

**Title: Deaf women's experiences of maternity and primary care: an integrative review**

**Abstract:**

**Background:** An estimated 24,000 people in the UK report using British Sign Language (BSL) as their first language. Misconceptions about deaf culture and language mean that deaf people have less access to health information and their health literacy is lower. Deaf people's health needs go under the radar in primary care with ensuing poorer health outcomes. Deaf women's experiences of maternity care are poorly understood.

**Methods:** Using Whittemore and Knaf's method for an integrative review, the following databases were searched: EMBASE, MedLine, CINAHL and Maternity and Infant Care. After reviewing 430 journal article titles and abstracts against the inclusion/exclusion criteria, 11 articles were included for final review. Selected studies were conducted internationally and were available in English. 10 were qualitative studies, 1 used survey design. They were reviewed using the Caldwell Framework.

**Findings:** These show that deaf women avoid seeking care, have a lack of access to health information and healthcare providers, including midwives, have a lack of deaf awareness. For deaf women, during pregnancy, birth and postnatal periods, this can mean having longer hospital stays and more complex postnatal care needs in both the hospital and community setting.

**Conclusions:** Current care provisions do not always meet the needs of the deaf BSL using women who use maternity services. Midwives should be aware of deafness as a culture and how to best meet the needs of the community to improve health outcomes for women and their babies.

**Key words:** Maternal Health Services; Deafness; Sign Language; Deaf Culture; Midwifery.

## **1: Introduction**

Deafness, partial or total inability to perceive or understand sound, affects an estimated 1 in 5 people in the UK (Action on Hearing Loss, AoHL, 2019). Deafness has four categories, mild, moderate, severe and profound (World Health Organisation, WHO, 2019).

Severe and profound deafness (prelingual) from birth or at a very young age affects an estimated 370 children a year in the UK; approximately 1 in 1000 children are severely or profoundly deaf by the age of 3 (National Institute of Health and Care Excellence, NICE, 2019). It is estimated that there are 900,000 adults in England and Wales with prelingual deafness. Around 22-24,000 people report using British Sign Language (BSL) as their first language (AoHL, 2019). In 2017, there were 83,386 people of childbearing age (16-49) reporting "hearing difficulties" in the UK (Office of National Statistics, 2017).

In the UK, the "Sick Of It" report (Sign Health, 2014), which surveyed 213 deaf people of all ages, found that the general health of the deaf signing population in the UK is poorer compared to the general population despite healthier lifestyles, including lower rates of smoking or alcohol consumption (Emond et al., 2015). There were also higher rates of misdiagnoses of conditions such as high blood pressure for patients presenting in primary care (Emond et al., 2015). Furthermore, deaf people were unwilling or unable to attend appointments with their GP as often as they wished due to not having access to adequate communication (Emond et al., 2015).

There are limited data about pregnancy outcomes for deaf women. In the USA, a longitudinal study between 1987 and 2013 which included 645 deaf women, found that women were more likely to have a caesarean section, or an increased length of hospital stay following vaginal delivery (Schiff et al., 2017). Additionally, a second American study

analysing hospital records between 1998 and 2013 which included 1,385 deaf or hard of hearing mothers found that deaf mothers were more likely to have pregnancy complications such as placental abruption or pre-eclampsia (Mitra et al., 2020). Deaf women were also more likely to have pre-existing hypertension or diabetes.

These disparities in healthcare outcomes and access may be linked to the history of oppression faced by deaf communities (Emond et al., 2015). There is evidence of a deaf community using a manual alphabet in the writings of Socrates and Plato (Lang, 2003). It was believed that deafness was a curse and that deaf people could not be educated. This belief persisted until 1760 when a French monk set up the first school for the deaf using both spoken and manual language to educate children. This marked the beginning of what American literature calls “the golden age of deaf education” (Hunter, 2013). However, in 1880, a conference for deaf educators was held in Milan to debate the use of oral or signed methods of education. A vote was held to ban sign language in deaf education worldwide meaning that deaf children were only allowed to access education via spoken language. It resulted in the immediate loss of jobs for large numbers of deaf people, including deaf educators (Kyle and Woll, 1994).

The legacy of this ban means that many deaf children left school with little to no functional education beyond being able to make sound (Lang, 2003). This left them in limbo, between a hearing world they could not fully access and a deaf world that they could not fully communicate within (Baker and Wright, 2017). In the UK, the ban was lifted in the 1980s and deaf children are now able to access flexible communication which has seen a return to both oral and signed communication. However, deaf children remain less likely to leave school with GCSEs equivalent to that of their hearing peers (National Deaf Children’s

Society, NDCS, 2016). Research shows that even in developed countries, lower educational attainment is linked to poorer health and poorer life expectancy (Zajakova and Lawrence, 2018).

Deaf people are less likely to know about health and healthcare systems (Kuenberg et al., 2016; Naseribooriabadi et al., 2017). This is because they do not pick up incidental information such as overhearing dinner table conversations and have limited access to interpreted or subtitled media (Kuenberg et al., 2016; Hall et al., 2018; Lesch et al., 2019). For many deaf BSL users, accessing an interpreter in a healthcare setting is a difficult and a relatively lengthy process (Emond et al., 2015), with some NHS trust websites citing from 3 days to 3 weeks' notice being required for bookings. The introduction of the Accessible Information Standards (NHS England, 2017) advised health professionals to ask about and document preferred communication needs and ensure this is provided. Many deaf people do not feel their access to either primary or secondary healthcare has changed (France, 2019).

When exploring communication needs, it is important to recognise that many in the deaf community identify as a cultural and linguistic minority as opposed to a disability group (Higgins and Lieberman, 2016). In the 1980s the term "Deaf" with a capital "D" was established in America and was used to signal those deaf people who chose to identify as a cultural minority. This terminology is now under debate and considered to be divisive in a world where deaf children are more likely to be accessing both oral language and sign language (De Meulder et al., 2019). 90% of deaf children are born into hearing families and, as such, may wish to be a part of both the deaf and hearing worlds. Therefore, it may be problematic for people to self-define purely as "Deaf". Furthermore, terms such as "hearing

impaired” or “hearing loss” may be considered offensive within the deaf community (Bennett, 2019). Deaf people may argue that they are not impaired and, if born deaf, did not lose anything. Conversely, some deaf people may use or prefer the term. This review will use the term “deaf” throughout and not seek to define identity on behalf of individuals within the deaf community.

Understanding the experiences of deaf signing women and equipping midwives with tools to meet their needs is vital for improving health literacy and engagement with the maternity services. This is important in improving the overall health of the family and the long-term outcomes for the newborn.

## **1.2: Purpose**

The aim of this review was to investigate the care experiences of deaf women in maternity and primary healthcare settings.

The objectives were to:

- Explore deaf women’s experiences of maternity services.
- Explore deaf women’s experience of primary healthcare.
- Identify barriers as experienced by deaf women to accessing maternity care or primary healthcare.

## **2: Method**

### **2.1: Search strategy**

An integrative review of literature allows knowledge to be sought from a range of studies using multiple methodologies (Cowell, 2021). Following Whittemore and Knafli’s (2005)

method for an integrative review the purpose of the review was identified, a database search conducted, studies were reviewed and themes were extracted from the literature.

Based on the purpose outlined above, a database search was completed using search terms and inclusion/exclusion criteria (Table 1).

Insert Table 1

A database search was conducted of EMBASE, MedLine, CINAHL and Maternity and Infant Care. The initial search yielded 430 articles; after review of journal article titles and abstracts against the inclusion/exclusion criteria, 12 articles were selected. One article was not available in English and was excluded, resulting in 11 articles for final review.

## 2.2: Review of literature

Articles were reviewed and the key features and themes from each article were put into an Excel spreadsheet (Table 2). Predominantly qualitative research, the articles were reviewed and appraised for quality using the Caldwell Framework (Caldwell et al., 2011). This framework was also appropriate for the one quantitative study which used survey methodology.

Insert Table 2.

## **3: Results**

11 papers dating from 2000 to 2017 about deaf women's experiences of either accessing healthcare or maternity care were analysed. Five articles related to healthcare and seven related to maternity specifically. Three themes were identified: i) inadequate or inaccessible health information or care; ii) lack of deaf awareness from health professionals; iii) women avoid care or delay care . The studies that were reviewed were conducted in

South Africa (n=4), America (n=4), United Kingdom (n=2) and New Zealand (n=1) and results are applicable across a range of healthcare styles and populations.

#### **4: Findings:**

##### **Inadequate/inaccessible information and care**

Deaf people are less likely to have knowledge about good health practices and healthcare systems (Steinberg, 2002). Five of the studies reviewed discuss issues around deaf people's awareness of their rights with regards to healthcare access (Steinberg et al., 2002; Steinberg et al., 2006; O'Hearn, 2006; Chin et al., 2013; Kritzinger et al., 2014). Many deaf people are not aware of their legal rights and entitlements when trying to access healthcare and this can have a detrimental effect on their health outcomes (Steinberg et al., 2006; Haricharan et al., 2013). For example, in O'Hearn's (2006) study involving 23 deaf women and 32 hearing women, 100% of the hearing participants felt it was the responsibility of doctors to ensure communication was clear, however, only 82% of the deaf women agreed.

A further barrier to healthcare access was the use of medical language in healthcare. Deaf people are less likely to have incidental knowledge around specific terminology related to aspects of their healthcare (Steinberg et al., 2002). In women's health, for example, deaf women reported not understanding terminology around sexual health, contraception or childbirth (Steinberg et al., 2002; Ubido, et al., 2002; Gichane et al., 2017). 100 deaf women completed a questionnaire on healthcare access in the UK and many of them reported attending healthcare appointments not knowing the purpose of their meeting when they arrived due to misunderstanding the terminology used by healthcare professionals (Ubido, 2002). This finding is echoed in a case study by Haricharan et al., (2013) that reported a

woman not knowing the reason for an admission to hospital. This miscommunication may have a significant impact on understanding treatment plans (Witko et al., 2017).

Many deaf women understand the risks of miscommunication but may feel unable to speak up (Kritzinger et al., 2014; Swannack, 2018). In interviews with 16 deaf South African Sign Language users, Kritzinger et al. (2014) found that many deaf women felt that, growing up, they had become reliant on their families to speak for them and now did not have confidence to speak for themselves. Conversely, Chin et al. (2013) found that deaf women have strong self-advocacy skills which increases the rates of breastfeeding success.

### **Lack of deaf awareness among health professionals**

Steinberg et al. (2002) conducted interviews and focus groups with 55 deaf American Sign Language users and reported what they term “insensitive practices” from healthcare professional working with deaf people. The details of similar practices are found in most of the studies (n=10). These practices include the need to phone for appointments, no patient displays in waiting rooms, relying on lip reading and intercoms on ward doors.

The most prevalently reported practice that deaf people found challenging was the use of written information. Seven studies specifically discuss the use of writing down information or the giving of printed leaflets as a method of communication employed by health professionals when an interpreter is not present (Steinburg et al., 2002; Ubido et al., 2002; O’Hearn, 2006; Steinberg et al., 2006; Haricharan et al., 2013; Gichane et al., 2017; Witko et al., 2017). One South African study highlight that although English is the official language within healthcare it is often not the first language of the families accessing healthcare. In the case of deaf South African Sign Language users, English may be their third language (Gichane et al., 2017). The issue of educational disadvantage is also raised highlighting the



fact that deaf people may have lower levels of reading and writing than their hearing counterparts (Haricharan et al., 2013). Studies from America and the UK, discuss the grammatical difference between signed languages and English (Ubido, 2002; Steinberg et al., 2006). They report assumptions about the linguistic attainment of deaf sign language users in English, which is essentially a second language, meaning that health professionals do not modify their language to make it understandable to deaf people (Krtzinger et al., 2013). Interestingly, as found by one study with deaf women, as the number of appointments went up the level of satisfaction with their overall care decreased (O'Hearn, 2006). It was felt by many deaf people across four of the studies that health care professionals were not adequately adjusting their communication practices to meet the needs of deaf people, for example, by inaccurately assuming levels of knowledge, not giving more time in appointments, not simplifying their language or not knowing how to work with interpreters (O'Hearn, 2006; Krtzinger et al., 2014; Witko et al., 2017; Swannack, 2018).

The use of interpreters featured in five studies (Bramwell et al., 2000; Steinberg et al., 2006; Haricharan et al., 2013; Krtzinger et al., 2014; Witko et al., 2017). One study with 16 participants found that deaf people felt that health professionals were not adequately trained to work with interpreters and so, rather than facing and communicating directly with the patient and allowing the interpreter to translate, healthcare professionals would face and talk to the interpreter (Krtzinger et al., 2014). The main concern highlighted across three studies was deaf users being accompanied by friends or family members as interpreters and the impact this had on patient confidentiality, with one study highlighting a case whereby a deaf woman felt sure her HIV status had been disclosed to her community by a friend who had been acting as an interpreter when she received the results (Haricharan et al., 2013). A further case study highlighted the use of a family member during a scan

appointment whereby a deaf mother did not want to know the gender of her unborn child but the accompanying family member did and so deliberately misinterpreted what was being said to the health care professional during the meeting (Bramwell, 2000). On the other hand, Witko et al. (2017) point out that deaf people may prefer or feel more secure with a family member acting as their interpreter.

### **Avoiding or delaying care**

Six studies suggested that deaf people avoid or delay care or have accepted that they will receive inferior levels of care (Steinberg et al., 2002; Steinberg et al., 2006; Haricharan et al., 2013; Kritzinger et al., 2014; Gichane et al., 2017; Witko et al., 2017). While the majority (n=4) of studies reporting this originate in South Africa, both a large American study with 91 deaf American Sign Language (ASL) users and a study of 32 New Zealand Sign Language users support this. Steinberg et al. (2002) and Gichane et al. (2017) highlight that a lack of a shared language impact trust and communication with healthcare professionals. Wilko et al. (2017) suggest that a lack of understanding of deafness and deaf culture mean there is a cultural barrier between deaf sign language users and healthcare services. A finding supported in other studies (Swannack, 2018; O’Hearn, 2006; Chin et al., 2013). This lack of understanding compounds the communication issues already experienced and results in fear or mistrust from deaf people which, in turn, may result in them choosing to delay accessing care (Steinberg et al., 2006; Gichane et al., 2017). In the case of maternity care, deaf women were choosing to book later in their pregnancies and this delay results in missed health education opportunities around screening, infant feeding and parenting skills (Gichane et al., 2017).

### **Discussion:**

Insert Table 3

This review, while containing a small number of studies, suggests that there are challenges for deaf people who access healthcare and/or maternity services. Most of the studies found in this review explored healthcare access as opposed to maternity specific access, however, the issues are directly applicable to maternity care provided by midwives both in the hospital and community setting.

While the evidence for pregnancy complications in deaf signing women is fairly new and limited, it suggests that deaf women are more likely to have pre-existing hypertension or diabetes (Mitra, 2020). This finding was true in the general health of deaf BSL users in the UK (Emond et al., 2015). With these pre-existing conditions come the risks of pre-eclampsia, growth restricted fetuses and placental abruption (James and Nelson-Piercy, 2004). In turn, these risks may increase the risk of pre-term birth, traumatic births and require longer hospital stays and more support in the postnatal period. The implications of booking later for pregnancy care, not being able to fully access treatment plans or properly consent to them and not having adequate support in the postnatal period may have a profound and lasting effect on the health of mother and baby. There are also implications for deaf BSL women in relation to their preconceptional needs as in other groups of marginalised women (Second author et al., 2018). They argue that preconception needs in groups of marginalised women go unrecognised in primary care by both midwives and other health care professionals.

The review shows examples of good practice and examples of areas for improvement for midwives caring for deaf women. The best way to improve deaf women's access to maternity care services is to improve communication and deaf awareness in all healthcare

settings. Health promotion leaflets, posters and advertising have been used since the nineteenth century to educate and inform the public about healthy behaviours (Robertson, 2008). However, deaf people are less likely to have access to incidental information, overheard at dinner tables and from the TV or radio (McKee, 2015). As the studies in this review show, they are less likely to benefit from leaflets written in or translated from English. Assuming that the grammar of signed languages and English are the same can lead to simple miscommunication (Meador and Zazove, 2005; Scheier, 2009). Recognising BSL as a visual language and using pictures or diagrams to support explanations may help to overcome some of these barriers (Jackson, 2010).

Swannack (2018) identifies that hearing health professionals and deaf people may have a different understanding of what it means to be deaf. Often deaf sign language using mothers are part of a wider community of deaf people with whom they have a shared language, culture and history (Najarian, 2010). The support of peers with whom they share this understanding is beneficial in improving health behaviours (Chin et al, 2013).

Understanding deaf sign language users to be a cultural and linguistic minority as opposed to a disabled group may facilitate health professionals in meeting the needs of postnatal mothers as they navigate the role of the mother (Najarian, 2010). The use of peer support in maternal and child health is common and may be particularly beneficial for groups that struggle to access healthcare services or with lower health literacy levels (Sokol and Fisher, 2016). Chin et al. (2013) clearly identify how the use of technology to connect peers improved breastfeeding success among deaf ASL using women.

It is important for midwives to recognise the preferences of mothers when implementing care plans. Witko et al. (2017) suggest that deaf people may wish to use family members as

interpreters while other studies highlight the risks of this (Bramwell et al., 2000; Haricharan et al., 2013). When considering the needs of a new family, deaf women are more likely to have a deaf partner. The use of an intimate partner may be the first choice of some women to avoid having extra people around her during antenatal care and birth, however, they may wish to have an interpreter to allow their partner to be free to support them in other ways (Jackson, 2010). Sensitive care practices that incorporate the preferences of women is fundamental to maternity care (National Maternity Review, 2020).

Women may choose to decline care and while it is the right of pregnant women to do so in the UK, the findings of Gichane et al. (2017) study imply that this may not always be an informed choice. Lower levels of health literacy mean deaf women may not know how to access maternity care as early as possible or they may choose to avoid accessing services if they feel the care will be poor (Haricharan et al., 2013). In the UK, delays in accessing maternity services have a knock-on effect on the Royal College of Midwives (RCM) Public Health initiatives such as encouraging mothers to stop smoking, whooping cough immunisations offered at 16 weeks, Down syndrome or fetal anomaly screening.

Alternatively, women may consent to care but not know the purpose of the intended care episode, for example, arriving for a routine antenatal check and discovering that they have been booked in for an induction (Ubido, 2002). Checking understanding relies on the communication skills of the midwife and needs to be done with open questions or asking the woman to repeat what she has understood (Bramwell, 2014). Alternatively, Kritzing et al. (2014) found that deaf women may just answer “yes”, leading health care professionals including midwives to believe consent has been obtained.

**Conclusion:**

This review has shown that midwives can improve the experiences and overall health of deaf women and their families. Starting with health information and literacy, midwives can ensure that information is available in sign language, visual images and simplified written language. Engaging with the deaf community will ensure that health education is shared through peer interactions in much the same way as in hearing communities. Secondly, deaf awareness training will ensure sensitive communication practices and better awareness of the challenges faced by the deaf community. Learning to assess and meet the communication needs of individual deaf women will improve their confidence in health provisions and ensure that they feel able to access appropriate information and care in a timely way.

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Table 1:

Search terms	<u>Inclusion</u>	<u>Exclusion</u>
Terms related to deafness: Deaf, hearing impaired.	Deafness or hearing impairment	Age related hearing loss
Terms related to women: Women, female.	Included the experiences of female service users	Experiences of health professionals Experience of deaf children Experience of deaf men only
Terms related to healthcare or maternity care: Maternity, pregnant, prenatal, antenatal, obstetric, healthcare, primary healthcare.	General healthcare or maternity care	Other specific services (for example, breast screening services) Experiences of access to education



Table 2

Author	Title	Date	Focus	Country	Method	Participants	Themes
Bramwell R; Harrington F; Harris J	Professional issues. Deaf women: informed choice, policy and legislation.	2000	HEALTHCARE	UK	Case study	1	Communication difficulties Inappropriate use of family
Steinberg A; Wiggins E; Barmada C; Sullivan V	Deaf women: experiences and perceptions of healthcare system access.	2002	HEALTHCARE	USA	Interview/Focus group	45 Deaf American Sign Language (ASL) users.	Lack of health literacy/ knowledge of terminology. Poor experiences (off putting) Lack of deaf awareness from professionals
Ubido J; Huntington J; Warburton D	Inequalities in access to healthcare faced by women who are deaf.	2002	HEALTHCARE	UK	Interview (questionnaire)	13 Hard of Hearing 14 Deaf British Sign Language (BSL) users (100 deaf or hard of hearing)	Lack of deaf awareness Avoiding care Lack of health information
O'Hearn, A	Deaf Women's Experiences and Satisfaction With Prenatal Care: A Comparative Study	2006	MATERNITY	USA	Questionnaire	55 deaf women	Beliefs about who is responsible for communication. More appointments = Reduced

							satisfaction with care.
Steinberg, A; Barnett, S; Meador, H; Wiggins, E and Zazove, P	Health Care System Accessibility Experiences and Perceptions of Deaf People	2006	HEALTHCARE	USA	Focus group	91 Deaf ASL users	Less knowledge of legal rights. Use of insensitive communication practices. Mistrust of health professionals.
Haricharan, H; Heap, M; Coomans, F; London, L	Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a Deaf woman in Cape Town, South Africa.	2013	HEALTHCARE	SA	Case study	1	Ineffective communication from healthcare professionals Avoid care/accept inferior care Inappropriate use of friends to interpret.
Chin, N; Cuculick, J; Starr, M; Panko, T; Widanka, H	Deaf Mothers and Breastfeeding: Do Unique Features of Deaf Culture and Language Support Breastfeeding Success?	2013	MATERNITY	USA	focus group	15 Deaf ASL users	Strong self advocacy supports help seeking behaviour Use of tech for social support



Kritzinger, J; Schneider, M; Swartz, L; Braathen, S	'I just answer 'yes' to everything they say': Access to health care for deaf people in Worcester, South Africa and the politics of exclusion.	2014	MATERNITY	SA	interview	16 Deaf South African Sign Language (SASL) users	Communication barrier Raised to be unquestioning. Deaf people need more time in appointments.
Gichane M, Heap M., Fontes M., London L.	"They must understand we are people": Pregnancy and maternity service use among signing Deaf women in Cape Town.	2017	MATERNITY	SA	interview	42 Deaf SASL	Linguistic barrier Mistreatment Staff do not understand deaf people. Delay seeking care.
Witko, J; Boyles, P; Smiler, K; McKee, R	Deaf New Zealand sign language users access to healthcare	2017	HEALTHCARE	NZ	focus group (32) Interview (9)	New Zealand Sign Language (NZSL) users	Lower treatment compliance. Poor communication practices. May prefer family to interpret.
Swannack, R	Deaf Futures: Challenges in Accessing Health Care Services	2018	HEALTHCARE	SA	Ethnography	6 Deaf SASL users	Fear of the risks of miscommunication. Deaf people are a different culture – needs to be understood.



Table 3:

Finding	Summary of literature	Possible solutions
Inadequate or inaccessible health information	Deaf people may be unaware of rights Use/ overuse of medical terminology Deaf person needs strong self advocacy skills	Setting up or using existing peer support within the deaf community. Avoid closed questions to confirm understanding
Lack of deaf awareness in health professionals	Use of insensitive practices eg. Phones, door intercoms, reliance on lip reading. Overuse of written information Assumptions about BSL and English similarity Lack of awareness of deaf culture Knowing how to book, use and work with an interpreter	Deaf awareness training for staff that includes training in deaf culture, BSL and other communication tools. Use of visual tools as well as verbal/written English. Training to understand how to book and work with interpreters.
Avoiding or delaying care	Fear of receiving inferior care Lack of trust with health professionals	Deaf awareness training specifically: Awareness of deaf community as a culture Awareness that not all deaf people perceive deafness as a disability or in need of cure.