

Best Practice in Maternity and Mental Health Services? A Service User's Perspective

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the strengths led approach, which is underpinned by a belief in clients' capabilities and strengths, not their deficits.

Introduction

The birth of a baby is a much-anticipated event. However, for some women diagnosed with mental health needs their pregnancy and potential parenting are seen as problematic. Even if the child is much wanted and the pregnancy is planned, this news can be greeted with uncertainty and concern by the medical and maternity services. They need to plan how they will “manage” the mother's behavior and protect the child from her potentially risky behavior. Most literature focuses on the negative impact that mental illness has on the development of the baby and the young child.^{1,2} It emphasizes the risk factors that specific mental illness diagnoses might have and the mother's potential for abuse of her offspring.^{3,4} However, qualitative literature, which has been undertaken with mothers with a diagnosis, introduces a different perspective. Indeed fear of removal of the child,⁵ a perception of the intrusiveness of services^{5,6} and the stigma of mental ill health dominate their contact with mental health and child development services.^{7,8}

In this article, I use a synthesis of first person narrative and research to explore the experience of being a both a pregnant woman and new mother who has a diagnosis of schizophrenia and my relationship with both mental health and maternity services. I describe the best practice care I received from the mental health services and the reactive, diagnosis led service that was set in motion by the maternity services. I intertwine the 2 elements of research and experience to explore how service provision can be more effective when it is built on a model that promotes shared decision-making and a sense of trust with shared responsibility. I seek to challenge the process led nature of care that leads professionals to become unquestioning actors in a game of risk management and discuss how practitioners can work with people as individuals. In this discussion, I highlight the importance of

The Background

Women with a diagnosed mental health condition were historically viewed as metaphorically sterilized (and in some cases were forcibly sterilized) through their desexualized nature due to segregation in institutionalized care.⁹ Indeed if a woman had a child, it was likely to be removed and adopted into a “normal” family. With the process of deinstitutionalization and the advent of community care in more developed countries, women with a diagnosis of mental ill health are now much more likely to become mothers and take on a parenting role; although this may be a partial parenting role if they do not retain residency of their children. One in 5 adults in the United Kingdom experiences mental health problems, with approximately 30%–50% of all mental health service users being parents.¹⁰ Approximately 2 million children in the United Kingdom live in a household where at least 1 parent has a mental health problem.¹¹

Research has generally focused more on the experiences of women as parents and the impact that mental ill health has on the life of children rather than their experience of pregnancy and mental health, although this literature also describes the mother's potentially harming behavior to the fetus.¹² I focus on the former topic of research because it shows the evidence base that informs professional practice and impacts on the delivery of care to mothers with a diagnosis, and in the context of this article, personally influenced the way professionals planned my care.

Women with mental health needs have been characterized as poor parents, who interact ineffectively with their children.^{1,2} Indeed, increased incidence of mental illness diagnoses (including schizophrenia) has been found in parents of children who have been abused.^{3,4} The diagnosis given to women was found to indicate the quality of the parenting relationship and the developmental

outcomes of the child.^{1,13} Depressed mothers were less likely than other mothers to engage in positive behaviors with their children, such as reading, playing, or talking to the child,^{2,14,15} and were less sensitive and less consistent care givers. This behavior could result in poor or disorganized attachment between child and adult negatively influencing the child's future development.¹⁶ These observations applied across the socioeconomic and intellectual range to women experiencing depression. Women with a diagnosis of schizophrenia were rated as having the lowest quality of parenting, when compared with women with depression and affective disorders¹³ because they were more withdrawn and emotionally uninvolved with their children. In a study from the Republic of Ireland children of a parent with schizophrenia experienced more psychiatric disturbance and more problems at school, spending more time at home and becoming socially isolated when compared with children of parents with good mental health.¹ This research has been used to identify potential risk factors in the population of women with specific diagnoses and informs the evidence base that practitioners use to plan and moreover target treatment to specific women.

I focus now on what women have said in a small number of qualitative research studies about their own experiences of being mothers with a diagnosis as they manage both their mental health condition and care for their children. This kind of research enables practitioners to learn more about the "individual experiences" that women have reported rather than "trends" extrapolated from research with bigger sample populations. This influences how practitioners might relate more to the individual they work with and modify their practice accordingly.

Common to all the qualitative studies focusing on the experiences of motherhood and mental health were 4 themes: the stigma of mental illness, the difficulties associated with day-to-day parenting, managing mental illness while looking after children, and fear of loss of custody of and contact with children.⁵ Having a label as a mother with a diagnosis was viewed in a complex way dominated by stigma and discrimination. Women reported that the label of "mother" was valued and respected by both society and themselves whereas being a "mental health patient" was a label of social exclusion⁷ that predicated their inability to nurture their children effectively. This belief was perpetuated by women with a diagnosis themselves who simply reacted to this negative stereotype by denying their own status as mental health service users.¹⁷ They felt that many professionals acceded to this belief fearing that if they reacted negatively to their children during the day-to-day stresses of parenting then their mental health symptoms would be blamed.^{5,7} They feared the reactions of other mothers to their mental health diagnosis and concealed it from their community further compounding their experience of stigma and isolation.⁸

Women reported that they feared losing custody and residency of their child. They were concerned about who would care for the child if they became unwell for a long period⁸ because prolonged separation from the child could impact negatively on the child's sense of security and development.¹⁸ Moreover, although they relied on their family in periods of ill health, they reported that close family could undermine them and try to replace them as the responsible caregiver for their child leaving them feeling disempowered, devalued, and undermined in their roles.^{17,19} Large scale research studies have emphasized the importance of family support, including close family and partners, in mediating the effects of mental ill health,^{20,21} yet women reported that partners could be unsupportive and unsympathetic to their mental health needs.¹⁹ Indeed, some women feared that if they broke up the relationship with the father, then they would lose residency of their children simply because of their mental health diagnosis.

Women struggled with the care and treatment they received as mothers with a diagnosed mental health problem. Some felt ambivalent about medication, both about the unknown effects on the fetus during pregnancy and the sedative side effects of medication when they needed energy to look after their children.⁵ Adherence to treatment regimes and being a parent could be in conflict: attendance at a day center could not be complied with, or medical appointments attended or hospitalization undertaken during periods of acute illness if there was no childcare available for the mother.^{5,7} They feared the trauma of hospitalization with its experience of chaos and confusion.⁸ They felt pressured to be compliant with treatment plans and cooperative with services despite all these difficulties. Indeed, nearly 20% of parents perceived that they might lose child custody or visiting rights if they were not compliant with treatment procedures.⁶

When we listen to research, we can detach ourselves from situations and disassociate from experiences as we have different experiences from the lives of women with a diagnosis. Indeed contrary to the image portrayed, most women with mental health needs are good enough parents¹⁰ and the majority of women place precedence on having a good relationship with the child.^{8,22} Yet, most practitioners fail to assess the strengths and abilities of parents²³ having a presumption of their inadequacy until proved otherwise,^{5,8,22} as my experience suggests. In this next section, I present contrasting examples of good and bad practice from my perspective when I became pregnant and show how my diagnosis impacted on the type of treatment I received and the choices in maternity care.

My Experience of Mental Health and Motherhood

I have a number of different identities in my life: a researcher and lecturer, a PhD student, and an expert by experience with a diagnosis of schizophrenia. I had

become somewhat distanced from the identity of a “service user” and had become an expert by experience, using my experiences to teach and train. However, as an expectant mother with a diagnosis, I became a service user again. I experienced the sense of disempowerment and disablement that can be caused by contact with services that are thoughtless and diagnosis led. I present the experiences from my perspective, although I acknowledge that there are other ways this story could be told.

Before I became pregnant, my psychiatrist and I discussed at length the right medication to manage my mental health symptoms that would be as safe as possible for the unborn child. He had the foresight to warn me of the reactions I might receive from the maternity services because of my diagnosis. We agreed that I would see a Community Psychiatric Nurse (CPN) for the duration of the pregnancy to monitor my mental health and provide support when working with medical and maternity staff. I felt informed, in control of the process, but felt a safety net had been set up “just in case.” On a personal note my husband and I drafted an advanced statement to enable 2-way communication between him and the practitioners if he had any concerns about my mental health. I became pregnant, my psychiatrist continued to monitor me, and I met monthly with a CPN from when I was 6 months pregnant.

At 24 weeks of pregnancy, I saw a registrar obstetrician who was happy with how the baby was progressing. At this stage, no comments were made about my mental health status, and I felt respected and “normal.” When I was 30 weeks pregnant, I saw another registrar who again declared an unremarkable pregnancy. However, a little while later I received a patient copy of the doctor’s report following the consultation which was copied to a number of different practitioners. The registrar had felt prompted to send a copy to the Safeguarding Midwife for Vulnerable Adults and Children (In the United Kingdom, the Safeguarding Midwife for Children and Vulnerable Adults is responsible for coordinating the care for mothers who are defined as vulnerable or babies who are seen as “at risk of harm.” She/he is responsible for ensuring communication between all professionals involved in the care of this group.) (the midwife responsible for perceived or potential harming behavior to babies) and the CPN with responsibility for maternal mental health. I did not know why this letter had been copied to these people and was surprised at this action. I can only presume she did this because of my mental health diagnosis, as the content of the letter contained no concerns about the baby or my mental or physical health. It would have been more appropriate for the registrar to inform me of her actions and discuss her reasons. Indeed, the importance of giving information and discussing intended actions cannot be underrated as poor communication builds suspicion and resentment.

My CPN informed me a few weeks later that she had been contacted by the CPN with responsibility for maternal mental health to ensure all was well with me and the unborn child. In addition, I received a letter a couple of weeks later inviting me to a meeting of professionals involved in my care—from the Safeguarding Midwife for Children and Vulnerable Adults. The letter contained no information about the purpose of the meeting. After an exchange of emails, I was informed it was a care-planning meeting to facilitate the communication between the different disciplines, which came in contact with me. I was feeling less and less excited about the birth and more apprehensive at the involvement of services and their intrusion in my baby’s life. I felt bound by rules of compliance and compulsion to cooperate. The processes had begun to alienate my relationships with the professionals because I felt disempowered with no choice or control.

The Midwife for Safeguarding Children and Vulnerable Women chaired the meeting. My husband and I, my CPN, the community midwife, and the health visitor were present. I made it clear that I was unhappy with the way the meeting had been organized with little information given. This problem was acknowledged and recognized. It was advised that following the birth I should stay in hospital for 48 hours to monitor my mental health, and it was recommended that we have post natal visits at home by a small number of professionals for the first 4 weeks after the baby’s birth. I would also have to have a discharge-planning meeting with all the professionals in my care after the birth of my daughter.

I felt that these decisions were not best for my mental health. The hospital ward was noisy—how would I sleep? If I felt any sense of paranoia would it be appropriate to stay in a crowded maternity ward? Indeed when I got home, waiting for someone to come to visit me every day for 4 weeks would feel like being under house arrest. I was distressed and frustrated. I had frightening dreams about my baby being taken away and felt unhappy and helpless. My husband had advised me not to appear an antagonistic patient. Over reaction is often perceived as a mental health problem rather than a human emotion, I felt cornered and coerced into co-operating. I explained my fears about staying in the hospital and they said they had no powers to hold me if I wanted to go home: these actions were recommended. The health visitor (In the United Kingdom, the health visitor is responsible for ensuring the health and well-being of children in the community from 0 to 5 years old. She/he builds up a relationship with parents and monitors the baby/child at different points in this age range.) came to see me and meet me. She seemed very competent and knowledgeable about mental health. My background as a qualified and registered (In the United Kingdom, the title “Social Worker” is a protected title and people who have qualified as social workers must register with the General

Social Care Council, which governs social work practice, to use this title and work in this profession.) social worker helped me to understand the individual practitioners and their professional responsibilities. This allayed some of my fears and influenced the positive working relationship I had with individual practitioners.

As the time progressed, I stopped feeling confident about my own mental well-being and my abilities as a mother. I no longer felt regarded as a respected and trusted mum-to-be. Although on one level I felt “consulted,” I did not feel “involved” in planning my care—or that I had the opportunity to reject it. Moreover, I felt coerced and silently threatened with unknown consequences if I did not adhere to the recommendations of the maternity team. I had to date been open about my diagnosis but now I felt perturbed and under suspicion, identified as a person to be watched and monitored.

As the days passed, the baby did not come, and I was induced. Because the obstetrician led birth unit was full, I had my daughter in the maternity led unit (In the United Kingdom, maternity units in hospital can be obstetrician led or midwife led. In midwife led units, care is often characterized by fewer medical interventions thus making the experience of birth less medicalized.) I was treated like a normal mother and the birth was not over-medicalized. I had one night in hospital and was discharged because the community midwife (In the United Kingdom, the community midwife is responsible for the health of the mother and baby “before” the birth and “in following up” the birth immediately after discharge from hospital.)—who by chance was on the ward that day—saw that all was well. When I got home, I was visited daily for the first 5 days. It became very intrusive and did feel like being under house arrest. My CPN intervened and advocated on my behalf. The visits were reduced, but an enhanced service was offered for a further 4 weeks. The midwife and community health visitor were very human but didn’t really understand that I had no mental health symptoms. My problems were being physically sore, not mentally unwell! I was advised to attend a new mums’ group at the health center. This was a mainstream group for new mums, in the local area, which I felt compelled to attend but indeed found quite useful. The health visiting team soon realized that both my husband and I were competent parents and we had a very happy, healthy, and thriving baby. They withdrew their extra support and were content to leave us to build up our lives as a new happy family.

Implications for Practice

This story of care could be presented as a good outcome for the services because mum and baby were well and happy and effective support provided. Yet at the same time, I experienced this “best practice outcome” as intrusive, diagnosis and process led. My experience shows how

the mental health services worked in partnership providing me with individualized and needs-led support that was based on a shared model of responsibility, while the maternity services were reactive, basing their care on diagnosis, and process led models. Indeed, mental health and child protection services sometimes work in opposing rather than complementary ways^{24,25}: the former focusing on the needs of the parents and how removing residency might affect the parent; and the latter focusing on the needs of the children but often unsure of the fluctuating and episodic nature of mental health and the need for rapid responses to changing situations. The mental health services knew me and worked with me as an individual, taking account of my own ability to manage my mental health with insight into my own needs and the capacity to request support when needed. The maternity services felt the need to monitor and review my care of the baby, undermining and deskilling me. They did not know me but felt a need to impose their model of care based on a diagnosis that is often misunderstood and demonized.

To provide positive and strengths led support, practitioners have to understand how to work with individuals to plan for success, while if they plan for failure, mothers will internalize this sense of incapacity and their confidence will be undermined.²⁶ My experiences of services left me feeling marked out by my diagnosis. Indeed despite the data which suggests that women with schizophrenia are often poor mothers,^{1,13} other studies have contradicted the correlation between diagnosis and poor parenting demonstrating that the mother’s current symptomology and community functioning are much greater indicators of her ability to care for her child than the diagnosis.²⁷ If a strengths approach had been applied, my personal capacity would have been foremost rather than my diagnosis. Indeed, positive and supportive services will build cooperation while a sense of negativity and coercion builds barriers and blocks to shared decision-making and practice. It discourages a sense of openness and trust on the side of the service user reducing their cooperation.

How can services work more effectively together in partnership with mothers with a diagnosis in a wider context of providing and delivering care? Services have tried to respond to the needs of mothers and developed different models of best practice. Mother and baby units were developed in the United Kingdom so that a woman experiencing postpartum mental health symptoms could access treatment with her baby rather than be separated from him. There are however few mother and baby units, and almost none for children aged over 1 year.⁹ Yet, still 50% of women with schizophrenia and 10% of mothers with affective disorders in a mother and baby unit were discharged without their baby.²⁸ In another example of best practice, an education class was set up to provide support for a group of mothers with a diagnosis.²⁹

It provided mental health support to the mothers, gave them an opportunity to make friends with their peers, helped them to access mainstream services for their children, and allowed child development services to monitor the baby in an informal setting. A final example details how maternity led services piloted a project providing intensive home visiting to potentially “risky mothers” in order to mediate harm to the children.³⁰ The results provided evidence to suggest that intensive home visiting by UK-based health visitors during the perinatal period improved parenting and increased the identification of infants in need of early removal from harmful families.

The support I received conformed to this best practice. I did not need to attend a mother and baby unit as my mental health was unaffected by both the birth of the baby and the postpartum period. However, I had discussed this with my psychiatrist who believed I would remain well throughout the period. I was encouraged to attend an education class for new mums. This enabled me to build friendships, learn about topics of care for the baby, and also allowed the health visiting team to monitor my baby. The services also wanted to implement intensive home visiting in the first 4 weeks of my baby’s care—although I managed to reduce this to 5 days. This service model could be described as best practice but was not experienced as such. Although the practitioners were individually very skilled and competent, the system distressed and frustrated me leaving me disempowered and deskilled. I felt upset, monitored, and labeled. If I had received more information about what procedures were being followed, this would have allayed my fears, reduced my distrust of the services, and encouraged me to cooperate willingly.

In order to learn lessons from my experience, I would suggest that practitioners consider the following:

1. The practitioner should see the person not just the diagnosis and respect the mother’s professional, educational, and family background.
2. They should be aware of their own values and beliefs and understand how the stigma of mental ill health influences their management of the patient.
3. They should be open and transparent in discussing any concerns to enable 2 way communication and foster trust.
4. They should explain their actions fully giving as much information as possible.
5. They should be aware of the professional power they possess and be aware of its effects on the mother in silently coercing her to be compliant to treatment plans.
6. They should develop a shared model of responsibility that enables both parties to trust each other.
7. They should negotiate the service provision and not just presume that they desired.
8. They should believe first in success and only plan for failure if that occurs.

In summary, in my experience suspicious and paternalistic care can only alienate once cooperative clients from working with services, while simple and transparent communication with shared ownership of decisions and responsibilities can only build trust. Professionals have a responsibility to work “with” people as individuals rather than “against” them as recipients of maternity and mental health services. Furthermore, practitioners must plan for success not failure, have a belief in capacity rather than incapacity, and support individuals rather than follow procedures that are diagnosis and process led.

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