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Title: Preconception care for infertile couples: nurses' and midwives' roles in promoting better maternal and birth outcomes

Short title: Preconception care for infertile couples

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ABSTRACT

Introduction Preconception care promotes better maternal outcomes, may assist in preventing birth defects and improves fertility awareness among healthy childbearing couples. Yet the significance of preconception care for infertile couples is undeveloped area of practice in Europe.

Aim We discuss the importance of nurses and midwives in providing preconception care to infertile couples in the United Kingdom and Spain.

Design Discursive paper

Method A comparison of different midwifery and nursing approaches to preconception care for infertile couples in two European countries.

Findings At present infertile couples' needs for preconception care are not routinely identified or understood. There is an opportunity for these needs to be considered and identified by nurses at the time of investigation for infertility or when planning pregnancy with assisted conception.

Conclusions We argue that by providing preconception care, nurses and midwives have an opportunity to deliver important advice to infertile couples in both primary care and specialist infertility services.

Key words: preconception, infertility, midwifery, nursing

What does this paper contribute to the wider global community:

- This paper builds on existing literature on preconception care for fertile couples, those who conceive spontaneously.
- We address the gap in nursing and midwifery practice internationally in preconception care for infertile couples.
- We suggest a framework for nursing and midwifery-led preconception care for infertile couples.

INTRODUCTION

Overview

Preconception care promotes better maternal outcomes, may assist in preventing birth defects and improves fertility awareness among healthy childbearing couples (Atrash, Johnson, Adams, Cordero & Howse, 2006; Atrash, Jack & Johnson, 2008; Temel, van Voorst, Jack, Denktas & Steegers, 2014; Hemsing, Greaves & Poole, 2017; Poels, van Stel, Franx & Koster 2017). It is beginning to be recognised that preconception care is also important for infertile couples in both primary care and fertility clinics (Kelly-Weeder & O'Connor, 2006; Homan, Davies & Norman, 2007; Vause, Jones, Evans, Wilkie & Leader, 2009) as well as interconception care between pregnancies (Hemsing et al., 2017).

Countries differ in the availability and delivery of preconception services

(Backhausen, Ekstrand, Tyden, Magnussen & X, 2014) and consequently X et al., (2015) have argued for the development of standard European guidelines.

Preconception care is

the provision of biomedical, behavioural and social health interventions to women and couples before conception occurs in order to improve pregnancy outcomes, women's health and the health of future generations. (Posner, Johnson, Parker, Atrash & Biermann, 2006, s198; World Health Organisation [WHO] 2013a, p.1).

There are national and population-based systems to monitor maternal behaviours, conditions, and experiences that occur before, during, and after pregnancy (Robbins, Zapata, Farr, Kroelinger, Morrow, Ahluwalia, D'Angelo, Barradas, Cox, Goodman, Williams, Grigorescu & Barfield, 2014; NIHR Dissemination Centre, 2017) but it is estimated that essential preconception health interventions will be provided too late in 40% of all pregnancies (WHO, 2013b). Unhelpfully all preconception guidance presumes women schedule pregnancies when many pregnancies are unplanned (Fabre, 2014; Oza-Frank, Kachoria, Keim, Klebanoff, 2015).

Preconception care given at the right time is known to improve a range of health outcomes (Association of Maternal and Child Programs, 2007) during pregnancy and childbirth. These include lower maternal and child mortality and fewer complications in pregnancy (WHO, 2013). The review "Better beginnings. Improving health for

Pregnancy” (NIHR Dissemination Centre, 2017) suggests healthcare professionals have opportunities to improve maternal health when women access health services unconnected with pregnancy. However, as the antenatal period is generally when contact is first made by women, opportunities for optimal preconception interventions may be missed (Nekuei, Esfahani & Kazemi, 2014; Goossens et al., 2016). A UK survey suggested that, on average, contact with a healthcare professional is first made at eight weeks gestation (Redshaw & Henderson, 2015). Eight weeks gestation is too late for lifestyle changes to improve pregnancy outcomes as critical fetal organ development occurs before this, when a lot of women may not realise they are pregnant (Goossens et al., 2016; Tydén, 2016).

Europe is seeing delayed childbearing, increasing obesity, gestational and pre-gestational diabetes and smoking among women (Bortolus, Oprandi, Morassutti, Marchetto, Filippini, Agricola, Tozzi, Castellani, Lalatta, Rusticali & Mastroiacovo 2017). These all contribute to poorer outcomes for pregnancy, and negatively effect women’s reproductive health. Preconception assessment presents an opportunity for identifying women with or at risk of these morbidities (Hemsing et al., 2017).

However, current policies and guidance for preconception care for otherwise healthy couples are fragmented if not inconsistent (X et al., 2015, Bortolus et al., 2017) with little evidence of why preconception care is a) not a priority for women and b) why healthcare professionals do not routinely deliver preconception care (Tuomainen, Cross-Bardell, Bhoday, Qureshi & Kai, 2013; Goossens et al., 2016).

Preconception care may include the delivery of a number of preventative and interactive programmes (Bortolus et al., 2017), including advice on lifestyle, to optimise pregnancy outcomes on issues such as folic acid, genetic screening, environmental health, interpersonal violence, planned pregnancies, sexually transmitted infections, mental health, drug and alcohol use, vaccination programmes, female genital mutilation (FGM) and infertility/sub-fertility. This advice is important at a societal and individual level and can be empowering, particularly for women (Katz Rothman, 2014). Delivering preconception care may therefore produce the holistic, woman-centred care (Royal College of Midwives, 2014) that nurses wish to provide.

Infertility and preconception care

Infertility is present when a couple do not become clinically pregnant after a year or more of regular unprotected sexual intercourse. The WHO (2016) see it as a serious disability in the childbearing population (WHO, 2016); 48.5 million couples are estimated to be infertile worldwide (Mascarenhas, Flaxman, Boerma, Vanderpoel & Stevens, 2012).

Physiological, genetic, environmental and social factors contribute to a couple's infertility and to the inability to deliver a healthy infant. In the UK and Spain, the incidence of infertility has risen with one in seven heterosexual couples affected (NICE, 2013). In 30% of referred cases for infertility investigations, two or more causes of infertility co-exist which make diagnosis and treatment challenging (Sociedad Española de Fertilidad, 2016). After diagnostic testing, 15-30% of couples are diagnosed with unexplained infertility (NICE, 2013).

Biologically women are most fertile between ages 18 and 30 years and the ability to conceive and bear children decline progressively (Balasch & Gratacós, 2011).

However the reproductive behaviour in most European countries has shifted to later childbearing (Kocourkova, Burcin & Kucera, 2014). Births are more strictly planned, with greater numbers of women delaying conception until age 40 or over (Fulford et al., 2013) and choosing to have fewer children (Mascarenhas et al., 2012). Older age at conception affects fertility but seemingly the need for preconception advice and care in this respect may go unrecognised by health professionals and couples themselves (X, 2015).

If planning to have a child is delayed, seeking advice about preconception care may also be delayed. This is important given that preconception care can raise awareness of the menstrual cycle and the optimum times for conception. In addition, awareness of age-related fertility and infertility is low. Habbema, Eijkemans, Leridon, & te Velde, (2015) have shown how young people overestimate the effectiveness of fertility treatments like in vitro fertilisation (IVF), believing they can conceive spontaneously and easily after 35 years of age. The optimum age for conceiving spontaneously is 32 years old or younger for a single child, at 27 years for two, and at 23 years for three children. While it is the choice of each individual and couple to determine if they intend to have a child, and if so the size of their family unit and the timing, the authors suggest that this knowledge is important for couples to plan their family. Habbema et al. (2015) recommend preconception care to increase public awareness of age-related fertility. According to Kocourkova et al., (2014), delayed birth timing is key to understanding the increased demand and provision of assisted reproductive techniques (ART). Chodorow (2003) argues delayed child bearing is

socially reproduced both through couples' ambivalence over parenthood but also by the availability of ARTs. She argues that women are disconnected from their biological, reproductive age by social factors such as work. They are encouraged in this by changing social pressures for women to be independent. ARTs may suggest to young women and the public that childbearing can be delayed. But little evidence that health professional curricula are changing to challenge these perceptions or to motivate health professionals to support young women in their reproductive choices (Nekuei et al., 2012; Nekuei, Kazemi & Hasanzadeh, 2014).

Preconception care for infertile couples, also through raising awareness of these issues and providing interventions, may enhance chances of conception and pregnancy; however neither the awareness or interventions can be introduced if this service is not sought in the first place (Chodorow, 2003; Joelsson, Berglund, Wanggren, Lood, Rosenblad & Tydén, 2016). The number of infertile couples seeking a referral for infertility varies enormously worldwide (Boivin, Bunting, Collins & Nygren, 2007). A referral for fertility advice includes initial consultation with a primary care practitioner for difficulties in conceiving to attendance at a specialist fertility clinic. There is also wide variation in the provision and funding of fertility services(Boivin et al., 2007). In developed countries, despite the demand being around 42%, less than 25% receive any specialist infertility treatment (Boivin et al., 2007). In nations like the UK, only 56% of couples seek help from a doctor when they have problems conceiving, with 20% delaying this for over two years. Fulford et al., (2013) argue that in general couples are not well informed about fertility issues and this can contribute to delay in identifying infertility risk factors and then seeking medical help.

According to the International Standards of Infertility Practice (2015, p.2),

Women and their partners who seek advice and help to conceive should be provided with information and support to optimise their health and environmental circumstances in order to improve their reproductive potential and the outcome for both mother and baby.

As discussed the most critical period for fetal organ development is between three to eight weeks, (Tydén, 2016). As infertile couples are intensively monitored and in contact with a range of health professionals while attending infertility clinics, they are well placed to optimise their pre-pregnancy health (Anderson, Norman & Middleton 2010). There may be a gap in preconception care between healthcare professionals in general practice who may have a poorer understanding of infertility and fertility specialists who may be focused on the infertility and not on pre-conception advice (X, 2017).

AIMS

We discuss the role of midwives and nurses in providing preconception care to infertile couples by comparing nursing and midwifery-led preconception services in the UK and Spain.

METHODS

This position paper was written after a study trip to the United Kingdom (UK) from Spain by one of the authors (X). We compare nursing and midwifery-led preconception services in the UK and Spain to add to the emerging international literature on preconception care for infertile couples. All four authors are nurses

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and/or midwives who have researched preconception care (Stephenson, Patel, Barrett, Howden, Copas, Ojukwu, Pandya & X, 2014) or infertility (X et al., 2009; X 2015; X, 2017). We have all noted the lack of pre-conception care for infertile couples (X and Finnerty, 2007; X & X, 2015; X 2015; X, 2017) and, with others (Goossens, Delbeare, Dhaenens, Willems, Van Hecke, Verhaege & Beeckman, 2016), the lack of attention to this area of practice in curricula and professional practice guidelines. Methods included i) a literature review to identify papers relating to the role of nurses and midwives in providing preconception and interconception care for fertile and infertile couples. The review was conducted using the databases MEDLINE, CINAHL and Cochrane Library, using the Boolean operators AND and OR, databases reviewing Studies with an unlimited publication date, English and Spanish language. Key search terms were used: preconception care, interconception care, infertility, nursing, midwifery. The search was conducted in 2016 This review suggests that infertile couples do not access preconception care either in primary care or in specialist fertility clinics despite guidance (European Society of Human Reproduction and Embryology [ESRHE], 2015). ii) a comparison of Spanish and British nursing and midwifery-led preconception care which illustrates different models in the provision of preconception care for infertile couples. We argue that the benefits of preconception care to promote better maternal outcomes and to prevent birth defects in all couples are well known. Yet the significance of preconception care for infertile couples is undeveloped area of nursing and midwifery practice in Europe.

FINDINGS

Preconception care in the UK and Spain

Women with pre-existing medical conditions are considered 'high-risk' for pregnancy and so may receive preconception advice as part of the multi-disciplinary model of care (Bick, Beake, Chappell, Ismail, Cance, Green & Taylor, 2014; MBRRACE 2017). However, as discussed earlier, this often only happens once women are already pregnant and as X et al., (2015) argue, while preconception care for women with existing morbidities is accepted practice, the provision for healthy women is less consistent across Europe. Even in Spain where preconception care is available, only ten percent of Spanish couples voluntarily access a preconception clinic even when planning pregnancy (Sociedad Española de Ginecología y Obstetricia (SEGO), 2010). Despite this it is claimed that 70% of couples are interested in increasing their knowledge of pregnancy and optimal pre-pregnancy lifestyles (Vause et al., 2009). Fulford, Bunting, Tsibulsky & Boivin (2013) found that where women report an intention to take action to improve pregnancy outcome, this is based on their knowledge about fertility, and their perceived or known risk of infertility.

Preconception care in the UK is not provided routinely although women may seek advice from general practitioners, practice nurses and community midwives (Heyes & Long, 2004). Thus the delivery of preconception care is seen as part of the public health role in nursing and is included in the nursing and midwifery UK curricula ((Nursing & Midwifery Council (NMC) 2009; Bye, X, Stephenson, Bick, Brima & Micali, 2016), but whether such public health roles are effective and which

professional group is ultimately responsible for preconception care is remains unclear (X et al., 2015; Bye et al., 2016; Sanders, Hunter & Warren, 2016).

In Spain there is publically funded provision for preconception care; women can request an appointment for preconception advice with a midwife or attend preconception clinics in primary care. In Spain, it is expected that preconception should be individualised and delivered by all health professionals involved in providing reproductive care (SEGO, 2010).

In both countries, antenatal care and pregnancy guidelines promote the importance of good health before pregnancy for all women; campaigns, such as folic acid supplementation before conception, are supported nationally (SEGO, 2010; X et al., 2015; National Institute for Health & Care Excellence (NICE) 2017).

Fertility services and preconception care

A systematic review (Anderson et al., 2010) found no evidence that preconception care is offered routinely to infertile couples. Anderson et al.(2010) make the point that this gap in provision is important because infertile couples' chances of conceiving and becoming parents, affected by social factors such as lifestyle choices and delayed childbearing, could be improved if supported through preconception care. This gap is particularly significant for the many couples who delay or do not seek specialist advice for infertility, despite being seen in primary care by GPs, nurses or midwives for other reasons. Providing these couples with preconception

care may go some way to filling this gap and improve both their chances of conception and healthy pregnancy.

There is evidence that some fertility clinics are introducing fertility enhancing lifestyle support (Klonoff-Cohen 2005). X et al. (2009) argue that women are proactive in seeking pregnancy even if this means greater surveillance by health professionals including increased surveillance of their bodies (Lupton, 2012; Gentile, 2013; Katz Rothman, 2014). At the same time, there is growing evidence that infertile couples proactively and independently, i.e. without health professional guidance or interference, manage their infertility and any attempts at achieving parenthood through using ARTs (Hawkins, Rossi, Correi, Lipskind, Hornstein & Missmer, 2014; Rossi, Bressler, Correia, Lipskind, Hornstein & Missmer, 2016). Infertile couples often also anticipate that ARTs may be unable to overcome their infertility and decide to take action themselves. They consult many sources for health advice, not only doctors, and alternative and lay help-seeking behaviours are common (X, 2015; X, 2017).

The public perception of ART availability is also at odds with the financial reality in which many treatments are rationed (X et al., 2009) and there is widespread variation in which services, such as ART treatments and preconception care, are covered internationally through medical insurance (International Federation of Fertility Societies (IFFS), 2013).

In the UK, couples would self-refer to their publically funded general practitioner in primary care where initial investigations would be undertaken. There is little reported nursing input at this stage. Unlike in Spain, it is rare for nurses or midwives to be involved in providing a service such as running preconception clinics at this point. After referral to specialist fertility clinics, there may be further opportunity for preconception care but no evidence that this is delivered (Kelly-Weeder & O'Connor, 2006; X & X, 2009). Instead X (2017) found that the focus is immediately on the potential for ARTs. X (2017) argues that couples resist this technological imperative by seeking self-help or complementary health advice.

In Spain, women and couples can self-refer or be referred to a gynaecologist in primary care by their GP for information regarding care and treatment options for sub/infertility. Spanish midwives, unlike in the UK, also provide care to women planning for pregnancy in the community; in other words, they may offer preconception care, although this practice varies across the country and is not evaluated (X, 2015). Midwives in Spain are obstetric and gynaecologist specialist nurses and register as a midwife after completing a nursing registration. Community midwives offer obstetric clinics (e.g. pregnancy care, antenatal classes, postpartum care, breastfeeding support but not home delivery) and gynaecological care (e.g. contraception care, sexually transmitted infections, preconceptual care, cervical cancer screening). These services are publically funded (Departament de Salut, 2016). Women who experience problems in conceiving are seen at the primary care clinic at the sexual and reproductive health unit either by a gynaecologist or a midwife. Couples are then referred together to the specialist gynaecologist in primary care where initial information regarding care and treatment options are provided.

Couples who fail to conceive at this point are referred to specialist fertility services in tertiary care (Departament de Salut, 2016).

DISCUSSION

For those couples who remain unable to conceive or continue pregnancies, conception may be delayed and referral to specialist teams may become necessary (NICE, 2016; X, 2017). ARTs may be enhanced by self-help and lifestyle changes which a couple may make to increase their chances of conceiving prior to and during cycles of assisted conception (NICE, 2013). Preconception care may increase these agentic acts (Kelly-Weeder & O'Connor 2006; Hemsing et al., 2017). X (2017) has shown that infertile couples resist the hegemony of ARTs by seeking preconception care themselves from complementary health practitioners.

We argue that more awareness of the potential of preconception care and its outcomes needs to be raised in both primary care and fertility clinics among health care professionals including nurses and midwives. Primary care and fertility clinic health care professionals can provide couples with preconception advice. Research shows that despite guidance on referrals for infertile or sub-fertile couples (NICE, 2013; Departament de Salut, 2016), many couples experience a delayed referral and as a consequence do not receive either investigations of infertility or preconception advice sufficiently early enough (Anderson et al., 2010; ADECES, 2011; X 2015; X 2017).

ESHRE (2015) recommends assessment of the psychosocial needs of women and men before fertility treatment to enable a psychosocially healthy experience of their treatment. As Kelly-Weeder & O'Connor (2006) suggest, chances of conception can be optimised by couples themselves with information and advice and encouragement. Many unhealthy behaviours and lifestyle choices that negatively affect general and reproductive health, as well chances of treatment success, are amenable to change (Klonoff-Cohen, 2005). Preconception counselling can assist (Joelsson et al., 2016; ESHRE Psychology and Counselling Guideline Development Group, 2016) women and men in this endeavour. .

While it is possible to change unhealthy lifestyle factors, to reduce or even eliminate them to help couples to conceive, adherence with these recommendations could be improved through greater awareness among health professionals in primary care and fertility clinics (Joelsson et al., 2016). However how effective preconception interventions can best be delivered, and whether specific recommendations change behaviour (Anderson et al., 2010; Barret et al, 2015; X et al, 2015) and who should deliver preconception interventions (Kelly-Weeder & O'Connor 2006; Hemsing et al., 2017) are future research questions.

RELEVANCE FOR CLINICAL PRACTICE: NURSING, MIDWIFERY AND PRECONCEPTUAL CARE

While European fertility guidance recommends that couples have access to preconception care (ESHRE 2015), it is unclear who assumes responsibility for delivering this care. In the world of assisted reproduction self-help strategies for

couples are not promoted (X et al., 2009; Ockhuijsen et al., 2012). Such strategies as Ockhuijsen et al., (2012, p. 1157) suggest, 'receive little attention in the often commercial race to push couples through IVF treatment before they have had the opportunity or support to optimize the physical and mental circumstances for a pregnancy to occur'. Indeed, as X (2017) argues, in the UK the tenor of initial fertility clinic consultations is frequently focused on directing couples to IVF. Nevertheless recent interest in the nursing role in preconception care for infertile couples is beginning to emerge slowly (Kelly-Weedor & O'Connor 2006; X and X, 2015).

In the UK a major barrier to this is the model of service provision; contact with nurses or midwives is not routinely offered at an early or pregnancy planning stage, for example in primary care. This differs from Spain where women/couples can request preconception care from midwives or GPs, although X (2015) shows that this advice is not routine. Spanish midwives assume responsibility for preconception care in primary health services as well as in maternal health (although this is not evaluated), whereas in the UK, midwives would not expect to deliver preconception care but neither would fertility clinic nurses (Ockhuijsen et al., 2012; X, 2013; Nekuei et al., 2014) or indeed primary health nurses (X and X, 2015). This UK experience reflects a general pattern in health systems across Europe in relation to preconception care (Van Heesch, de Weerd, Kotey & Steegers, 2006; Anderson et al., 2010; X et al., 2015). In the Netherlands for example, Van Heesch et al, (2006) suggest the vast majority of community midwives were willing to provide preconception care and over half felt it was their responsibility to do so, however, most (79%) claimed to lack knowledge and time to deliver preconception care.

In the UK it is possible that case-load midwifery model could allow some preconception care by midwives (Killingley, 2017) although inadequate awareness of infertility and fertility treatments among midwives (X, 2009) might hamper its effectiveness. Midwives would not normally encounter couples outside pregnancy and therefore their role in providing care and advice to infertile couples would be unusual (Wilson & Leese, 2013). Unfortunately, although the provision of women-centred care is a key issue in midwifery practice (NMC, 2009) the requirement for the midwife to provide preconception care has not been reiterated in the latest standards.

CONCLUSIONS

We have argued that currently nursing and/or midwifery-led preconception care in Spain is not evaluated and in the UK is not routinely offered or utilised, despite there being a clear need for infertile couples. In the UK this may be due to the gap between primary and infertility care provision, especially where couples delay childbearing and may subsequently require assistance to conceive. In Spain preconception care is more widely available, but uptake is low and not routine. The lack of preconception care for infertile couples may be a reflection of a lack of continuity in women's health reported elsewhere (Royal College of Obstetricians and Gynaecologists, 2011).

We have argued that infertile couples' preconception needs are unrecognised yet the opportunities for fertility awareness exist in both primary care and fertility clinics. We suggest patient-centred preconception care for infertile couples should encompass four components:

- (1) Risk assessment which may lead to further screening, investigations and referral to fertility/other specialists
- (2) Health promotion, including periconception folic acid supplement use and well-being advice to deal with the stress of infertility (Anderson et al., 2010).
- (3) Life style intervention and modification advice to change or eliminate risk factors such as smoking cessation and weight loss (Van der Steeg, Steures, Eijkermans, Habbema, Hompes & Burggraaff, 2008).
- (4) Counselling for family planning including age related fertility awareness

Preconception care should be actively offered by all health-care professionals.

Nurses in fertility clinics and GPs in primary care are ideally placed to open up a discussion about preconception care with infertile couples, promoting the agency of these patients during otherwise relatively powerless investigation and treatment stages. Infertile couples could be offered an initial fertility and preconception assessment prior to referral for specialist consultation to discuss medical options for conception. As the Spanish community midwife's role shows, there are also models for integrating preconception care for women and couples in the community.

Education standards and curricula for both midwives and nurses should include preconception care for both the fertile women and her partner and the infertile couple.

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