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## Providing effective maternity care for women affected by fibromyalgia

### Abstract

Fibromyalgia is a condition for which information is not readily accessible in midwifery or obstetric text books. This 'invisible disability' can have detrimental implications for all aspects of maternity care. From the physiology and psychology of fibromyalgia during the antenatal through to the postnatal period, this article highlights key issues which can have a hidden but significant impact on the maternity experience

of women with fibromyalgia. These issues are discussed and suggests ways in which midwives can improve the quality of the care given to women affected with this condition.

### Key points

- Fibromyalgia is a physiological and psychosocial affective condition
- Facilitating informed decision making for women with cognitive dysfunction is an ongoing challenge
- Midwives caring for women with fibromyalgia should remember that these women requires a multi-dimensional intraprofessional approach to improve their experiences of maternity care.

### Introduction

Fibromyalgia is a non-inflammatory rheumatologic disorder characterized by chronic widespread musculoskeletal pain, fatigue, depression, cognitive dysfunction and non-restorative sleep (Starlanyl and Copeland, 2001). Rheumatologic disorders include clinical problems which involve joints, soft tissues and allied conditions of connective tissues. Fibromyalgia is thought to amplify pain causing the body to exaggerate light, vibration, smells and to interpret these sensations anywhere along the spectrum from discomfort to unbearable pain (Table 1). As with rheumatoid arthritis and systemic lupus erythematosus, fibromyalgia is classed as a syndrome rather than a disease.

The World Health Organization (2008) estimated the prevalence of fibromyalgia to be between 3–6% of the world's population, while Arthritis Care UK (2010) stated that fibromyalgia will affect 1 in 50 people at some point in their lives, although it is most likely to occur during the ages of 25–55 years and affects

women seven times more frequently than men. Whether increasing numbers are due to improved diagnostic techniques, an increased awareness among GPs and rheumatologists or for some other reason is as yet undefined. There is thought to be genetic link (Ablin et al, 2006; Buskila et al, 2007) and the onset of the symptoms often follow an emotional or physical trauma (Amital et al, 2006; Arguelles et al, 2006). It has been nicknamed the 'invisible disability' as people who suffer with fibromyalgia may appear outwardly well but are often unable to function within the demands of 'normal' day-to- day life. (Dell, 2007).

### **Fibromyalgia in midwifery**

Fibromyalgia is not a condition on which information is readily accessible in midwifery or obstetric text books. However, during the years the author worked as a team leader in an obstetric antenatal clinic, an increasing number of women presenting with fibromyalgia as a pre-pregnancy clinical diagnosis has been noticed.

The pain of fibromyalgia is generally wide- spread, involving both sides of the body. Pain usually affects the neck, buttocks, shoulders, arms, the upper back and the chest. Assessment of pain threshold in various localized tender areas of the body that can bring on widespread pain and muscle spasm when touched is used as part of the diagnostic technique (Arthritis Research UK, 2007). Tender points are commonly found around the elbows, shoulders, knees, hips, back of the head, and the sides of the breast bone. A series of blood tests are performed to rule out other conditions such as chronic fatigue syndrome, lupus, under-active thyroid, multiple sclerosis, myositis, rheumatoid arthritis, and Sjogren's syndrome.

Women are presenting in increasing numbers for obstetric care and the question needs to be asked if midwives are equipped with the knowledge and skills necessary to provide the additional care they may require. As the link midwife for the Fibromyalgia Association UK, the author has found this is also reflected in the number of contacts and queries from women with fibromyalgia who are either pregnant or wishing to become so. The aim of this article is therefore to make relevant information more accessible to midwives and other health professionals who may be involved in the maternity care of these women. In this article, the disorder will be broken down into areas which may have an impact on women's maternity care requirements. In addition to the physical symptoms of fibromyalgia, there is the additional potential complication of depression and anxiety which are present in 30–45% of patients (Dell, 2007).

## Dyscognition

Women with fibromyalgia often have memory and cognitive complaints including impaired control of attention and a weakened working memory (Starlanyl, 2001). Their neurocognitive deficits highlight the possibility that there may be additional or increased implications for processing information in order to make informed choices and giving informed consent. Women need varying amounts of time to process the information given to them during their pregnancy and postnatal puerperium (Campbell, 2002). Arguably the majority of the 'routine' information is given during the booking visit (Baston, 2002). 'Fibrofog' is a common complaint of women with fibromyalgia, and refers to the impaired cognitive processing which can make someone with fibromyalgia more likely to miss appointments, appear slow to process new information, or behave as if they are lost in thought. If fibromyalgia is known to cause dyscognition then should women with this syndrome be offered assessment in an attempt to discover the extent of their additional needs?

## Additional needs

It could be argued that the impact of the symptoms of fibromyalgia during pregnancy need to be recognized and addressed. A woman with fibromyalgia could be considered as 'disabled' during her pregnancy because of the large number of informed health care choices expected of her and the challenges the cognitive dysfunction linked with fibromyalgia poses. However, there is agreement that 'labelling' these women as 'disabled' could have a negative impact and worsen their condition. Their additional needs, however, must be considered so that the care can be modified. Perhaps women with fibromyalgia should be offered an additional component of the booking visit and returning at a later date to assess comprehension and obtain required consents? (Department of Health (DH), 2007). Perhaps labelling her as 'additional needs' could resolve or simplify the issue of how to assist a pregnant woman with fibromyalgia to absorb the information required in order to make an informed choice? It is clear that this issue needs to be investigated further in an attempt to derive methods of offering the best care without compromising the woman or opening her up to areas of unnecessary discrimination. McKay-Moffat (2003) suggested that there is a rise in the numbers of women with disabilities choosing to become pregnant, although there is no statistical data to support this. It was also suggested that midwives need to be particular about the terminology they use, for example using 'alternative or additional' needs rather than 'disabled' or 'special' needs. It could be argued that the terms used are, on the whole, not as significant as the midwife's attitude toward the discussion topic and the amount of time he/she is able to devote to facilitating informed decision making (Thorley and Rouse, 1993; Marteau et al, 2001).

Wald et al (2000) stated that anxiety is minimized by inviting women to become involved in the decision-making process and encouraging them to make informed choices about their care. Again, with the influence of the dyscognition experienced by many of these women, one could conclude that Wald's suggestions may actually increase stress levels in this instance for both the woman and the midwife. Furthermore, time is always a precious commodity within the health-care service and there is not always the necessary or appropriate amount of time to dedicate to each woman. It should be argued that it is important to consider the demands on midwives with the advent of the 'modern ways of working' and to maintain an awareness that effective communication is becoming increasingly difficult for midwives to provide while trying to perform under the weight of their increasing workloads (Levy, 1999).

### **Restorative sleep**

Lack of restorative sleep, which is required to promote physical and emotional recuperation, is a common complaint among new mothers. Most manage to cope with disturbed sleep cycles for varying periods of time until their baby/child learns to settle for extended durations through the night. Sleep is known to be important in the maintenance of a strong immune system, neuroendocrine and body temperature functions. Many of the body's cells also show increased protein production and reduced breakdown during sleep (Starlanyl, 2001). Women who have fibromyalgia already lack restorative sleep cycles (Starlanyl, 2003) and therefore may be additionally compromised in their ability to cope with increased night-time activity while coping with the demands of a new baby.

### **Medications**

The management of pain associated with fibromyalgia will vary depending on the individual's needs and the practitioner responsible for the patient's medical care. However, some general guidance has been produced following a review of 146 studies on fibromyalgia including 39 pharmacological and 59 non-pharmacological ones (Carville et al, 2007). There were nine recommendations formulated from this review which address the general, pharmacological and non-pharmacological management of fibromyalgia.

### **Pharmacological management**

The pharmacological recommendations include using tramadol as well as simple analgesics such as paracetamol and other weak opioids. Antidepressants known to reduce pain and improve function, such as amitriptyline, were recommended along with drugs effective in the treatment of neuropathic pain such as pregabalin. Clearly these all have implications during the ante-natal period and

within the postnatal period if the woman chooses to breastfeed.

## **Non-pharmacological management**

The non-pharmacological recommendations included the use of a heated pool, individual exercise programmes, cognitive behavioural therapy, physiotherapy and psychological support. Good multidisciplinary working relationships are the key to coordinating the best possible care available to pregnant and perinatal women with a diagnosis of fibromyalgia.

## **Antenatal care**

Flare ups of the pain associated with fibromyalgia are often linked to triggers. These seem to be as individual as the person suffering the flare up. Women the author has met through the Fibromyalgia Association UK have reported flare-up triggers that range from stress, alcohol, caffeine, cold, inactivity, too much activity, and from being overweight.

Without knowledge of these triggers it would be very easy as caregivers to overlook the many clinical experiences that provide just such triggers. Lying still for the duration of a nuchal translucency scan, amniocentesis or other clinical procedure may be physically challenging and painful for women with fibromyalgia. Women have reported to me of being able to feel the scan impulses passing through their abdomen, sensations which they described as 'hot tingling' or as a 'zapping' sensation. Additionally all women with fibromyalgia under the author's care as a midwife have complained that the sensation of a 'full' bladder they needed to have for their nuchal translucency or dating scan was extremely uncomfortable. Several women complained of feeling faint on emptying their bladder and one said that it made her feel sick. Admittedly these reactions are not unheard of in the non-fibromyalgic population but what can be stated with conviction is that these complaints are far more frequent from women with fibromyalgia.

Pellegrino (2005) warned that increased stress will compound the fibromyalgic tendency toward fainting and it could be argued that the anticipation of seeing her baby during an ultrasound scan could increase a woman's stress levels. Unquestionably, health professionals will want to do their best to ensure that women with fibromyalgia have a good experience while under care, but the difficulty lies in how to facilitate this for them. Knowing what triggers affect each individual is the best starting place and from there the midwife can discuss with the professional performing the procedure if there is anyway in which the woman's discomfort can be minimized (UK National Screening Committee, 2007; Nursing and Midwifery Council (NMC), 2008). For example, it may be most

appropriate for the woman to void her bladder slightly or be encouraged to move prior to the commencement of the invasive portion of the amniocentesis.

Health professionals need to be alert for signs of depression and anxiety beyond levels that are usually experienced by the woman. Mood disturbances are common although antidepressants are often prescribed to aid the onset of restorative sleep rather than for the treatment of depression in every case.

## Labour

A literature review demonstrated that the most commonly held belief about fibromyalgia is that it is a disorder which amplifies pain (Fregni et al, 2006; Longley, 2006; Marinus, 2006). However Starlanyl (2003) suggests that some women may experience a temporary remission of their fibromyalgia symptoms for the duration of their pregnancy and the author has seen evidence of this in the women she has encountered. In the author's experience, women with fibromyalgia seem to have higher pain thresholds during labour than women without fibromyalgia. This may be due to them having built up a certain amount of tolerance to pain through living with fibromyalgia. Having a warm room and space to mobilize seem particularly pertinent in relation to increasing the fibromyalgic women's ability to tolerate the pain associated with labour. Mobility is vital to women with fibromyalgia during labour in order to prevent the discomfort associated with muscle stiffness. Additionally, the ambient room temperature needs to be stable at all times which makes hydrotherapy an ideal option due to the carefully monitored temperature and the added buoyancy provided by the water.

## Postnatal care

Initiating difficult conversations about topics such as depression are important in the care of all postnatal women, but particularly vital for women with fibromyalgia who are thought to be prone to depressive episodes (Dell, 2007). The midwife will need to discuss postnatal depression as early as possible, preferably at least once in the antenatal period and broach the topic of postnatal depression early on in the postnatal period in an attempt to facilitate disclosure from the woman about her emotional wellbeing (Silverman et al, 2005). The midwife also needs to encourage her client to see her GP for a medication review within the first few days after the birth of her baby. Preparation and planning during pregnancy is necessary in order for the fibromyalgic woman and her family to be organized. She is likely to physically recover from

*Lack of restorative sleep, which is required to promote physical and emotional recuperation, is a common complaint among new mothers.*

the birth slower than her non-fibromyalgic peer group. It may be necessary to double-up on baby supplies so that there is a stock on each floor of the house and the new mother does not need to climb the stairs to the nursery countless times per day. Careful consideration will need to be undertaken in order to ensure that the woman has the support she needs to cope with the demands of the new baby after her partner returns to work. The lack of sleep may also have a stronger impact than usually seen in postnatal women, due to the fact that these women already struggle with periods of non-restorative sleep. If she is being treated with antidepressants in order to encourage periods of restful sleep, then assurance will have to be sought that she can be roused from her slumber when her new baby needs attention.

The woman may struggle to maintain one position during a long infant-feeding session or suffer the after effects of doing so. The list is virtually endless and the named care giver can only provide advice on ways in which the woman and her partner may cope with these issues. Signposting these families to support groups and other facilities where help is available will be invaluable. Their pain medications and antidepressants may need reviewing depending on how they react postnatally and whether they are contraindicated with breastfeeding. Being organized is the key to coping for many of these women due to the dysfunction discussed earlier. A simple list may make each day flow smoother and provide a means of recognizing their achievements during a time when their life may seem a little overwhelming.

## Conclusions

Fibromyalgia is a condition which affects the whole person. Along with the physiological effects which can vary widely from woman to woman and from the pre-conceptual to postnatal periods, the negative impact of the cognitive dysfunction must also be addressed. Very little is known about the best ways in which to ensure that the maternity experience is holistic for women with fibromyalgia. Innovative, individualized, multiprofessional care remains the ideal way to currently ensure their needs are met. Unfortunately, in these modern times in a resource-challenged NHS, this is an ideal rather than the norm. Without local targeted support groups to which these women can be signposted, ideal care is a long way from being achieved for the majority of women with fibromyalgia.

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