

Women's experiences of participating in a prospective, longitudinal postpartum depression study: insights for perinatal mental health researchers

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Abstract

Purpose—Barriers to recruitment for research on mental illness include participant distrust of researchers and social stigma. Though these issues may be acutely important in perinatal mental health research, they remain unexplored in this context. In order to inform strategies to more fully engage women in perinatal mental health research, we explored the motivations and experiences of women with a history of major depressive disorder who participated in a prospective longitudinal research study on postpartum depression (PPD).

Methods—Sixteen women with a history of depression who had either completed, or recently made a decision about participation in a longitudinal research study about PPD were interviewed by telephone. Qualitative, semi-structured interviews explored participants' decision-making about, and experiences of, participation. Interviews were audio-recorded, transcribed, and qualitatively analyzed using elements of grounded theory methodology. Follow-up interviews were conducted with four participants to refine and clarify preliminary results.

Results—Foundational elements necessary for women to consider participating in PPD research included personal acceptance of illness and trust in the research team/institution. Other main motivators included perceived personal relevance, anticipated benefits (including access to support/resources, learning opportunities, and improved self-worth), altruism, and accessible study procedures.

Conclusions—Our data suggest that participating in perinatal mental health research may help women make meaning of their mental illness experience, and is perceived as providing support. The findings - particularly around the importance of participant-researcher rapport and

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accessibility of study design - may inform strategies that improve participation rates, decrease attrition, and maximize participant benefits in perinatal mental health research.

Keywords

Research participation; postpartum; mental health; participant recruitment; participant retention

INTRODUCTION

Major depressive disorder is characterized by persistent low mood, anhedonia, and associated somatic symptoms that cause significant impairment in social and occupational functioning (American Psychiatric Association, 2013). Depression affects 10–20% of women in the postpartum period (Gavin et al. 2005; O’Hara and Swan 1996), with 50% of postpartum depressive episodes beginning prior to delivery (American Psychiatric Association, 2013). Perinatal and postpartum depression (PPD) is a significant public health issue associated with risks to both mothers and babies, including premature delivery, impaired mother-infant bonding, and poorer cognitive and social development in children (Gjerdingen and Yawn 2007; O’Hara and McCabe 2013). One of the most significant and well-described risk factors for PPD is having a previous history of major depressive disorder (O’Hara and Swan 1996). Thus, pregnant women with a history of depression are a key population to target for prospective studies of PPD.

A review of the literature reveals a lack of studies investigating motivators to participate in research among the population of pregnant women with mental illness. However, in other non-mental health related populations that have been studied, altruism and desire for personal benefit are commonly cited motivators for research participants (Soule et al. 2016; Dhalla and Poole 2013; Hallowell et al. 2009; Costenbader et al. 2007).

In general, research participation rates among individuals with mental illness tend to be low, and several barriers have been identified that limit participation. These range from practical issues like transportation difficulties, to more complex barriers like distrust of researchers and stigmatization of mental illness (Woodall et al 2010). For the particular population of pregnant women with a history of mental illness, these barriers may be even more pronounced than for the general mental illness population, given that women may experience further practical difficulties in the context of pregnancy, as well as increased sensitivity about mental illness in the perinatal period, especially given societal expectations of a joyful pregnancy and fears about judgment of one’s mothering ability (Malpass et al 2009; Mulder et al 2012; Battle et al 2013). A deeper understanding of the experience of participants in PPD research is important; it may help researchers to design strategies to optimize recruitment and retention of participants in future research on women’s mental health. Our group has been recruiting women with a history of mental illness to participate in a prospective longitudinal study of risk factors for postpartum depression, and we have accrued a cohort of 365 participants. This ongoing research study has provided us the unique opportunity to explore women’s decision-making process regarding participation in perinatal mental health research. We sought to explore factors that motivate women to participate in research, including their motivations for continued engagement over the course of a

longitudinal study, and their perceived benefits of research participation. In addition to women's own perceptions on motivations and benefits of research participation, we also aimed to examine their view on what researchers often perceive to be motivators and/or benefits of research participation, specifically the provision of a honorariums and return of research results. As this topic is a novel area of study in this particular population, we set out to conduct an exploratory qualitative study with the aim of generating foundational knowledge to inform future work in this area.

MATERIALS AND METHODS

Ongoing prospective longitudinal research study on PPD

Since 2007, our group has been conducting a prospective longitudinal study involving women with a history of mental illness (confirmed by the Structured Clinical Interview for the DSM-IV, or SCID (First et al. 2002)), to explore the role of specific gene and environment interactions in relation to postpartum mental health. In the context of this study, each participant meets with a research genetic counselor once during her pregnancy and 3 times in the postpartum period (at 1 week, 1 month, and 3 months postpartum). Participation involves completing interviews and questionnaires about mood, mental health history, and social supports, and having blood drawn at each visit. Participants from throughout the Lower Mainland of British Columbia, Canada are recruited during pregnancy through events for pregnant women, internet advertisements, posters, and healthcare practitioners' offices. Participants have the option to meet for study visits either at BC Children's and Women's Hospital, or in their own home, with the research genetic counselor travelling to meet with them at each of the four visits.

Current study – recruitment, data collection, & analysis

The current study utilized a qualitative study design to explore women's experiences of deciding about and completing participation in PPD research. Institutional Review Board ethical approval for this study was received from the UBC Children's and Women's Research Ethics Board. Women with PPD who participated in the previous longitudinal study and provided their consent to be re-contacted for future research opportunities were contacted by their preferred means (telephone or email) and provided with information about the present study and a detailed consent form. Semi-structured telephone interviews, ranging from 30 to 60 minutes in length, were conducted with consenting participants from August 2013 to July 2014. All interviews were conducted by HA, who was involved in the PPD research study, but had not previously met any of the participants that were interviewed for the present study. Initial interview questions broadly explored women's decision-making processes and perceptions about participation in the above PPD research study (see initial interview guide in supplemental info). Interviews were audio-recorded, transcribed verbatim, and checked for accuracy.

This study utilized elements of grounded theory methodology, including open and axial coding, the constant comparison method, and theoretical sampling (Corbin and Strauss 1998). As there are no previous studies that have explored the process of women's decision-making about PPD research participation, we utilized elements of grounded theory, a

flexible methodology that is well suited to exploring new topics, particularly about social processes, such as decision-making processes. Applying elements of grounded theory also allows the study findings to be rooted in participants' words and experiences and highlights what is most important to them (Corbin and Strauss 1998). This exploratory study sought to generate foundational knowledge, which can be used to inform future, more in-depth studies that are designed to generate a theoretical model of women's decision-making process about participation in PPD research.

Data analysis of transcripts began with open coding, whereby concepts were identified and codes were generated. Conceptual codes were then grouped into major categories. Analysis proceeded with axial coding to explore relationships between major categories. Throughout the analysis, we employed the constant comparison method, whereby data are continuously compared and contrasted within and between transcripts, as well as within and between newly identified concepts as well as major categories. Written memos were used throughout to capture impressions of the data and to record emerging concepts and categories. All transcripts were coded by HA; a subset were also coded by AS. Any discrepancies in coding were discussed and resolved between the two coders.

Following other procedural elements of grounded theory, our study also utilized an iterative approach to data collection and analysis, interview guide refinement, and theoretical sampling. More specifically, the initial analysis of transcripts from women who had completed the longitudinal PPD research study (i.e. "Completers") suggested that we might not be capturing a broad view of women's decision making about PPD research participation. Thus, to access a wider range of experiences and perspectives, we recruited women who declined research participation in the longitudinal study (i.e. "Decliners"). Our initial analysis also demonstrated that women who had already completed research participation had a difficult time differentiating between their experiences and perceptions at the time of the initial recruitment, compared to their experiences and perceptions following their participation. Thus, we also sought to recruit women who had consented to participate in, but had not yet completed the PPD study (i.e. "Consenters"). This allowed us to capture women's perspectives at a different time in their decision-making process about research participation. Women who declined to participate in the previous longitudinal study, or those who had consented to participate but had not yet done so, were asked by a PPD study researcher whether they were willing to be contacted by HA with information about a related interview study. These women were contacted by their preferred means and provided with information about the present study and a consent form. The original interview guide was revised into three separate versions, one for each study group (i.e. "Completers", "Consenters", "Decliners").

The second phase of participant recruitment, data collection, and analysis proceeded until data saturation occurred, whereby no new information regarding the major categories emerged following coding. Upon completion of the second phase of data collection and analysis, member-checking follow-up interviews were conducted with four study participants. A member-checking interview guide was developed to confirm, clarify, and refine the major categories.

RESULTS

Study participants

A total of 16 women were interviewed for this study, including 8 Completers, 5 Consenters, and 3 Decliners. Their demographic characteristics are summarized in Table 1. All 16 women (100%) had a history of major depressive disorder, which was confirmed by SCID (First et al. 2002) for Completers and Consenters, and based on self-report for Decliners. In addition, all 16 women (100%) reported their marital status as married or common law, and all 16 (100%) reported having had at least some postsecondary education.

Overview of foundational concepts and major categories

Two concepts emerged that appeared to be **foundational elements** for a woman to begin the process of decision-making regarding participation in PPD research – these were *1) illness acceptance* and *2) establishment of trust* with the research team and institution. Participants discussed four main categories of **motivators for their participation** in research: *1) perceiving personal relevance* of the study topic, *2) anticipating benefits* of research participation, *3) giving back* to others with mental illness, and *4) viewing the study as accessible*. Finally, individuals identified three major categories of **perceived benefits of their participation** in research: *1) gaining support* (both therapeutic support and connection to resources), *2) learning* about mental illness, and *3) improving self-worth* through a sense of accomplishment and having contributed. Below we further describe these foundational concepts and major categories, illustrated by quotations from interview transcripts.

Foundational elements for women’s decision-making

It became evident throughout this study that while there were many things that influenced a woman’s ultimate decision about whether to participate in PPD research, there were two major foundational elements that needed to be present in order for her to even begin the process of decision-making about participation in PPD research:

1) Illness acceptance—In order to consider participation in the PPD research study, it appeared to be necessary for women to have come to accept their own mental illness and the specific diagnostic label associated with it. While the degree to which participants had accepted their mental illness was both varied and subjective, at minimum all participants recognized that they did indeed have a history of major depressive disorder:

“When you are depressed, you are in denial for a long time. You think you’re just sad, you don’t really understand... To be part of a research study [about mental illness] is admitting that maybe you’re not normal, or maybe that something is wrong, and I think that is hard for a lot of people.” – Completer 4

More specifically, we conceptualized illness acceptance as a complex and active process whereby the individual recognizes the reality of their mental illness and has begun integrating this information into their sense of self. The process of coming to a place of illness acceptance appeared to be closely related to the concept of “openness” about one’s depression:

“At this point, I am open about it... I mean, I don’t go around saying ‘oh hi! I’ve dealt with depression’, but if it comes up, I am not shy talking about it. [I was less open] when I was starting to first deal with it, because I didn’t know what was happening to me in the first place, but now that I have more information, I am definitely more open about talking about it.” – Completer 5

Participants described having come to this place of acceptance and openness about their depression through counselling, learning coping skills, and developing support networks. These factors seemed to work together to minimize their felt self-stigma, which in turn allowed them to openly acknowledge their depression, consider participation in research related to their mental illness, and feel comfortable talking to other people in their lives about their depression and/or participation in PPD research.

“Everybody I know... knows I have a history of depression and that I was off my meds for the pregnancy, because... I needed people’s support around it. So I’m not concerned, I’m able to talk to my partner about it, to say ‘I’m going to be in this study’... But I could see that if I had a less supportive partner, I might not want to be taking part in something that is specifically about mental illness.” – Completer 1

“It might be difficult for [some people] to be more open... It’s hard to admit that they might be actually experiencing a problem or they might not recognize it... Before I sought any help, I didn’t want to believe that I had any sort of problem... Now that I’ve gotten help and I have a support network, my views on things are completely different.” – Consenter 2

In the same way that illness acceptance appeared to be necessary in order for individuals to begin the decision-making process regarding research participation, denying one’s depression seemed to act as a barrier to initiating this process. More specifically, some participants described having previously been in a place of denial, which made them unable to acknowledge their experience of depression or consider participation in research on mental illness:

“About 20 years ago, [I declined participation in a study] about depression... because it was related to mental health and I wasn’t as comfortable with my mental health at the time.” – Completer 7

As described by participants, the process of coming to accept one’s mental illness resembles a continuum that ranges from complete denial to complete acceptance. While individuals’ illness acceptance appears to be fluid, waxing and waning over time, there seems to be a threshold of illness acceptance that once reached, enables them to engage in the decision-making process around participation in mental health research.

2) Trust—Trust emerged as another foundational concept that appeared to be essential for women to begin the process of decision-making about participation in PPD research. Basic underlying trust in both the research team and the research institution seemed to be necessary for women to begin the process of deciding whether to participate in the study. Participants implied that the establishment of this initial trust occurred in an unconscious manner, which resembled a “gut” reaction.

Participants described how they judged the trustworthiness of the institution conducting the research largely based on its reputation and perceived motivations for conducting research. They discussed how they held academic universities and hospitals in high regard and viewed the research conducted by these institutions as legitimate, “*real*” research that is conducted in a genuine effort to help society. Several participants contrasted academic research to market or pharmaceutical research, which they viewed as research that is less valuable and primarily conducted for the purpose of financial gain. Consequently, participants questioned whether these other institutions had their best interests in mind:

“I know UBC has a connection, they train doctors, so I knew that they have a reputation within the medical field, so I don’t think I would’ve done it if it was just some research company.... As soon as you hear it’s UBC, I didn’t even give it a second thought. I trusted that they would do things with validity, and in a trustworthy, private way... I think that was really big.” – Completer 4

“I definitely would not have done [a study] by a pharmaceutical company because I am not a medication person at all. I do not believe in medicating, therefore I would have said ‘absolutely not, no thank you’... really it’s what their motivations are.” – Consenter 1

Participants who had learned of the research study from members of the research team through an in-person interaction talked about how this provided the opportunity to form an initial opinion on the research team’s characteristics and conduct, which appeared to help establish basic trust. Subsequently, participants described how building trust throughout the course of the study was vital to their continued participation in the longitudinal study. Participants also highlighted several characteristics of the research team and their interactions with participants that helped to establish rapport and build trust. In particular, participants discussed how the researchers’ approachable demeanor had a significant impact on their trustworthiness:

“The women that interviewed me, and did the blood draws and everything, were extremely personable... I guess it didn’t seem sterile, like the relationship that I had with them was very professional, but at the same time it was very easy and chit-chatty... once I met them, they just made me feel comfortable.” – Completer 2

Particularly in the context of mental illness and the postpartum period, participants described how important it was that their communication with researchers demonstrated a safe, non-judgmental environment, in which researchers discussed mental illness in a matter-of-fact manner, and showed genuine empathy and positive regard for participants:

“[The researchers] understood that they were talking to a new mum, who was probably very frazzled, and might have had a baby crying during the interview, so there was no pressure to get it done quickly, and they understood that the person had experienced, and could be experiencing depression or anxiety at the time, so they were very careful in the way that they worded things, and respectful of all of those factors.” –Completer 6

“When you’re talking about such personal things that have happened to you... you want somebody who’s caring and understanding, who seems supportive.” – Completer 8

The gender of the researcher appeared to be important in the establishment and maintenance of trust and rapport throughout the study, at least for some of the participants:

“I don’t know if I would’ve been as comfortable, if [the researcher] would’ve been a man... if it had been a man, coming into my home while I’m alone with a newborn baby, whether or not they’re sanctioned by a hospital, or university, or whatever, it’s still... not such a comfortable thing... it possibly would’ve affected whether or not I would’ve continued [participation]. It maybe also would’ve affected whether or not I would have agreed [to participate]. – Completer 2

Factors motivating women’s research participation

Participants identified a number of motivating factors they considered during their decision-making process regarding participation in the PPD research study. These largely fell into four major categories, including *perceiving personal relevance*, *anticipating benefits*, *giving back*, and *viewing the study as accessible*. Participants also discussed their motivations surrounding their continued participation in longitudinal research and the impact of their mood on their decision to participate.

1) Perceiving personal relevance—The personal relevance of the research study topic appeared to be an important motivator for women when deciding about research participation. Having a personal connection to depression and PPD seemed to make participants perceive the research as more meaningful, important, and valuable, which motivated them to get involved:

“My cousin had really, really severe postpartum depression, and I had depression as a teenager, so it’s something that I’ve been really worried about. So when I saw that they were doing the study, I thought, that would be great, to find out more about what causes it.” – Consenter 5

“During my pregnancy... there was a woman [in Manitoba] who killed her two children... really bad postpartum depression... this is someone who’s from the same small town as my husband... [it was a] very strange feeling that she’s sort of our age... [so] if me answering some questions and getting a blood draw a couple of times can keep that from happening again, that would be worth it.”- Completer 2

Exploration of links between categories suggested that a woman’s perception of the personal relevance of the research study seemed to be related to her illness acceptance. That is, if she did not recognize/accept her own mental illness and the specific diagnostic label, then she was less able to perceive the research topic as having personal relevance.

2) Anticipating benefits—The benefits women anticipated receiving as a result of their participation in the PPD study appeared to act as another major motivator for research participation. The anticipated benefits participants described fell into three main categories: the ability to gain support, the opportunity to learn, and an improved sense of self-worth.

Importantly, the benefits that women anticipated appeared to ultimately be the same benefits that they reported actually gaining as a result of their participation; and thus they are described in the section of “Perceived benefits of participation” below.

3) Giving back—An altruistic desire to “give back” to society seemed to be another major factor described by participants that motivated them to participate in the PPD study. The women we interviewed described specifically wanting to help others that had similar mental illness experiences to their own. They expressed their hopes that their contributions to research would ultimately make others’ experiences more positive by improving knowledge, prevention, and treatment of mental illness:

“I felt like, because I had mental illness and was getting so much help through the reproductive mental health clinic, I should try and give back, so they can find better treatments and maybe help other women in the future.” – Completer 8

Participants also described their hope that the research they contributed to would help society in other ways, such as by decreasing the social stigma surrounding mental illness, or improving the mental healthcare system:

“I thought that being a part of the study would help maybe, provide better service, that the government would see that you need more money in the system...it’s like, there’s all these resources, but then none of them are really available because there’s not enough funding... so I think that was a part of my [motivation for] being involved [in the study], just getting that awareness out there.” – Completer 4

Women also described how the rapport they had built with the research team further motivated them to continue participating, in order to give back to the researchers themselves:

“I had the same interviewer each time... you spend that time with someone and you get to know them a little bit, and feel also a personal obligation to continue on and help her out.” – Completer 1

4) Viewing study as accessible—The women we interviewed described how the accessibility of the PPD study was a key factor that motivated them to participate. Individuals assessed the accessibility of the study from the moment they first learned about the study. Women viewed the active recruitment strategies employed in the longitudinal PPD study (i.e. researchers telling potential participants about the study in person) very favorably by women. Participants discussed the importance of having immediate access to the research team, as it provided them the opportunity to ask questions about the research study upfront, which in turn appeared to aid in the establishment of trust and rapport.

Participants viewed the in-home study visits offered in the longitudinal PPD study, whereby the researchers travelled to participants’ homes to conduct interviews and draw blood samples, as a powerful motivator for participation. This procedure seemed to drastically increase the study’s perceived accessibility and was viewed by participants as highly convenient. Moreover, it minimized the time commitment and any travel-related costs incurred by participation:

“Honestly it was so accessible, I mean, [the researcher] would come to me, to my apartment, and it was convenient because I didn’t have to go anywhere...If I had to go to her, that would’ve been way more difficult, maybe I wouldn’t have done that.” – Completer 3

Participants discussed how this convenience and accessibility was particularly important in the postpartum period, given the additional practical challenges they experienced at this time. Moreover, several participants expressed that, if the study had not been so convenient and accessible to them, they may have ultimately chosen not to participate, despite all of the other factors that strongly motivated them to want to be involved.

“If I had to go somewhere, I absolutely couldn’t have [participated]. It just would’ve been impossible, and in the beginning, you don’t really want to take your newborn baby out into the car more than you have to.” –Completer 2

Motivators for continued participation in longitudinal research

Participants described how the establishment of trust and rapport with the research team encouraged them to continue participation in the longitudinal PPD study over the course of several months. Once participants had met with the researchers and begun to build a trusting relationship in the context of a safe, non-judgmental environment, they appeared to be more motivated to continue participation throughout the duration of the study:

“I think one time I was really tired and had just had a really hard night and I considered being like, ‘I can’t do [the study visit] today’ ... [but] because I kind of built a trusting relationship with the person doing the study, I knew that they weren’t going to come and be like ‘you look like a mess, you haven’t had a shower or brushed your teeth’ They wouldn’t care. So it helped, that I had a good relationship with her.” – Completer 8

Participants also described how once they began participating in the study; the benefits of research participation that they had anticipated began to be actualized (described below). These realized benefits then appeared to motivate them to continue participation, in order to reap further benefits. In particular, participants discussed a desire to follow through and accomplish what they started:

“I felt that if I didn’t follow through, my input would have no value... I [would have] failed to make a difference when I had an opportunity to... contribute to something meaningful.” – Completer 2

Overall, it appears that the factors that motivated individuals to initially decide to participate in the PPD study were the same factors that motivated them to continue participation throughout the course of the longitudinal study.

Impact of women’s mood on participation

Participants described how their mood at any given time was a factor that impacted, or would have impacted, their willingness to engage in the decision-making process around participation in the PPD study. Interestingly, however, women felt the impact of mood differently.

Some participants described how their depressive symptoms acted as a motivator for their participation. Participation seemed to provide them the sense that they were contributing to something worthwhile, which may help bring them out of their depression:

“I’ve been battling with feeling down and being depressed... and feeling useless and [unable] to give to my family... there have been days that I had things I had to do and I didn’t want to get out of bed but I know that in my heart this [research] is a positive thing... I need to push myself [to participate] in order to get out of this funk and that’s why I’ve decided to go ahead with it.” – Consenter 1

Similarly, some women’s low moods appeared to motivate them to participate because they saw the research as an opportunity to receive support, which may help improve their mood:

“I get depressed, and having [the researcher] come over and talk to me... [it’s] a big thing and it helps me sort of get out of that funk, I guess you could say.” – Consenter 5

Conversely, some women described how the experience of depression could act as a barrier to research participation. These women felt that low mood would decrease their desire to participate primarily because of the time and effort required to do so. In essence, they could become “consumed” by depression and consequently would not have the ability to participate in research:

“If I had not been in a good place mentally, I would not have felt comfortable signing up and I wouldn’t have wanted to talk with other people about what I was going through or what I was struggling with... you know, trying to [participate] when you’re just trying to cope with life, that would be difficult.” – Consenter 3

“If I had gotten really depressed, after the baby...that could have actually stopped me from participating... because I wouldn’t want to get out of bed, I wouldn’t want to do anything.” – Completer 3

For some women, their *stable* mood at the time of recruitment acted as a motivator to participate in the PPD study:

“I just think that when you are feeling more healthy, then you are a little more willing to be open and share your feelings and experiences, as opposed to if I wasn’t feeling so good, I wouldn’t want to talk to anyone about it.” – Consenter 2

Interestingly, one participant felt that stable mood might actually act as a barrier to participation, because they may not want to talk or think about previous negative experiences with their mental health:

“I think [people who have had depression who don’t participate] don’t want to be reminded of that, maybe they’re feeling good at the moment, and they don’t want to go back, they don’t want to think about it.” –Completer 3

Overall, mood status at the time of recruitment, and throughout the longitudinal study, appeared to have a variety of impacts on women’s decisions around initiating and continuing participation in PPD research.

Women's perceived benefits of participation

Participants described the benefits that they felt they gained as a result of their involvement in the PPD study, and these largely fell into three main categories – *gaining support, learning, and improving self-worth*.

1) Gaining support—The women we interviewed described feeling that they had benefited from receiving support as a result of their participation in the PPD study. The support they experienced appeared to come in the form of both *therapeutic support*, and *resource support*.

The benefit of *therapeutic support* participants described experiencing throughout the course of the PPD study appeared to be the result of simply sharing their mental health experiences with the researcher, feeling heard and validated, and having someone “check in” on their mental health status during their pregnancy and/or postpartum period. Members of the research team seemed to play a key role in this process by discussing mental illness in a non-judgmental manner, having an empathetic presence, and validating participants’ feelings and experiences:

“When it came to postpartum and doing the study, it was sort of a part of my healing, or a part of my prevention [of PPD], like it was part of me being proactive... It was almost like a mini therapy session, talking about all those things and reviewing what was going on with me... It was just another chance for someone to listen to me... someone that you felt like understands what you are going through, even if that person is not necessarily a therapist.” – Completer 4

Participants also described how this perceived therapeutic interaction helped to normalize and validate their mental illness experiences, which appeared to help facilitate their illness acceptance and decrease the self-stigma they felt:

“I feel a little less of a stigma, because I got to talk to a lot of people who deal with [mental illness] for a living and are really quite matter-of-fact about it... it certainly made me feel like things that I either was feeling or that I had felt in the past were totally normal... So I think its maybe affected how I consider depression as a whole... It's one thing to see ads about things, but it's quite another to actually meet real people who are dedicating a portion of their lives to something that affects you. It makes a big difference.” – Completer 2

Several women discussed finding comfort in knowing that there were other people participating in the PPD study who had similar experiences to their own. As a result, participants described feeling less isolated. This supportive interaction with the researcher was described as being especially welcome in the postpartum period, given the isolation that participants experienced being at home with a newborn.

“Hearing [the researcher] talk about other women going through the same things, and putting it in perspective... really did help me, and was something I thought about in the period following that.” –Completer 1

Participants also discussed receiving support in the form of *resources* as a result of their participation in the longitudinal PPD study. More specifically, the women described how helpful it was to be connected to external resources in their community by the researchers, including mental health care services (i.e. psychiatrists and counsellors), mental health advocacy organizations, and peer-support groups. Participants viewed these external resources as having the ability to provide them with both information and support. Some women discussed their intention to reach out to these external resources immediately, while others did not plan to engage with these additional support resources but indicated that they appreciated and took comfort in having the knowledge of these resources, should the need or desire to utilize them present itself in the future:

“[The researchers] gave a lot of information like where to call, and what to do... there were really good resources. I remember, [after] the last session [with the researcher], I decided to phone the reproductive mental health clinic” – Completer 4

“I liked... knowing that maybe if I did start to experience... depression, I had [the researchers] as a support network or at least somewhere that I knew I could go and get information” – Completer 5

Overall, the women we interviewed described feeling like they benefited by gaining support in a variety of ways through their participation in the study, including through the therapeutic effects of their interaction with the researchers, and their increased knowledge of, and connection to, community resources that provided further support.

2) Learning—Participants described the opportunity to learn as a benefit that they experienced as a result of their participation in the PPD study. Specifically, they described how they acquired new information about depression and PPD, including information that modified or reinforced their existing knowledge. This learning process appeared to provide some participants with a greater awareness of their own mood status and mental health:

“When you’re [participating], you pay more attention to what state you’re in, or how you’ve been feeling, or your mood... because before I didn’t really know a lot about [postpartum depression].” – Completer 6

This increased consciousness of their own mood status seemed to help empower women in their ability to adapt or change their behaviors in order to better manage their mental health:

“It certainly made me aware of things that I should watch for... it made me quite grateful that I at least knew to look for it... at least I knew what to watch out for... I considered how I was feeling a lot more than I normally would... it gave me a chance to examine how I was feeling, whereas I normally wouldn’t... I think that was a positive thing.” – Completer 2

3) Improving self-worth—Participation in the PPD study appeared to benefit women by improving their sense of self-worth. Participants discussed how they found it fulfilling to do something “good” for others, which in turn seemed to have a positive impact on their self-esteem and mood status. Women described the sense of achievement and pride they felt in their ability to contribute to the study, particularly in the face of their struggles with

depression, and during a difficult time of adjusting to new motherhood. Participants further described how their research participation provided them the opportunity to make meaning of their experience with mental illness. They discussed how, after participation in the study, they were able to view a negative experience in their life (i.e. their depression) in a positive light because it allowed them to contribute to a cause they valued and give back to others.

“I felt proud that I was part of it, and that I hopefully had this small part in helping women in the future with post-partum depression... [Participating] made me feel worthwhile, and that I was helping other people, and helping myself – proactive... I think it lifted me up... just another part of feeling better.” –Completer 4

“I felt satisfied that I completed something... even in a difficult time in my life, I still made time for that, so it helped to remind me that I’m more than just a new mom... At the end, you feel good about having done it... You feel like you’ve done something.” – Completer 2

Women’s views on researchers’ perceived motivators/benefits of participation

Given the wealth of existing research on the impact of honorariums and compensation on participation in research, particularly in vulnerable populations (Grady 2001; Kaminsky et al. 2003; Bentley and Thacker 2004), we explored this area specifically in the course of our interviews. Interviews also explored the idea of the return of research results to participants and the impact this had on their decision to participate.

1.) Impact of honorariums on participation—Participants in the PPD study each received a \$10 cash honorarium at each of the four time points, for a total of \$40. Each study visit took between 1 and 2.5 hours. Interestingly, almost all women we interviewed seemed to view the honorariums in the PPD study as a neutral factor; it appeared to be neither a motivator nor a barrier to participation, but more of a nice “bonus”:

“I mean no one’s going to say no to money... of course that’s nice, to be given ten dollars, but that was not a huge factor for me.” – Completer 4

2.) Impact of return of research results on participation—In the context of the PPD study, we performed research-based genetic testing, but participants did not receive information on their genetic test results. In general, the women that we interviewed saw this as neither a positive nor a negative. While some women indicated that they might be “curious” to know the information had it been available to them, they ultimately perceived these individual genetic results as having little meaning or value to them.

“I would be interested in the results, even if they are totally meaningless, I think it’s interesting to know about your DNA... but I wouldn’t say it was a major consideration in whether I would participate... I would have seen it as an additional bonus, but not something that would have tipped a balance for me.” –Completer 1

Participants were also asked their opinion about receiving overall study results (i.e. having a publication circulated to them). Though this was not described as being a motivator for their participation, participants expressed an interest and desire to learn about the overall outcome of the study they were involved in. Moreover, the women indicated that they would

appreciate receiving the overall study results and would view it as a sign that their participation was valued and made a difference.

“I would particularly like to hear [overall] results... it’s maybe just a sign of respect, that even after you’ve participated we still value that participation... and for me, the learning something is a benefit of taking part... If I never received any follow-up results or anything, after a fair amount of time had passed, I might be a little less likely to participate [in future studies]” – Completer 2

Insights from Decliners

Three of the women we interviewed had considered participation in the PPD longitudinal study, but ultimately decided not to participate. The reasons for ultimately declining participation were personal (i.e. phobia of needles or blood) or specifically related to the PPD study procedures (i.e. concerns about caring for other children in the home during the study visits). Importantly, however these three women also described the same motivations to participate and engage in the research process as women who consented to and/or completed the study. Specifically, they felt trust in the research team and institution, viewed the study as having personal relevance, had the desire to “give back”, and thought that they might benefit from participation by receiving support, and information, and gaining a sense of personal achievement. Aside from the specific reasons that caused each woman to decline participation, these women, like those who consented or completed the study, were unable to identify any other perceived disadvantages or barriers to participation in the PPD study.

DISCUSSION

This exploratory study provides a first look into women’s decision-making process regarding participation in perinatal mental health research. It provides novel data on factors that motivate women to participate in PPD research, including longitudinal research, and their perception of the benefits of research participation. These data give insight into what conditions are necessary in order for women with a history of depression to consider participation in PPD research – namely, acceptance of their own depression history, and initial trust in the research team and institution. This study also highlights factors that motivate women with depression to participate in PPD research – including personal relevance of the research, anticipation of personal benefits, a sense of altruism, and accessible/convenient study procedures. Our data also suggest that the benefits that women anticipated and ultimately gained from participation in PPD research included therapeutic and resource support, learning, and a sense of pride and accomplishment. Taken together, our data suggest that perhaps for the women in our study, participation is about making meaning, purpose, and “good” out of an experience with mental illness that otherwise, is very hard, and often negative.

Our findings are supported by data generated in other contexts. For example, Woodall et al. (2011) showed that while experiencing their first episode of psychosis, people considering research participation in a study on genetics and psychosis described being motivated by altruism (wanting to “do something”), wanting to learn, and a desire to talk about their mental illness experience with a researcher, who was seen as being less intimidating and

judgmental than a clinician. Participants described how their participation in the genetics and psychosis study was facilitated by the researchers' strong communication skills and their positive interactions with the research team. Similar to our findings, individuals who declined research participation in the Woodall et al. study cited primarily practical issues as barriers to participation, including fear of blood draws, and issues around managing family and other commitments. Interestingly, the participants who declined participation in the Woodall et al study described how they chose not to participate in the genetics and psychosis study because they felt that they did *not* have mental illness but were "just stressed". These findings are consistent with our finding that acceptance of one's mental illness and specific diagnostic label is a prerequisite for participation in mental health research, while disagreement with the diagnostic label can act as a barrier to participation.

Our finding regarding the importance of establishing a trusting relationship is also supported by the findings of Bootsmiller et al. (1998), who explored strategies to promote retention of research participants in a longitudinal study of mental illness and substance use. In this study, participants described the importance of the relationship and rapport established with members of the research team to be more important than any material incentives in motivating them to continue participation. This also supports the notion that genetic counselors in particular can be valuable in a translational research setting (Zierhut and Austin 2011), given their unique skill set and ability to build trusting relationships with participants that facilitate recruitment and retention; this may be applicable to other clinician researchers as well, who have the clinical skill and insight to make participants feel safe and supported throughout their participation. In addition, our finding about the importance of accessibility has also been recognized by other studies and as such is often considered in the design of research studies to ensure research visits are scheduled at locations that are convenient for participants (Bootsmiller et al. 1998; Gunn et al. 2015).

Interestingly, in our study, both honoraria and the prospect of return of research results appeared to be neutral factors when individuals considered research participation. Women in our study indicated that these factors, often believed to be incentives for participation by researchers, actually played little role in their decision-making and experiences. Conversely, an individual's mood status seemed to impact their decisions about research participation, with some individuals being more likely to participate when in good mental health, and some more likely to participate when not doing well. These differing views are similar to those expressed by participants in research on systemic lupus erythematosus, some of whom were motivated by stable health status, while others were motivated by feeling ill at the time of recruitment (Costenbader et al. 2007).

Our study aimed to specifically explore factors that women with mental illness see as advantages of research participation, with the goal of increasing recruitment and retention by supporting the attainment of these benefits. Our data suggest that women perceived participation in research on PPD as a source of support, in that it increased their sense of self-worth, helped them to make meaning of their own mental health experiences, and empowered them to adopt positive mental health management strategies. The idea that research participants anticipate direct benefits from study participation is interesting from an

ethical perspective, especially given that in this context, the informed consent process and related form articulated that there were no anticipated direct benefits to participants.

This study contributes to a growing body of literature that suggests that participation in research can actually improve the mental health of participants (Campbell et al. 2004; Gunn et al. 2015; Kurtz et al. 2013; Lyubomirsky et al. 2006). Gunn et al. (2015) demonstrated that sex workers participating in research had decreased depression and anxiety and improved self-esteem, and they posit that perhaps there is less social stigma attached to participation in research studies than accessing more traditional mental health therapies. Research increasingly suggests that there can be great benefits to participants through sharing their difficult experiences with a researcher, and that research-oriented interviews can be healing for participants even when they are not intended to be therapeutic (Campbell et al. 2004; Lyubomirsky et al. 2006; Kurtz et al. 2013). This is demonstrated in our work, with participants emphasizing the support gained through their participation as a highlight of their experience. Our participants described perceiving their relationship with the researchers as being supportive and therapeutic, despite the fact that our research team did not purposefully set out to provide therapeutic support to participants.

Crucially, the growing body of evidence that participation in research can positively impact participants' mental health has key implications for studies that seek to document or measure mental health symptomatology and/or outcomes. Essentially, the combined body of work in this area suggests that these kinds of studies may be exquisitely sensitive to the Hawthorne effect (the act of observation changing the outcome). Specifically, being prompted to reflect on current psychiatric state, interacting with a researcher in the context of a trusting relationship, and/or feeling that one has the opportunity to meaningfully contribute altruistically all have the potential to protect mental health and thereby impact the expression of the phenomenon of interest. Further exploration of this issue merits additional research.

Limitations & future directions

This is an initial exploratory study into the experiences of women with depression participating in longitudinal PPD research. Further work is needed to validate the properties and dimensions of the main concepts and categories and explore in more detail how they relate to one another in order to generate a fully valid theoretical model of women's decision making in this context. Our cohort was primarily married, Caucasian, well-educated, and of fairly homogeneous socioeconomic status, and consequently this group may have different perspectives on mental health research than women of other demographic groups. The demographic characteristics of these participants are reflective of, and thus limited by, the cohort of the longitudinal study from which we recruited. Further, when exploring participants' decision-making about participating in research, it is possible that some Completers were commenting on what they enjoyed about their research experience rather than what motivated them to initially participate. However, interviews with Consenters and Decliners who had not yet participated helped to delineate this distinction and identify motivators for participation prior to enrolment in the PPD study. Finally, participants in this qualitative study were self-selected, and the perspectives of the women who chose to

participate in interviews may differ in some salient way from those of women who participated in the PPD study but did not choose to participate in qualitative interviews about their experiences.

CONCLUSIONS

These data provide novel insights into women's experiences of participation in research on postpartum depression. The results highlight the importance of researchers being empathetic and non-judgmental, and working to build positive rapport with participants, as well as making an effort in study design to make research as accessible and convenient as possible for participants to help overcome any practical barriers to participation. Furthermore, this work suggests that participation in mental health research can have benefits for participants in terms of additional support and increased understanding of mental illness. Mental health researchers, particularly those working on women's mental health and the postpartum period, should consider these issues when designing and implementing research studies, in order to maximize participant recruitment and retention as well as optimize benefits to mental health research participants. Future work should consider investigating the impact of the Hawthorne effect on studies of mental health symptomatology and/or outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographic characteristics of participants

	n	%
Diagnosis: major depressive disorder	16	100
Marital status: married/common law	16	100
Education: 1+ years postsecondary	16	100
Reported racial background:		
Caucasian	12	75.0
Asian	2	12.5
Mixed race	2	12.5
Reported annual household income (Canadian \$):		
<\$20,000	1	6.2
\$21,000 – \$40,000	2	12.5
\$41,000 – \$60,000	5	31.2
\$61,000 – \$80,000	1	6.2
\$81,000 – \$100,000	3	18.8
>\$100,000	4	25.0