Access and utilisation of maternity care for disabled women who experience domestic abuse: a systematic review

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Abstract

Background
Although disabled women are significantly more likely to experience domestic abuse during pregnancy than non-disabled women, very little is known about how maternity care access and utilisation is affected by the co-existence of disability and domestic abuse. This systematic review of the literature explored how domestic abuse impacts upon disabled women’s access to maternity services.

Methods
Eleven articles were identified through a search of six electronic databases and data were analysed to identify: the factors that facilitate or compromise access to care; the consequences of inadequate care for pregnant women’s health and wellbeing; and the effectiveness of existing strategies for improvement.

Results
Findings indicate that a mental health diagnosis, poor relationships with health professionals and environmental barriers can compromise women’s utilisation of maternity services. Domestic abuse can both compromise, and catalyse, access to services and social support is a positive factor when accessing care. Delayed and inadequate care has adverse effects on women’s physical and psychological health, however further research is required to fully explore the nature and extent of these consequences. Only one study identified strategies currently being used to improve access to services for disabled women experiencing abuse.

Conclusions
Based upon the barriers and facilitators identified within the review, we suggest that future strategies for improvement should focus on: understanding women’s reasons for accessing care; fostering positive relationships; being women centred; promoting environmental accessibility; and improving the strength of the evidence base.

Keywords:
disability; domestic abuse; pregnancy; maternity; access; utilisation; review
Background

Domestic abuse during pregnancy has such negative consequences for maternal and infant health that the World Health Organization has declared it a significant global concern [1]. More than 30% of domestic abuse begins during pregnancy [2,3] and there is evidence to suggest that pre-existing abuse may escalate during the prenatal period [4-6]. Although 10% of women giving birth in the United Kingdom (UK) are reported to have some degree of disability, there is little understanding of disabled women’s experiences of domestic abuse during pregnancy. Disabled women in general are two times more likely to suffer physical abuse from an intimate partner than non-disabled women [7], and it is therefore likely that disabled women may be particularly vulnerable to pregnancy-related abuse. Nixon [8] has suggested that disabled women who experience domestic abuse face compound oppressions. Several studies have linked domestic abuse with adverse maternal and infant outcomes [9-13]. Potentially compounding these negative consequences, certain disabled women may be more susceptible to pregnancy complications than non-disabled women [14,15]. Moreover, studies have suggested that abused women delay accessing maternity services until the third trimester [16-18] and that disabled women are also likely to have delayed or suboptimal access to healthcare [14,19,20].

Disability and domestic abuse during pregnancy may therefore have compounding effects on women’s access to and utilisation of maternity services, placing them at increased risk of undetected pregnancy complications. As yet, however, there is little understanding of the relationship between disability, domestic abuse and access to maternity care. Previous research in the UK [21,22] and the
United States (USA) [23,24] has provided some insight into disability and domestic abuse more generally, however little is known about how domestic abuse impacts upon disabled women’s access to and use of maternity care. Until there is a good understanding of the factors that compromise or facilitate disabled women’s access and utilisation of maternity services when they experience domestic abuse, the priority areas for improving access and utilisation remain elusive. The purpose of this systematic review was therefore to explore the antecedents and consequences of inadequate access to maternity care when disability and domestic abuse co-exist. By summarising and synthesising the literature relating to disability, domestic abuse and access to maternity care, the review supports the future development of robust improvement strategies and highlights key directions for future research.

**Methods**

Although typically associated with reviews of randomised controlled trials, it is now recognised that the standard approach to systematic reviews can be adopted for different questions and study designs [25]. Our systematic review addressed the following questions in relation to disabled women experiencing domestic abuse:

1. What are the barriers that compromise access to and utilisation of maternity services?

2. What are the facilitators to accessing and utilising such services?

3. What are the consequences of inappropriate and/or delayed access to maternity care for women’s reproductive health and wellbeing?

4. How effective are existing strategies to enhance access and utilisation of maternity services?
Key definitions

Domestic abuse, also referred to as domestic violence, intimate partner violence or violence against women, is defined by WHO as “physical, sexual or mental harm or suffering [caused] to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life” [26]. This systematic review forms part of a larger study of the relationship between domestic abuse, disability and access to maternity care in the UK and therefore, for the purposes of the review, the WHO definition is supplemented by the UK policy definition of domestic abuse: “any incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse between those aged 16 or over who are or have been intimate partners or family members regardless of gender or sexuality” [27]. This includes psychological, physical, sexual, financial and emotional abuse. Generally within the UK, the term ‘abuse’ is preferred over ‘violence’ because this most adequately captures the range of abusive behaviours extending beyond physical abuse.

We used the term ‘disabled’ as defined by the United Nations to refer to any person with “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” [28]. This definition is supplemented by the UK Government Equality Act [29], where ‘long term’ refers to a health condition or impairment which lasts longer than 12 months, or is likely to reoccur within 12 months. The term ‘disabled women’ is preferred to ‘women with disabilities’ as this reflects the social model of disability, which contends that people have impairments
but are disabled by social factors [21]. The definitions of disability and domestic abuse were intentionally broad in order to increase the sensitivity of the literature search and ensure that there were a sufficient number of articles to review. ‘Maternity care’ relates to maternity care of any kind, including primary and/or secondary care, pre and post-natal care, and private, voluntary or state funded services. ‘Access’ to services is defined as having the opportunity to use maternity services, whilst ‘utilisation’ refers to the actual or realised use of services [30].

Search Strategy

A systematic approach was adopted in order to minimise bias and reduce the risk of errors or omissions [31]. To access data about the health, social and psychological dimensions of the review questions, six electronic databases were searched, encompassing literature from 1946 to 2013 (Medline, Embase, Cinahl, ASSIA, SSCI, and PsycINFO). For pragmatic reasons, the search was limited to English language titles. To ensure that the search strategy was sensitive to a broad scope of literature, no other limits or filters were applied. It was anticipated that studies may be indexed under either ‘disability’ or ‘domestic abuse’ and so, to avoid missing relevant data, ‘maternity’ and ‘disability, and ‘maternity’ and ‘domestic abuse’ were searched separately before combining the results. Table 1 summarises the basic search architecture. Search strings were created in each category, using a combination of subject headings and key words. Multiple synonyms and related terms were used, for example ‘domestic violence’, ‘intimate partner violence’ etc. These are demonstrated in Table 2, which shows the search process used in Medline and Embase.
The electronic database search yielded 6007 potentially relevant articles. Additionally, a hand search of main journals in the field yielded 162 potentially relevant articles. A total of 6169 abstracts were therefore screened for inclusion. All titles and abstracts were screened against the inclusion criteria by four pairs of independent reviewers (n=8). Abstracts were included for review on the basis of the inclusion and exclusion criteria presented in Table 3. If it was unclear from the abstract whether or not a paper met all four inclusion criteria, it was taken forward to the next stage of screening.

Selection
Forty-nine full text articles were screened for eligibility against the inclusion criteria. All articles were read in full by the first author and then reviewed independently by other members of the team to moderate the screening process (each member of the team read 7 full text articles). As recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (www.prisma-statement.org), Figure 1 provides a flow diagram of the full screening process. Nine papers met all four inclusion criteria and were included for review. Although a total of twenty studies included all three key elements (disability, domestic abuse and pregnancy), only nine focused upon access and utilisation of maternity services. Figure 1 documents the reasons for exclusion of the remaining articles. To ensure an exhaustive search and to prevent omissions, Barrosso and colleagues [32] have
recommended that researchers continually evolve their search strategy. A final hand
search was therefore conducted using the reference lists of the nine included papers.
This yielded a further 15 papers of interest, two of which met all four inclusion
criteria after independent review by two authors.

Data extraction and analysis

A standard form was designed to structure the data extraction process, using the
headings: setting; aims; sample; methods; findings; relevance to review questions; and
methodological critique. The first author extracted data from each of the included
studies and tabulated the findings under each heading. Data extraction was double
checked by the rest of the research team and any disagreements were resolved through
discussion. Methodological critique was supported by reference to the Critical
Appraisal Skills Programme (CASP) checklists for observational studies (www.casp-
net.uk). Given that qualitative research is distinctly different to quantitative research,
a different framework was used to support critical appraisal of the qualitative studies
included within the review [33]. The rigid use of checklists has been criticised within
qualitative research and Barbour [34] has argued that appraisal checklists should be
used flexibly and in a manner that is apposite to individual study design. Although we
were guided by Walsh and Downe’s [33] criteria for assessing qualitative studies, we
were more concerned with a global assessment of quality rather than firm adherence
to the checklist. The studies were of varied design and quality, however all were
included in order to capture the broad range of perspectives in this area and permit
reflection on the current quality of the evidence base. This is addressed later in the
paper. Data from all eleven included studies were synthesised by categorising them under the four review questions. Data relating to each of the review questions were then analysed inductively to identify themes and make comparisons across studies.

**Results**

Eleven articles met all four inclusion criteria and are summarised in Table 4. The majority of studies were conducted in the USA (n=6). Two studies were conducted in Brazil, one in India, one in Zambia and one in Australia. Eight studies used quantitative methods, one study used a qualitative approach and two studies utilised both quantitative and qualitative data. Five studies surveyed pregnant women [35-39], three utilised a prospective cohort design [40-42] and a further study tracked pregnant women through police records [43]. One study sought the views of maternity care practitioners only [44], whilst another interviewed both women and practitioners [45]. By identifying barriers and facilitators to accessing and using maternity care, the majority of studies addressed review questions one and two. There are fewer data to support questions three and four regarding the consequences of inadequate maternity care and the effectiveness of current strategies to improve access and utilisation for disabled women who experience abuse. The findings from the review are expounded below, in relation to each of the review questions.

**Barriers that compromise access and utilisation of maternity care**
Eight studies highlighted barriers which compromise access to maternity care [35,37,38,40,41,42,44,45]. The identified barriers related to: mental health diagnosis; poor relationships with health professionals; environmental barriers; domestic abuse.

**Mental health diagnosis**

Three studies hypothesised that mental illness is linked to inadequate maternity care [35,40,41]. In Ferri et al’s [35] study of the interactive effects of violence and mental disorder on maternal health, nearly 30% of their total sample (n=930) received less than the recommended six antenatal appointments. For women with a common mental health disorder (n=226, defined as depression, anxiety, post-traumatic stress disorder, somatoform or dissociative disorder) 25.1% had between one and five antenatal appointments and 14.3% received no antenatal care at all. Interestingly, however, Ferri et al [35] identified similar statistics for women without a mental health disorder who experienced domestic abuse. They have suggested that mental illness and domestic abuse have independent, rather than compounding, effects on access to services. This is similar to the study by Huth-Bocks et al [40] which reported that, although maternal depression was significantly associated with domestic abuse, it did not account for abused women’s later entry into prenatal care. Thus, whilst there is evidence to suggest that a mental health diagnosis can compromise access and utilisation of maternity services for women experiencing domestic abuse, the exact nature of this relationship is unclear.

Kim et al [41] found that current psychiatric diagnosis had no adverse effect on the frequency and timing of antenatal visits; however, they also identified that women with a past psychiatric illness were significantly likely to be non-compliant
with at least 50% of their scheduled antenatal appointments. This suggests that longer
term conditions may present women with greater difficulties in accessing care.
Having assessed psychiatric symptoms at single time points during women’s
pregnancies, Ferri et al [35] and Huth-Bocks et al [40] were not able to account for
the effects of long term mental health issues. Further longitudinal research is therefore
required to more fully understand the impact of a mental health condition on
maternity care access and utilisation. Moreover, all three studies exploring the
relationship between mental health and access to services quantitative methodologies;
while quantitative research can identify associations between certain health conditions
and service utilisation, it cannot necessarily provide a nuanced understanding of how
living with a mental health condition affects when and why women access maternity
care.

Poor relationships with health professionals
Three studies highlighted that negative past healthcare experiences, poor relationships
with health professionals and fear or judgement from staff could compromise
women’s access to services [37,44,45]. In Nosek et al’s [37] survey of women with
physical impairments (n=475), 26% of women lacked confidence in their care
provider and did not believe that their physician was well informed about how their
disability affected their reproductive health. This lack of knowledge often manifested
in women being refused treatment: 31% of participants in Nosek et al’s [37] study
were refused care because of their disability and both Kopac and Fritz [44] and Smith
et al [45] noted that maternity care providers were reticent to provide treatment to
‘high risk’ women. Many disabled women feared that practitioners would condemn
their pregnancies as abnormal, dangerous or wrong [45] and many had been advised
against getting pregnant by healthcare staff [37]. Both Kopac and Fritz [44] and Nosek et al [37] identified that ineffective communication between staff and patients prevented women from getting appropriate reproductive healthcare. Factors influencing poor communication include: professionals’ lack of patience; lack of empathy; and a limited knowledge and understanding of disability issues [44]. Moreover, although very few women in Smith et al’s [45] study of disabled women’s access to maternity care in Zambia actually reported negative experiences with staff, the anticipation in itself was enough to deter women from utilising services.

Environmental Barriers

The physical, geographical and institutional environments in which maternity care occurs can present several barriers to accessing and utilising services. Four studies suggested that maternity care facilities are ill equipped to provide services for disabled women who experience domestic abuse [37,38,44,45]. In a study of 120 pregnant women with spinal cord injury, 56% reported that their local hospital could not accommodate their disability needs when they gave birth [37]. Similar findings emerged in a large nationally representative survey of pregnant women (n=35,248) across India [38]. Of the women experiencing pregnancy related blindness (12%), nearly 60% reported that they were concerned about the quality of maternity services. This presents a significant organisational barrier to accessing care. In Kopac and Fritz’s [44] survey of nurses working in hospitals, community services and physician’s offices across the USA (n=727), 65.5% stated that there was no one in their setting who specialised in working with disabled women (specifically women with intellectual disabilities) and 70% did not have the opportunity to undergo generic
disability training within their organisation. Many services therefore lack the staffing resources to meet the needs of disabled women.

In addition to issues with staffing, organisational and financing policy may also restrict disabled women’s access to care. According to Kopac and Fritz [44], many services choose not to treat women who are insured through Medicaid or Medicare (the social insurance systems in the USA designed to support individuals on low income or those with disabilities). There may also be restrictions within these policies themselves, whereby insurance schemes will not fund certain procedures or cater for the extra time required to carry out examinations when accommodating women with additional needs. Moreover, in countries where social insurance systems do not exist, the financial barriers to accessing maternity care are great, particularly for disabled women [38]. The high cost of transport was highlighted in two studies [38,45] and this was further compounded when women were refused treatment in their local hospital because of their disability and had to find care elsewhere. Women interviewed by Smith et al [45] reported that public transport out of town was too expensive to use frequently. Additionally, public transport was often inaccessible for women with mobility issues, further adding to the existing organisational, political and financial barriers to accessing maternity care.

Physical inaccessibility emerged as a major barrier to the effective utilisation of maternity services and all four studies identified problems with the physical environment [37,38,44,45]. 7% of nurse respondents in Kopac and Fritz’s [44] survey (n=727) found it difficult to arrange examinations for disabled women as a result of inaccessible offices, improper examination tables and inadequate equipment.
Speaking to Nosek et al [37] about her experience of maternity care, one woman was shocked that practitioners were not monitoring her weight: “could you believe that all through my pregnancy … they don’t know how much weight I’ve gained, because they don’t have a wheelchair or sitting scale” (p.22). Unlike Nosek et al’s study [37], Kopac and Fritz’s [44] findings are based only on the experiences of health care providers rather than disabled service users. It is thus possible that problems with physical accessibility are more significant to women than practitioners perceive. Over 26% of the nurses sampled did not respond to the question about barriers to accessing services, perhaps cementing the argument that practitioners may lack knowledge about the unique needs of disabled women.

Domestic abuse

Nunes et al [42], Huth-Bocks et al [40] and Kim et al [41] all concluded that domestic abuse is significantly associated with delayed entry into antenatal care, for women with and without a mental health condition. It could therefore be suggested cautiously that domestic abuse and mental illness have independent effects on service access and utilisation. For women with a physical health condition, however, physical barriers to care can be amplified in the presence of domestic abuse, particularly when women are reliant on their partners for physical assistance and transport to appointments. Many women in Nosek et al’s [37] survey reported that their partner had removed needed mobility devices, withheld transportation or refused to provide personal care. In Pandey et al’s [38] study of pregnancy related blindness in India, blind women were significantly more likely than women without blindness to have controlling husbands and limited autonomy to make decisions about their own healthcare needs. Conversely, women who were empowered to make their own decisions had more
positive health outcomes [38]. For women with physical and sensory impairments, then, the effects of domestic abuse may compound existing barriers to their access and utilisation of maternity care. Further studies are therefore required to explicate the relationship between domestic abuse and different types of disability more fully.

Factors that facilitate access and utilisation of maternity care

Six studies identified enabling factors that could facilitate potential and realised access to maternity services [37,38,39,40,41,43]. Typically, the factors that facilitated access and utilisation of services were direct opposites of the barriers identified above; for example, good relationships with staff or physical accessibility etc. Two additional factors were also identified as having the potential to directly increase access and utilisation of services: 1. women requiring access to health services as consequence of physical abuse; 2. women being encouraged and supported to access services by friends and family.

Health consequences of domestic abuse

Although domestic abuse has been identified as a barrier to accessing services, three studies identified that the health consequences of domestic abuse could actually prompt women to access services more quickly or utilise services more frequently [39,40,43]. Particularly within the context of domestic abuse, women experiencing physical violence during pregnancy are more likely than non-abused women to be hospitalised because of physical injuries [43]. Huth-Bocks et al [40] reported that abused women had longer stays in hospital, visited the emergency room more frequently and had a higher number of visits to their doctor for the infant during the postnatal period than non-abused women. Similarly, in a study of the effects of abuse
on maternal and infant outcomes, Webster et al [39] found that abused women had a significantly higher number of pregnancy-related hospital admissions than non-abused women.

It is suggested therefore that the consequences of domestic abuse on women’s physical health can amplify the need to utilise services during pregnancy. Even when women face existing barriers to care, such as the effects of a long term mental health condition, barriers may be overridden by necessity and immediate treatment needs which catalyse health service use. During pregnancy, women’s sense of necessity may be heightened and domestic abuse may cause women to worry more about the health of the baby than their own health and well-being [40]. Of course, ‘necessity’ is a subjective concept and women will interpret and respond to their current health issues in different ways. Although women may be forced into accessing services because of immediate treatment needs [43], they may also make judgments about the importance of maternity care prior to accessing services. The impact of women’s decision making, and their actual and perceived need for treatment, are discussed later in the paper.

**Social support**

It is well established in the general domestic abuse literature that social support facilitates improved access and utilisation of maternity services. Huth-Bocks et al [40] identified that, for women with mental health issues attending hospital and community based prenatal care (n=202), social support moderated between severe domestic violence and negative maternal health outcomes. By facilitating earlier access to services for women experiencing domestic abuse, positive social
relationships in turn resulted in improved health outcomes. Disabled women who experience domestic abuse, however, are likely to have small support networks, meaning that they miss out on social support as a protective factor [39]. Moreover, not all social relationships are supportive. Women may fear the judgment of others in the community and Smith et al [45] reported that disabled women attending maternity clinics were subjected to gossip and stereotyping by other non-disabled women in the waiting room. Relationships therefore have a critical role in supporting women’s utilisation of maternity care, however, disabled women who experience domestic abuse are less likely to experience positive relationships and social relationships may actually compromise, rather than facilitate, access to care. Thus, whilst social support has the potential to facilitate access and utilisation of maternity services, greater attention is needed to opening up this support to disabled women. Opportunities for capitalising on social support are discussed later.

Consequences of delayed or inappropriate maternity care on women’s health and wellbeing

Physical and psychological consequences of inadequate care were documented equally within the review papers: three studies identified direct consequences for women’s physical health [35,38,42] and three studies reported on the emotional consequences of inadequate care [37,38,39]. In Pandey et al’s [38] comprehensive study of pregnant women throughout India (n=35,248), only 37% achieved the WHO recommended minimum of four prenatal visits. Even after controlling for other risk factors, women who were concerned about the distance, cost and quality of maternity services were significantly more likely to develop blindness during pregnancy than women with satisfactory access to care. Under-utilisation of maternity services has
also been linked to insufficient pregnancy weight gain [42] and infants with low birth
weight [35]. Both Nunes et al [42] and Ferri et al [35] focused predominantly on
infant outcomes, giving only a limited insight into the direct consequences of
inadequate care on maternal health. However, infant outcomes may be a telling
reflection of maternal wellbeing. In relation to the emotional and psychological
consequences of inadequate maternity care, Webster et al [39] reported that women
with fewer prenatal visits had more depressive symptoms than women who had
adequate prenatal care. Women’s emotional wellbeing may also be compromised
when they have limited involvement in making decisions about their own health
[37,38].

Failure to recognise domestic abuse within maternity services was highlighted
as risky to maternal and infant health and authors have raised concerns about the
potentially negative consequences if domestic abuse is not sufficiently addressed
[44,38]. While Mitra et al [36] reported that practitioners were equally likely to ask
disabled women about domestic abuse as non-disabled women, Kopac and Fritz [44]
uncovered a lack of attention to disabled women’s experiences of domestic abuse
within gynaecological and reproductive health services. The contrasting findings may
be attributable to different samples within both studies: Kopac and Fritz [44] focused
explicitly on women with developmental disabilities and may therefore have
encountered more communication difficulties. Alternatively, Mitra et al’s [36] study
is more recent and may reflect the greater awareness of domestic abuse within current
policy and practice. Despite identifying adequate screening practices, Mitra et al [36]
were not able to ascertain whether disabled women received appropriate referrals to
domestic abuse agencies following disclosure. This is an important consideration,
given Nosek et al.’s [37] finding that disabled women face serious barriers to accessing existing programs that help women remove violence from their lives. Preventing negative consequences for women’s health and wellbeing therefore goes beyond issues of the quantity and timing of prenatal care. Services must understand the unique contexts in which women live; without due consideration of the social factors influencing women’s health and wellbeing, inappropriate maternity care may be inconsequential or further compound negative health outcomes.

Strategies for improving access and utilisation of maternity services for disabled women who experience domestic abuse

Only one study identified strategies used by maternity services to improve disabled women’s access to and utilisation of care. The safe motherhood and reproductive health services featured in Smith et al.’s [45] study aimed to improve access for disabled women by minimising the effects of poverty and stigma. To make services more financially accessible, family planning, antenatal and postnatal care were provided free of charge. This did not address additional costs, however, such as prescription charges or the cost of transportation. Similarly, the authors concluded that, while attempts to tackle stigma may have been well meaning, they had limited effectiveness. As a means of protecting disabled women from gossip or being stared at by other patients, disabled women were either referred to a hospital outside their own community or were treated quickly and discretely within local clinics. ‘Sheltering’ disabled women from stigma in this way, however, may serve only to reinforce negative stereotypes that pregnancy is abnormal or dangerous for disabled women; entrenching rather than removing stigma as a barrier to accessing care. While Smith et al [45] identified that many of the disabled women accessing these services
had experienced abuse in the form of sexual exploitation, their study did not explore whether or not this had an effect on women’s access to care and how it was addressed by maternity care practitioners. The evidence behind strategies for supporting disabled women’s access to maternity care when they experience domestic abuse is therefore very limited.

Discussion

This systematic review set out to identify the factors that facilitate or compromise maternity care access and utilisation for disabled women experiencing domestic abuse. It showed that access to maternity care is influenced by multiple factors, including mental health issues, the effects of domestic abuse, social and professional relationships and the environment in which services are delivered. These barriers are consistent with studies of domestic abuse and pregnancy [46,47], and disability and pregnancy [14,19], which have independently explored the reasons for delayed prenatal care in both groups of women. To the best of our knowledge, this is the only review to date that explores the antecedents and consequences of inadequate maternity care when disability and domestic abuse co-exist. The majority of studies included in the review focused upon the factors that compromise access, suggesting that more is known about why women do not access care than about the potential negative consequences of inadequate care or how to improve access and utilisation. A stark finding was that only one study documented strategies for overcoming these barriers to accessing care. On the basis of the review findings, we suggest that future research, policy and practice give further consideration to: understanding women’s reasons for accessing care; fostering positive relationships as a means to accessing
Understanding women’s reasons for accessing care

Several factors impact upon women’s utilisation of maternity services and it is permissible to draw conclusions about women’s access to care based upon the presence of certain barriers in their lives. It is important to remember, however, that each woman is an individual and will ultimately respond to barriers in different ways. Fundamentally, individuals must recognise a need for healthcare before actually using services; they must deem “their problems to be of sufficient importance and magnitude to seek professional help” [30 p.3]. Our review identified that domestic abuse can create or exacerbate an immediate health need which makes health service utilisation unavoidable, for example a serious physical injury requiring medical attention [43]. While this may create an opportunity for women to receive needed prenatal care, full and effective utilisation of services can only be realised if healthcare staff identify a pregnancy-related treatment need and respond with appropriate referrals. Moreover, by the time women access services out of necessity it may be too late to prevent negative consequences for maternal and infant health. Evidence also suggests that the majority of domestic abuse takes the form of psychological abuse, coercion and control [48] and therefore the consequences of abuse may not always demand immediate medical attention. Even in the absence of biological imperative, women make judgments about the necessity of accessing routine services [30]. Our review found that the difficulties associated with travel and the fear of negative attitudes from staff often outweighed ...
the perceived benefits of attending antenatal appointments [37,38,44,45]. Finlayson and Downe [49], in a metasynthesis of studies exploring why women in general do not use antenatal services in low and middle income countries, also identified that women continually weigh up their own priorities and beliefs against the expectation that they utilise care. Andersen [30] has differentiated this from the ‘actual need’ discussed above and women’s ‘perceived need’ for service utilisation. As a social phenomenon, the ‘need’ to seek professional healthcare is subjective and will be rationalised or exaggerated by outside factors. For example, social support was identified as having a positive effect on access to maternity care for women with severe levels of abuse, but not for those with lower levels of abuse [40]. This is perhaps because, for women with high levels of abuse, friends and family may stress the potential for negative consequences and emphasise the importance of accessing care. Conversely, for women experiencing low levels of abuse, social support may be seen as a replacement for professional input and women’s perceived need for maternity services may be smaller. To ensure future strategies for improving access to maternity care are effective, further research is required to understand women’s decision making processes more fully, particularly in the context of disability and domestic abuse where autonomous decision making may be restricted.

Fostering positive relationships as a means to accessing care

Relationships have a critical influence on women’s utilisation of maternity care [37,38,39,40,41,42,44,45]. Poor relationships with maternity care practitioners in the past deter women from utilising services again [37,44]. Even when women have had no previous negative experiences, the anticipation alone makes women reticent to attend appointments [45]. Although Finlayson and Downe’s [49] metasynthesis of
maternity care utilisation shared some similar findings with this review, they did not focus specifically on domestic abuse or disability. Therefore, where Finlayson and Downe [49] reported that women were reluctant to seek professional help for what is considered to be a ‘normal life event’, our review revealed that disabled women may be told repeatedly that their pregnancies are ‘abnormal’. This suggests that the internalisation of stigma and societal misconceptions can have a considerable impact on women’s perceived need for care and their willingness to use services. Walsh-Gallagher and colleagues [50] have warned maternity care practitioners against classifying all disabled pregnant women as ‘high risk’. Instead, professionals must establish positive, non-judgmental relationships with women and in so doing, change women’s negative perceptions of maternity care which are often a barrier to seeking help.

The extent to which maternity care practitioners are aware of the complexities arising from the combination of disability and domestic abuse remains unclear. Two studies recommended that maternity staff should receive additional education [37,44] and a further seven studies suggested that practitioners should know how to identify and respond to domestic abuse [35,36,39,40,42,43,45]. The need for increased practitioner knowledge and the provision of training is supported by other literature [51] and international policy and strategy documents [52]. According to WHO [26], current training interventions are targeted typically at the identification of domestic abuse, without adequate training in further care or how to change judgmental attitudes and cultural stereotypes. Effective prenatal care relies not only upon early access to services but also the continued utilisation of services. In the first appointment, practitioners have only a short window of time in which to develop a positive
relationship with women and encourage women to return for follow up appointments.

Further research, piloting and evaluation is required in order to develop effective staff training and, although it is beyond the scope of this paper to make specific recommendations about what staff education should entail, it could draw upon the key principles underlying positive practitioner-patient relationships identified within the review: effective communication, non-judgmental attitudes and encouraging active involvement in the treatment process.

Studies have shown that social relationships can have a positive or negative effect on women’s decisions to utilise maternity care [38,39,40,41,42,45]. Social support can promote early and continued utilisation of services; however disabled women may lack strong social support networks, particularly when they experience domestic abuse [53]. Fostering positive relationships within the community is therefore essential and improving access to maternity care cannot be achieved by addressing internal service barriers alone. Outward looking improvement strategies could capitalise on social support as a resource and involve colleagues in community education and health promotion. In an earlier study of access to gynaecological services for women with developmental disabilities, Kopac and colleagues [51] identified that support staff and formal carers have a key role in prompting women to attend services and accompanying them to appointments. Formal support is therefore also available within the community and by developing positive relationships with other services and ensuring that agencies are well informed about the importance of early prenatal care, improved access to maternity care may be achieved through multidisciplinary collaboration.
Being women centred

Delayed prenatal care and infrequent utilisation of maternity services have negative consequences for women’s physical and psychological health and wellbeing [35,37,38,39,42]. Optimal access to maternity care, however, extends beyond the timing and frequency of antenatal appointments. Services must also support women to make autonomous and informed choices about their maternity journeys [37,38]. Although WHO [26] promote women’s active involvement in their care, our review suggests that this is not being actualised for disabled women who experience domestic abuse. Good ‘access’ to maternity care must be both physical and cognitive [54].

While ‘physical’ access refers to women’s physical presence at appointments, ‘cognitive’ access implies that women have understood the information given and that her needs have been fully understood by the health practitioner. Even when physical barriers to accessing services have been removed, women may still experience restricted access to services if they are not fully engaged in the process. Services must therefore be women centred and based on sound communication. Adequate access to maternity care, then, relies upon the quantity and quality of service provision.

Promoting environmental accessibility

For disabled women, physical access may be a significant issue in itself and several studies identified problems with environmental accessibility [37,38,44,45]. To promote optimum access to maternity care, improvement strategies must tackle the physical, geographical, social, financial, organisational and political barriers facing disabled women who experience domestic abuse. Recent guidelines [26] reflect the need to address these barriers, however further work is needed in order to develop...
operational improvement strategies. Care providers must have ample and adequate facilities and equipment to support disabled women [26,37,44]. At an organisational level, policies should support access to maternity services for disabled women experiencing domestic abuse and should not stymie women’s opportunities for referrals to additional services [52]. Simply asking about domestic abuse does not necessarily create the opportunity for women to receive more effective care and practitioners must have the knowledge and resources to provide appropriate support [55]. In the UK, where this review was undertaken, the Royal College of Nursing [56] and Royal College of Midwives [57] have each produced guidelines on pregnancy and disability which emphasise that health professionals should be aware of how a woman’s impairment will affect her pregnancy, and how the pregnancy might in turn affect her health. These guidelines do not, however, mention anything about how to support disabled women who experience domestic abuse during their pregnancy. Given that nearly 50% of disabled women giving birth in the UK experience domestic abuse [15], it is essential that policy and organisational guidelines support practitioners to accommodate these issues and improve women’s access to adequate care.

External barriers to care, such as the cost and availability of transport, the provision of social insurance and the economic climate, remain a bigger challenge and are generally outside the control of individual maternity services. While services themselves cannot necessarily remove all of these barriers, any strategies for improving access and utilisation must match the structural, economic and cultural contexts in which people live. This is exemplified in the study by Smith et al [45], where providing services free of charge had limited effectiveness when transport was
inaccessible and prescription charges were too expensive. In addition to providing
‘core’ maternity services, the Global Action Report on Preterm Birth [52] has
recommended that social and financial support be integrated within routine antenatal
care. Service developments such as this would need to be based on the best evidence
and future research should be directed at identifying, honing and evaluating the most
effective models of antenatal service delivery. It should be cautioned, however, that
the nature of the social and financial barriers facing women may be different in the
context of both disability and domestic abuse, potentially influencing the nature and
scope of subsequent interventions. Further empirical research is therefore needed in
order to identify specifically the most effective ways of supporting disabled women to
overcome environmental barriers to maternity care when they are compounded by the
effects of abuse.

**Improving the strength of the evidence base**

This review has provided some new insights into the complex relationship between
disability, domestic abuse and access to maternity care, although empirical studies are
lacking. To ensure that improvement strategies are effective, they must be rooted in a
strong evidence base. Reflecting on the methodological strengths and shortcomings of
the studies included in this review, we recommend that research regarding the effects
of domestic abuse on disabled women’s access to maternity care should be more
visible, more consistent and more methodologically varied.

**Increased visibility**

Empirical studies of the relationship between disability, domestic abuse and
pregnancy are difficult to locate because the literature is compartmentalised, with
studies either: investigating the consequences of domestic abuse during pregnancy; exploring disabled women’s experiences of domestic abuse; or identifying pregnancy risks for disabled women. Data about the relationship between disability, domestic abuse and maternity care is also ‘hidden’ within broader studies; only two studies included in the review referenced these three elements explicitly in their titles [35,36]. Instead, studies either focused predominantly on disability with a minimal focus on domestic abuse [37,38,41,44,45], or focused predominantly on domestic abuse with limited attention to disability [39,40,42,43]. As a result, narrow search strategies may miss critical findings when studies are indexed either under disability or domestic abuse. Furthermore, findings about disability, domestic abuse and access to maternity care may be incidental For example, Webster et al [39] intended to explore the effects of domestic abuse during pregnancy and also identified a high incidence of epilepsy and asthma within their sample, making their findings relevant to our review. Empirical studies which address this complex relationship explicitly are therefore essential to strengthening the evidence base and facilitating meaningful conclusions across studies.

Increased consistency

Each study took different perspectives on ‘domestic abuse’, with some offering specific definitions differentiated by type and severity [39] and assessed by standardised domestic abuse measures [35,40,42]. Conversely, other studies used very broad definitions: Nosek et al [37] did not specify different types of abuse although noted that abuse was predominantly perpetrated by a husband or intimate partner; Kopac and Fritz [44] did not differentiate between partner abuse and abuse by family members or strangers; Smith et al [45] stated only that women had experienced
“sexual exploitation”; and Kim et al [41] did not provide a definition or state how abuse was identified. These differences ultimately affect the quality of the studies and compromise the confidence with which conclusions can be drawn about the effects of domestic abuse on access to maternity care. Both Mitra et al [36] and Lipsky et al [43] focused only on physical abuse, although the police reported incidents featured in Lipsky et al [43] may have been more severe than Mitra et al’s [36] study of mild to moderate abuse. Pandey et al [38] asked women about humiliation, control and physical abuse, although their findings were hampered by a large amount of missing data. Women were also asked about domestic abuse experiences at different times, meaning incidents of domestic abuse during pregnancy may have gone unreported.

Moreover, six studies sampled women who were already attending maternity services, meaning that women with no access to services, who were perhaps affected most severely by the consequences of disability and domestic abuse, were not represented within these studies [35,39,40,41,42,45].

Disability was similarly represented inconsistently across all eleven studies. Study samples were typically polarised between women with physical health conditions [37,39,45] and those with mental health issues [35,40,41,42,43]. Mitra et al [36] asked participants to self-identify if they had “physical, mental, or emotional problems” (p.803) but did not differentiate between these disability categories in their analysis. With the exception of Kopac and Fritz [44] and Pandey et al [38], women with sensory impairments or learning disabilities were under-represented in the review.

This limits the transferability of the review findings to these groups. Other than one study which reported that abusive partners directly prevented women’s access to care [37], all of the studies that identified barriers to maternity care were typically focused
on the effects of disability, rather than the effects of abuse. This perhaps indicates that
disability-related access problems have a greater impact on women’s access to care
than domestic abuse. The evidence is still very limited, however, and more research is
needed to explore the non-disability barriers for disabled women, particularly the
effects of abusive partner behaviour. Furthermore, ‘disabled women’ are not a
homogenous group and future research should continue to differentiate between
different types of disability in order to more fully understand women’s experiences.

Increased variation

The majority of studies used quantitative methods and while such approaches can
indicate associations between disability status, domestic abuse and prenatal care
utilisation, more qualitative research should supplement the evidence base to explicate
the complex nature of the barriers facing disabled women. When considering the
interplay between disability and domestic abuse, the challenge for researchers is in
disentangling cause and effect; it is difficult to differentiate the independent or
compounding effects of disability and domestic abuse when they are complexly and
insidiously intertwined. It is important therefore that future research explore in more
detail how women are affected by impairment related barriers, barriers associated
with domestic abuse, and how these impact upon one another. While the barriers
facing women with physical impairments have been considered from a qualitative
perspective, studies about how mental illness impacts on access to maternity care
have all been quantitative. Qualitative research may reveal connections that have not
become evident in quantitative data. Further quantitative research is also necessary,
and in contrast to Nunes et al [42], Huth-Bocks et al [40] and Ferri et al [35], studies
should explore the effects of long term mental health conditions on access to
maternity care when accompanied by domestic abuse.

Limitations

This review was based on eleven studies of varying quality and the limitations of
individual studies have been discussed. The studies originated in the USA, Australia,
Brazil, Zambia and India, potentially limiting the transferability of the review findings
to other countries, including the UK where this review was undertaken. Service
delivery in each of these countries occurs within different economic, cultural and
political contexts, rendering meaningful comparison across studies more difficult.
Similarly, it is difficult to make comparisons across studies which focus on different
impairments; for example, women with a visual impairment may experience
significantly different barriers to women with anxiety disorder. However, given the
paucity of literature relating to disability, domestic abuse and access to maternity care,
it would not have been feasible to narrow the focus of this review to a specific type of
impairment. Instead, this review lays the foundation for future research by
highlighting some of the general barriers and facilitators associated with disabled
women’s access to maternity care when they experience domestic abuse.

The search strategy employed was flexible and sensitive to finding ‘hidden’
data about the relationship between disability, domestic abuse and access to maternity
care. The search was limited to English language papers for pragmatic reasons but,
given the international spread of the included studies, it may have been prudent to
include non-English language papers. This is recommended as a future priority for
reviews on this topic. While review questions one and two were addressed fully, the
A review found limited information about the consequences of inadequate maternity care and strategies for improving access to services. Including non-English language papers may have yielded more data to address questions three and four.

Conclusions

While this review has gone some way to understanding how the coexistence of disability and domestic abuse might impact upon maternity care utilisation, there is still a limited understanding of the antecedent factors that prevent disabled women from accessing needed maternity services because of abusive partner behaviour. The review confirms that disability and domestic abuse both affect women’s access to maternity care, although methodological complexities make it difficult to draw conclusions about the extent to which these have a compounding effect. The timing and frequency of prenatal appointments is determined by multiple personal, social, organisational and environmental factors. To achieve optimum access to maternity services for disabled women experiencing domestic abuse this review has made recommendations in relation to: understanding women’s reasons for accessing care; fostering positive relationships; being women centred; promoting environmental accessibility; and improving the strength of the evidence base. In addition to exploring the antecedents and consequences of domestic abuse for disabled women, future research must now actively explore potential solutions and develop robust strategies for improving access and utilisation of maternity services for this group. Priorities for future research, policy and practice are summarised in Table 5.
Authors' contributions

JPB carried out literature searching, co-ordinated and participated in screening, data extraction, data analysis and drafted the manuscript. CBJ conceived of the study, contributed to screening, data extraction, data analysis and helped to draft the manuscript. JD, TK, AL and JT participated in screening, data extraction, data analysis and provided feedback on drafts of the paper. All authors read and approved the final manuscript.

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Dr Steve MacGillivray, Senior Lecturer in Evidence Synthesis at the University of Dundee, who provided guidance on the systematic review procedure and helped with database searching and data extraction.

Fiona Duncan, Gender Based Violence Nurse Advisor at NHS Fife, who assisted with screening and appraising papers for inclusion in the review.

Competing Interests

The authors declare that they have no competing interests.

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Figures

Figure 1 - Flow diagram of screening process
(submitted as an additional file)

Tables

Table 1 - Search Strategy

<table>
<thead>
<tr>
<th>Table 1. Search Strategy</th>
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</thead>
<tbody>
<tr>
<td>1. Maternity</td>
</tr>
<tr>
<td>2. Disability</td>
</tr>
<tr>
<td>3. Domestic abuse</td>
</tr>
<tr>
<td>4. 1 and 2</td>
</tr>
<tr>
<td>5. 1 and 3</td>
</tr>
<tr>
<td>6. 4 or 5</td>
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</tbody>
</table>

Table 2 - Search strings used in Medline and Embase showing the number of results

<table>
<thead>
<tr>
<th>Table 2. Search strings used in Medline and Embase showing the number of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 exp Pregnancy/ (1278454)</td>
</tr>
<tr>
<td>2 exp Delivery, Obstetric/ (171535)</td>
</tr>
<tr>
<td>3 exp Hospitals, Maternity/ (581882)</td>
</tr>
<tr>
<td>4 exp Prenatal Care/ (124304)</td>
</tr>
<tr>
<td>5 exp Maternal Welfare/ (15097)</td>
</tr>
<tr>
<td>6 exp Obstetrics/ (43092)</td>
</tr>
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<td>7 exp Maternal Health Services/ (3212805)</td>
</tr>
<tr>
<td>8 exp Cesarean Section/ (89704)</td>
</tr>
<tr>
<td>9 exp Intensive Care, Neonatal/ (21892)</td>
</tr>
<tr>
<td>10 exp Neonatal Nursing/ (5932)</td>
</tr>
<tr>
<td>11 exp Neonatal Screening/ (17455)</td>
</tr>
<tr>
<td>12 exp Intensive Care Units, Neonatal/ (26699)</td>
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<tr>
<td>13 exp Prenatal Care/ (124304)</td>
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<tr>
<td>14 exp Prenatal Diagnosis/ (135024)</td>
</tr>
<tr>
<td>15 exp Prenatal Exposure Delayed Effects/ (33559)</td>
</tr>
<tr>
<td>16 exp Postnatal Care/ (73898)</td>
</tr>
<tr>
<td>17 exp Postpartum Period/ (85052)</td>
</tr>
<tr>
<td>18 exp Perinatal Care/ (39445)</td>
</tr>
<tr>
<td>19 exp Midwifery/ (34107)</td>
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<tr>
<td>20 exp Pregnant Women/ (28930)</td>
</tr>
<tr>
<td>21 exp Family Planning Services/ (54434)</td>
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</tbody>
</table>
Table 3 – Inclusion and Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion:</th>
<th>Exclusion:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presents empirical data (either qualitative or quantitative)</td>
<td>No empirical data presented</td>
</tr>
<tr>
<td>Focuses on or includes maternity care access and utilisation</td>
<td>Does not focus on access and utilisation of maternity or related primary care services</td>
</tr>
<tr>
<td>Focuses on or includes disabled women</td>
<td></td>
</tr>
<tr>
<td>Focuses on or includes domestic abuse</td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Inclusion and Exclusion Criteria

Inclusion:
- Presents empirical data (either qualitative or quantitative)
- Focuses on or includes maternity care access and utilisation
- Focuses on or includes disabled women
- Focuses on or includes domestic abuse

Exclusion:
- No empirical data presented
- Does not focus on access and utilisation of maternity or related primary care services
### Table 4 - Summary of articles included in the review

Table 4. Summary of articles included in the review

<table>
<thead>
<tr>
<th>Focuses on men only</th>
<th>Focuses solely on child abuse (under 16 years), elder abuse, abuse by formal carers or abuse that occurred outside a pre-existing intimate or familial relationship</th>
<th>Focuses solely on pregnancy outcomes and complications that are not associated with domestic abuse or issues of access and utilisation</th>
</tr>
</thead>
</table>

### Table 5 - Future priorities for research, policy and practice

Table 5. Future priorities for research, policy and practice

<table>
<thead>
<tr>
<th>Research</th>
<th>Explore the negative consequences of delayed or inappropriate maternity care for disabled women who experience domestic abuse</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Understand women’s reasons for accessing maternity services and the factors that influence their decision making, particularly disability and domestic abuse</td>
</tr>
<tr>
<td></td>
<td>Further explore the effects of long term mental health conditions on access to maternity care when accompanied by domestic abuse</td>
</tr>
<tr>
<td></td>
<td>Explore maternity care practitioners’ understanding of disability and domestic abuse and evaluate the effectiveness of existing staff education</td>
</tr>
<tr>
<td></td>
<td>Identify, develop and evaluate the most effective models of antenatal service delivery for disabled women who experience domestic abuse</td>
</tr>
<tr>
<td></td>
<td>Studies which focus explicitly upon disability, domestic abuse and access to maternity care, including more qualitative research</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Policy</th>
<th>Organisational policies and guidelines which account for the co-existence of disability and domestic abuse and establish core service requirements e.g. accessible facilities and appropriate referral pathways.</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Promote evidence based strategies for improving access to maternity care for disabled women experiencing domestic abuse</td>
</tr>
<tr>
<td></td>
<td>Incorporate outward looking improvement strategies which capitalise on community resources and involve colleagues in community education and health promotion</td>
</tr>
<tr>
<td></td>
<td>Involve other agencies in improving access to maternity services and ensure that non-maternity services promote the importance of early prenatal care</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Practice</th>
<th>Foster positive, non-judgmental relationships with disabled women who experience domestic abuse</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women centered care that does not perpetrate negative stereotypes about disabled women</td>
</tr>
<tr>
<td></td>
<td>Develop and implement evidenced based staff education in disability and domestic abuse issues</td>
</tr>
<tr>
<td></td>
<td>Improve access and utilization of maternity care through multidisciplinary collaboration</td>
</tr>
</tbody>
</table>

(Submitted as an additional file)
Figure 1. Flow diagram of screening process

Electronic database search (n=6007)

Abstracts screened (n=6169)

Full text articles assessed for eligibility (n=49)

Excluded with reasons (n=40)
- No disability (19)
- No domestic abuse (3)
- No pregnancy (2)
- Pregnancy only (1)
- Domestic abuse only (2)
- No empirical data (2)
- No focus on maternity care access/utilisation (11)

Included in the review (n=9)

Supplementary hand search of reference lists (n=15)

Included in the review (n=11)
Additional files provided with this submission:

Additional file 1: Table 4. Summary of articles included in the review.docx, 18K
http://www.biomedcentral.com/imedia/2105639566129461/supp1.docx