Denial of pregnancy – a literature review and discussion of ethical and legal issues

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Summary

Denial of pregnancy is an important condition that is more common than expected, with an incidence at 20 weeks gestation of approximately 1 in 475. The proportion of cases persisting until delivery is about 1 in 2500, a rate similar to that of eclampsia. Denial of pregnancy poses adverse consequences including psychological distress, unassisted delivery and neonaticide. It is difficult to predict which women will develop denial of pregnancy. There are a number of forms of denial of pregnancy, including psychotic and non-psychotic variants. Denial of pregnancy is a 'red flag' that should trigger referral for psychiatric assessment. A national registry may help to provide more information about this condition and implement appropriate care. This condition poses challenging legal and ethical issues including assessment of maternal capacity, evaluation of maternal (and possibly fetal) best interests and the possibility of detention in hospital.

Introduction

Pregnancy is a time of enormous emotional and physical change for women, who undergo a period of great transition. For some, the necessary emotional adaptations are not possible, resulting in maladaptive coping mechanisms. These range from depression and substance abuse through to overt denial of pregnancy.

Denial of pregnancy is an important condition, which is associated with suboptimal outcomes for both mother and child. Of prime importance is the association of this condition with neonaticide. Indeed, pregnancy denial has recently received media coverage following a series of French cases of neonatal killing.

We examine the literature to gain an overview of this important condition, including its incidence and main features. We discuss its subclassification, consequences and management. We then discuss some of the ethical and legal issues that may arise in these situations.

Literature review

Overview

Pregnancy is a time of physical and emotional development, in which women adapt to their future maternal role. The gestational period allows time to accept the pregnancy, become attached to the fetus and prepare for birth.[1,2] For many women, this time is full of fears and doubts. On occasion, these fears are so overwhelming that women are driven to deny their pregnancy. This inappropriate defence mechanism may be so powerful, that the woman is genuinely unaware of her condition.[1] She will not accept the pregnancy and is unable to progress to the stages of fetal attachment and preparation

for delivery. She will consequently be unprepared for delivery and motherhood. This is associated with significant risks for both the mother and fetus, including emotional disturbance, lack of antenatal care, precipitous delivery (often into the toilet bowl[1,3]) and neonaticide.[4–7] It is suggested that there are a continuum of pregnancy denial behaviours, ranging from full awareness of pregnancy with concealment, to suspicion of pregnancy, to full-blown denial.[1]

Incidence

Denial of pregnancy is more common than may be thought. A German study[8] suggested that the incidence of denial of pregnancy at 20+ weeks' gestation was 1 in 475 (0.21%). This is higher than that of rhesus haemolytic disease (1 in 1000) or uterine rupture (1 in 1500).[8] This incidence was collaborated by an Austrian study indicating a rate of 1 in 400 pregnancies (0.25%) and an American study suggesting a frequency of 1 in 516 births (0.19%).[9]

A series of 27 Austrian women[10] with denial of pregnancy indicated that in 11 cases, denial continued until delivery; in nine cases it resolved at 27–36 weeks, while in seven cases, it resolved between 21–26 weeks gestation. Other work suggests that the incidence of denial of pregnancy that continues until labour is approximately 1 in 2455 to 1 in 2500,[2,5,8] which is equivalent to the observed frequency of eclampsia[11] (1 in 2500), or three times more common than triplet births (1 in 7225).[8]

Characteristics of women

It was previously suggested that women who denied pregnancy were likely to be young, primiparous, with learning difficulties, poor social support, and a history of substance abuse or psychiatric disorder.[4,9] However, it now appears that there is no clear-cut typology of a 'pregnancy denier'.[5,11,12] On the contrary, the majority of women studied were in their early to mid-20s, multiparous, with good social support. Many were students or employed. Only a minority had diminished intelligence, substance abuse, mood disorder or psychiatric illness.[2,5,9,11–13] It seems that external stresses and psychological conflicts about pregnancy may lead to denial in otherwise well-adjusted women.[14] This suggests that women who deny pregnancy are a heterogenous group, with no clear-cut identifying characteristics. Consequently, a risk score is almost impossible to construct. It is therefore suggested that doctors should be more aware of the possibility of denial of pregnancy and should have a low threshold for pregnancy testing in women of childbearing age who present with symptoms compatible with pregnancy.[9,12,15]

Subclassification

Denial of pregnancy is most simply classified as psychotic or non-psychotic.[1] Those with psychotic denial tend to be chronically mentally ill (e.g. schizophrenia, bipolar disorder) and remain psychotic throughout pregnancy. They may experience physical symptoms of pregnancy, but contribute these to other delusional causes. They may oscillate between open acknowledgement and emphatic denial of their pregnancy. Those with non-psychotic denial have no primary psychotic illness. They have otherwise intact reality testing and often reconstitute after delivery.

Contemporary authors increasingly subclassify non-psychotic denial of pregnancy as pervasive, affective or persistent.[9] Pervasive denial occurs when not only the emotional significance but also the very existence of pregnancy is kept from awareness. Affective denial is when the woman is intellectually aware of the pregnancy, but makes little emotional or physical preparation for the birth. Persistent denial occurs when woman discover their pregnancy in the third trimester, yet fail to seek antenatal care. Friedman[9] examined the incidence of each subtype and found that 36% had pervasive denial, 11% had persistent denial and 52% had affective denial. There were no cases of psychotic denial.

There are calls to incorporate denial of pregnancy as a new category in the DSM and ICD classifications.[11,12] This would facilitate awareness and research, as well as enabling healthcare professionals to refer these women for appropriate psychological or psychiatric help. The term 'negated pregnancy' is suggested to incorporate both denial and concealment of pregnancy (in which the woman is aware of her pregnancy, but

makes efforts to hide this from others). Negated pregnancy could either be classified as a complete type (denied) or incomplete type (concealed). It could also be specified at which stage the pregnancy was eventually accepted.

Consequences

As described, the incidence of denial of pregnancy decreases with increasing gestation, from 1 in 475 at 20 weeks to 1 in 2500 at term. This indicates that the condition is transient for the majority of woman. Women with non-psychotic denial of pregnancy, who are not chronically mentally ill, often experience dissociation or conversion at the time of their delivery.[1] In some cases, women may acknowledge pregnancy after seeing prenatal ultrasound images.[10]

However, there is often a poor outcome, with postpartum emotional disturbance and increased risk of fetal abuse, child neglect or neonaticide.[1,4] There is also an increased incidence of precipitous or unassisted delivery (one study of 74 neonatal deaths revealed 18 cases that involved giving birth into toilets.[1] The majority of these involved denial of pregnancy). Poor outcome is also due to preterm births, small for gestational age babies, increased rates of neonatal admissions and increased infant mortality.[2,11,16]

In July 2010, some French cases of neonaticide drew media attention;[17] denial of pregnancy was thought to have played a significant role in some of these tragic situations. In instances of neonaticide, non-psychotic denial of pregnancy is most likely to result in passive death; the woman may become acutely confused and disorientated at the time of delivery, or panic after the birth and the infant may die from maternal negligence, through exposure. Psychotic denial is more likely to be associated with active killing, by means such as suffocation or strangulation.

Denied pregnancies have a statistically significant worse outcome compared with a normal group; at least some of these poor outcomes are potentially avoidable.

Signs and symptoms

The nature of the presentation of denial of pregnancy is variable and often depends on the underlying problems. A risk score is almost impossible to construct, meaning that it is extremely difficult to predict women who may suffer from this condition. In cases of psychotic denial of pregnancy, the families of the denier are often aware of the condition, because the patients make no effort to conceal their pregnancy.[1] Case reports of non-psychotic denial of pregnancy describe women who present with the abrupt onset of active labour, often resulting in an unassisted delivery.

Due to its variable presentation, denial of pregnancy is a difficult condition to diagnose. It is recommended that physicians should consider the possibility of denial of pregnancy in young women presenting with nausea, weight gain or abdominal symptoms, with or without amenorrhoea.[9] It is worth noting that in one cohort, 38% of the group had visited their doctor during their pregnancy without receiving a diagnosis of pregnancy.[11] This rate of presentation suggests that there may be scope for increased awareness and early recognition of the condition. This may improve the outcome for these women and their offspring.

Diagnostic criteria

Wessel *et al.*[5] base their diagnosis of denial of pregnancy on two criteria; the occurrence of a sudden delivery following (nearly) totally absent prenatal care or the late onset of prenatal care (after 20 weeks gestation). They also include women who have no subjective perception of their pregnancy up to or longer than 20 weeks gestation. These authors exclude women who do not present for antenatal care due to other, non-denial-related reasons.

Management

Due to the potentially catastrophic outcome, it is of prime importance to increase awareness of the significance and frequency of denial of pregnancy among the medical profession, in order that the condition may be recognized and appropriate treatment offered. Ideally, treatment should take place in a multidisciplinary setting that integrates psychiatric and obstetrical care.[4,9] Denial of pregnancy should be a red flag that such women

need to be seen and evaluated by a psychiatrist, given the high risk of neonaticide.[13] Ideally, referral to psychiatric services should occur as soon as the denial of pregnancy is recognized. Treatment may include pharmacotherapy and supportive psychotherapy, including evaluation of the woman's parenting skills and support network. Any underlying illness also requires treatment by a psychiatrist.[14] It is important that this referral is made in order to determine the type of help the woman needs, rather than simply undertaking substance abuse screens and reporting the incident to child services. Women should be seen regularly by members of the obstetric and psychiatric teams, in order that a plan can be put in place to support her both during and after the delivery. It is important to support the mother and acknowledge internal psychological conflict.

In one Welsh cohort,[2] no women with denied pregnancies were referred for counseling or follow-up. Nirmal suggests that a regional or national registry should be set up in order to gain more information about these women and to help implement appropriate care.

Postnatal care

It is important to remember that not all women with denial of pregnancy will harm their babies. Most will go on to take full responsibility for their children. However, a small proportion have the potential for infanticide, while for others, denial of pregnancy may be a sign of an underlying psychiatric condition. It is therefore imperative that all women with denial of pregnancy are assessed with regard to their parenting skills as well as undergoing a psychiatric consultation.

It is suggested that psychiatric referral is underrequested, with one study indicating a referral rate of less than 10%,[13] with another suggesting that psychiatric referral was never requested.[2] Consideration should be give to the fact that women in these circumstances are unlikely to return for evaluation after discharge, both because of their antenatal behaviour as well as the difficulties associated with returning to hospital in the postnatal period.[13] Referral should ideally be made while the woman remains an inpatient. This will allow for the possibility of thorough evaluation as well as instigation of treatment for any underlying condition. Subsequent follow-up can be arranged, depending on the woman's individual needs.

Of prime importance is the issue of child safety. All NHS staff have a duty to ensure that children are protected from harm. Any concerns should be reported to Social Work services at the earliest opportunity. Inter-agency child protection procedures must be followed, involving social workers, midwifes, health visitors, CPNs, drug workers, pscyhiatrists and obstetricians. Ideally, this will be arranged pre-birth. This will allow a care plan to be arranged for the child, which may involve simple observation through to removal of the child at birth.

In women with previous denial of pregnancy, any suspicion of a subsequent pregnancy should result in early referral to child protection services. A multi-agency meeting should be held to discuss any risks within this pregnancy and devise a future plan of action.[18]

Ethical and legal issues

Women who present in late pregnancy with persistent denial of pregnancy may present the clinician with a number of ethical and legal dilemmas. These include the determination of maternal capacity, consideration of her best interests and the interests (if any) of the fetus as well as the possible need for maternal detention in hospital.

Capacity

It is imperative to stress the principle that all adults must be assumed to have capacity to make their own healthcare decisions, unless there is clear evidence to the contrary. However, when faced with a labouring woman who does not believe that she is pregnant, there may legitimately be grounds for concern regarding her capacity to give or refuse consent should obstetric intervention become necessary. If an individual's capacity is seriously in doubt, it should be assessed as soon as possible by someone skilled in this field (e.g. a consultant psychiatrist). Criteria for the assessment of capacity include the ability to understand the salient information, retain that information and use the information as part of the process of decision-making. These criteria,

along with the ability to communicate the decision, have been adopted by the 2005 Mental Capacity Act in England[19] and the Adults with Incapacity (Scotland) Act 2000[20] as being necessary for autonomous decision-making.

Best interests – mother and fetus

When faced with any individual who lacks capacity to make their own healthcare decisions, clinicians should endeavour to act in the individual's best interests. In determining best interests, the Mental Capacity Act requires us to consider the person's past and present wishes and feelings, their beliefs and values and any other factors they would be likely to consider if they were able to do so. Any relevant written statement (such as an Advance Directive) made when they had capacity is particularly relevant. In Scotland, The Adults with Incapacity Act further states that no intervention should be undertaken unless it will benefit the adult and the proposed benefit cannot readily be achieved without the intervention. Furthermore, the least restrictive option should be chosen.

In the situation where urgent intervention is required to save the woman's life (e.g. emergency Caesarean section for antepartum haemorrhage), it seems clear that her best interests will be met be proceeding with the surgery. However, in the situation where intervention is recommended in the interests of the fetus (e.g. fetal bradycardia), the issue of best interests is less clear. It could be argued that maternal best interests are met by giving birth to a live baby. Equally, it could be argued that the woman's main interest lies in bodily integrity and that surgery without explicit consent is assault. In such situations, it is recommended that a multidisciplinary team including psychiatrists should be involved. It may also become necessary to involve the courts in the decision-making process.

If the woman does have capacity to make her own decision, then this decision must be respected. The law is quite clear that until the moment of birth, the fetus has no legal personhood and therefore no interests worthy of the protection of the courts. While it may be argued that due to their unique relationship, the mother owes the fetus a certain duty of care, this duty is not legally enforceable. The mother's interest in bodily integrity must take precedence over any fetal interest in being born alive and healthy. Therefore, the decision of a competent woman to refuse obstetric intervention must be respected, even if this results in harm to herself or the fetus.

The situation in which the mother's wishes and fetal 'interests' are opposed has been referred to as 'maternal–fetal conflict'. This is an unfortunate term that conjures up images of violence and rivalry. We suggest that it should be avoided where possible. Indeed, it could be argued that the real conflict in such a situation is between the woman and the doctor! This type of situation is best approached with good communication. The doctor can give advice and use effective communication (although never coercion) to aim for the best outcome for both mother and fetus. Provided the doctor does everything within his or her ability and the mother fully understands the situation, then the ultimate responsibility rests with the woman.[21] Good communication and record-keeping are essential.

Detention in hospital

Another issue that may arise is that of enforced detention in hospital. It is imperative to stress that detention under the 1983 Mental Health Act[22] is lawful only for the investigation and treatment of psychiatric illness. The Act cannot be used to authorize treatment for any other medical or surgical condition. Therefore, while a woman with denial of pregnancy may warrant admission for assessment and treatment of an underlying psychiatric illness, the Mental Health Act cannot be used to authorize treatment for obstetric complications.

Summary

Denial of pregnancy is an important condition that is surprisingly common, with an incidence at 20 weeks gestation of about 1 in 475. Denial of pregnancy persisting until the point of delivery occurs with a frequency similar to that of eclampsia. It poses potentially adverse consequences for both the mother and her offspring. These include psychological distress, unassisted delivery, preterm birth, SGA babies and neonaticide. It is almost impossible to predict which women are at risk, as no constant character traits have been

observed. Therefore, clinicians must have a high index of suspicion and ensure that pregnancy tests are carried out in any woman of childbearing age who presents with symptoms of pregnancy. There are a number of forms of this illness, including psychotic and non-psychotic variants, of which the psychotic type is vastly less common. Denial of pregnancy should be seen as a 'red flag' that triggers referral for psychiatric assessment in order that women can be given the appropriate help. A national registry may help to gain more information and to help implement appropriate care.

This condition poses challenging legal and ethical issues that require a carefully considered, multidisciplinary approach. Important considerations include the assessment of maternal capacity to consent to obstetric interventions and careful evaluation of her best interests if she lacks capacity. Any intervention must be carried out in the woman's best interests if she is incompetent to make her own decision. The decision of a competent woman must be respected, even if this results in fetal demise. Good communication and record keeping are essential. Finally, the Mental Health Act may only be used to detain patients for assessment and treatment of psychiatric conditions and may not be used to authorize any form of obstetric intervention.

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