), the same psychiatrist (83%, n=34) and the same midwife (78%, n=32) (Table 2).

Discussion

Findings from this qualitative study reflect a small number of women's pregnancy experience within the unique context of the CAMI clinic. Specific detail about the CAMI clinic was provided to facilitate understanding of where this study was situated within an antenatal model that combined obstetric, psychiatric and midwifery care. Rich description was offered so the reader can determine the transferability of these findings to other international contexts as is the goal of qualitative research (Polit & Beck, 2010).

Women in this study revealed how they valued the opportunity to build relationships with the multidisciplinary team to promote trust and safety. Other researchers have provided evidence around all women's experience of antenatal care which supports the importance of developing meaningful relationships with professionals, having continuity and feeling care was comprehensive (Novick, 2009). Two aspects noted in the literature but not expressed by CAMI women were being able to meet with other pregnant women or being actively involved in care

decisions. These women with a severe mental illness reflect different needs in relation to wanting to socially connect with other pregnant women with similar health issues. Our findings are contrary to another qualitative study with British women experiencing antenatal depression as these women shared feelings of emotional isolation, wanted peer support and the opportunity to connect with other pregnant women (Raymond, 2009). Differences with mental health challenges must be considered in these dissimilar groups and also highlight caution in interpretation of findings across groups.

The relationship with health professionals can enhance treatment compliance for patients with severe mental illness (Dearing, 2004). Increasing women's chances of seeing the same caregiver at each visit may not by itself improve the overall experience of care, but time spent personalizing each encounter in antenatal care may enhance acceptance with care planning. Similar to our findings, continuity of care has been associated with increased satisfaction with antenatal, labour and birth and aspects of postnatal care for pregnant women without mental health concerns, however, the greatest differences have been found with antenatal care (Biro, Waldenstrom, Brown, & Pannifex, 2003). Generally, pregnant women who felt their caregivers got to know and remember them were more likely to rate their care highly (Davey, Brown, & Bruinsma, 2005).

Although women with a severe mental illness are more able to form therapeutic relationships with care providers, they are sensitive to frequent changes (Fitzgerald, 2000) and therefore continuity of care is paramount. Women may have existing relationships with community mental health professionals, but becoming pregnant introduces a series of new maternity healthcare providers into their lives. Australian women who knew their midwife

during antenatal care reported receiving information tailored to their needs and were told as much as they wanted to know compared to women who received standard hospital antenatal care and seeing a different midwife at each antenatal visit (Johnson, Stewart, Langdon, Kelly, & Yong, 2003). Finally, women who had continuity of care were more likely to discuss antenatal and postnatal concerns, attend parent education classes, feel prepared and supported during birth, and feel prepared for child care (Hodnett, 2007).

Continuity of care often involves a one-to-one consistent relationship with a midwife over the childbearing continuum of pregnancy, labour, birth and the postnatal period (Page, 2003). Women regarded as low risk obstetrically are suitable for this model; however, CAMI women with a severe mental illness require complex care under the management of a multidisciplinary team. In fact, the National Institute for Health and Clinical Excellence (NICE) recommend careful planning across pregnancy, birth and the postnatal period be developed for pregnant women with a current or past history of severe mental illness (National Institute for Health and Clinical Excellence (NICE), 2007). Regardless of the number of maternity care providers, NICE suggests a focus upon developing a trusting relationship with the pregnant woman by a team she feels comfortable with (National Institute for Health and Clinical Excellence (NICE), 2008). Trust, choice and empowerment are also recognized as significant issues in mental health (Laugharne & Priebe, 2006) with continuity of care acknowledged as facilitating patient's trust (Mainous, Baker, Love, Gray, & Gill, 2001) and improving case coordination, the major goal of the National Action Plan on Mental Health 2006-2011 (Council of Australian Governments, 2006).

The concern of experiencing stigma for clients with mental illness is widely recognised (Hocking, 2003). In fact, other qualitative research findings with clients such as pregnant women who are obese have revealed how their pregnancy experiences resulted in feelings of humiliation and stigma (Furber & McGowan, 2011). Although there was a risk that CAMI women could feel labelled and stigmatised attending a specialist clinic, participants did not express these concerns. The effects of stigma are often associated with negative attitudes that produce discrimination (Carr & Halpin, 2002), however, the positive attitudes of the CAMI clinicians were protective of these women experiencing stigma whilst attending the clinic. In fact, a Welsh qualitative study noted how the challenges of managing the dual identity of mental illness and motherhood can be better integrated by positive surveillance by health professionals assisting mothers (Davies & Allen, 2007). Findings from a UK qualitative study where 28 perinatal psychiatry and antenatal service workers were interviewed reported recurring themes around the importance of service integration and continuity plus concerns with social stigma for women with schizophrenia (Wan, et al., 2008). The need for interdisciplinary communication was recommended as was mental health education for midwives whereas the multidisciplinary model at the CAMI clinic includes a midwife with ongoing access and support from mental health clinicians in the team.

Women in this study felt they were acknowledged as a person with special needs by attending the CAMI clinic during their pregnancy. This finding differs to another qualitative study with 19 pregnant women from Ireland with physical, sensory and/or intellectual disability who expressed an ambiguity around their experience as they encountered mixed reactions to the pregnancy with health professionals viewing them as a liability and high risk (Walsh-Gallagher,

Sinclair, & Conkey, 2011). These Irish women felt services were geared to the 'normal', able bodied women and not adapted to their individual needs.

Close liaison between health professionals during pregnancy and the postnatal period is recommended for optimal management of high risk pregnant women (Howard, 2006). In fact, authors in a recent British clinical article about one patient's journey with Bipolar Disorder highlighted how having continuity of care with a named midwife and obstetrician, and being managed by a specialist perinatal mental health team facilitated her postnatal recovery (Shah, 2012). Collaboration between community clinicians post birth such as the child health nurse, general practitioner and mental health clinician is especially important in relation to concerns around the ongoing mother-infant relationship (Stefan, Hauck, Fauckner, & Rock, 2009). To facilitate postnatal follow up support, the CAMI clinicians were able to highlight likely postnatal needs and organise support services with the woman's permission. This strategy facilitates continuing support after the baby is born as the prevalence of disorganised attachment can be as high as 80% in high risk populations such as those with severe mental illness (Carlson, Cicchetti, Barnett, & Braunwald, 1989; Marian, Bakermans-Kranenburg, Marinus, Van Ijzendoorn, & Femmie, 2005; van Ijzendoorn, Schuengel, & Bakermans-Kranenburg, 1999). The benefit of continuity of care contributes to health professionals 'knowing' the woman and being in a better position to assess, identify needs and refer to appropriate support services (Douglas & Arias, 2001) this facilitating the transition and coping abilities of the mother to her parenting role (Solari, Dickson, & Miller, 2009b).

Conclusion

Managing a severe mental illness in addition to the risks associated with pregnancy and birth requires special attention by mental health and obstetric services. Women who attended the specialized Childbirth and Mental Illness antenatal clinic within the public health system in Western Australia shared positive pregnancy experiences. Building relationships, being acknowledged as having special needs and being cared for with respect and understanding were notable for these women. Although provision of antenatal care is undoubtedly challenging and requires a multidisciplinary team for these women with complex needs, continuity of care within a small team can contribute to a satisfying pregnancy experience for these vulnerable women.

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Table 1. Experience of a pregnancy in the CAMI clinic: Themes and subthemes

Building Relationships			
Everyone knows everyone			
Trust and safety			
Acknowledged me as a person with special needs			
Respect and understanding without stigma			

Table 2. Importance of having continuity across the multidisciplinary team

How important was it to have the same	Doctor (GP)	Psychiatrist	Midwife
	n (%)	n (%)	n (%)
Very important	29 (70.7%)	25 (61.0%)	24 (58.5%)

Important	8 (19.5%)	9 (22.0%)	8 (19.5%)
Unsure	0	1 (2.4%)	1 (2.4%)
Not important	4 (9.8%)	6 (14.6%)	8 (19.5%)
Total	41 (100%)	41 (100%)	41 (100%)