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# Setting the global research agenda in psychosocial aspects of women’s health – outcomes from ISPOG world conference at The Hague

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# Setting the global research agenda from 2020 to 2022 in psychosocial aspects of women’s health - outcomes from ISPOG world conference at The Hague

The World Conference of the International Society of Psychosomatic Obstetrics and Gynaecology held in The Hague Netherlands in October 2019 ran a dedicated session debating the global research priorities for psychological and social aspects of women’s health. Member countries of ISPOG and individual members were invited to lodge abstracts arguing for topics that required, or would benefit from, a global effort to seek answers to important issues in clinical care. Using a deliberative decision making approach, a debate was held after presentations, and the audience voted for the top ranked topics (Table 1). Topics prioritised reflected areas of common clinical concern and those where gaps in knowledge were identified.

In this editorial we invite readers interested in one or more of these topics, who feel they could collaborate in a global project, to contact the named co-ordinator (Table 1).

## Collaborative management of endometriosis

The top ranked project was to develop internationally accepted models of care for endometriosis. Endometriosis is a common chronic gynaecological condition that can be associated with pelvic pain, profound adverse effects on quality of life, relationships, sex and intimacy, infertility, impairments in social and economic participation, and high personal and health service costs [1]. Many women wait for many years before receiving a definitive diagnosis, and medical and surgical treatments may not always alleviate all symptoms and can have side effects. Some women report dissatisfaction with health care, because their symptoms have been normalised or not believed, because they believe they received inadequate or false information or because their clinicians failed to address the psychosocial consequences of living with endometriosis [2].

International research priorities for endometriosis are concentrated on treatments, pathophysiology and epidemiology [3]. These investigations are important, but in the interim, women living with endometriosis need access to better quality primary and specialist care. This need has been identified elsewhere with the UK and Ireland advocating that one of their Top Ten research priorities is to investigate effective ways to educating health-care professionals about endometriosis [4]. Ensuring physicians have comprehensive, accurate, up-to-date knowledge is an important start. However, an understanding of normal and abnormal menstruation is also essential for women, and the wider community.  This is needed to facilitate early investigation, diagnosis, management and to reduce stigma.

Like other chronic conditions, endometriosis requires daily management and long term medical supervision. Health care characterised by inconsistent, outdated advice and limited treatment options, perhaps provided by a clinician who may doubt their own capability, can lead to frustration and helplessness for women as well as care providers [5]. Models of collaborative care that include the patient as collaborator, facilitate access to affordable multidisciplinary care, and promote active participation in decision making and activities to manage symptoms, treatment and psychosocial challenges, are needed. Care models should be co-designed with consumers, and tested using endometriosis-specific Patient Reported Outcome Measures (PROMS) as well as physician satisfaction and health economic indicators.

### Male infertility emotional and psychological support

The second ranked global topic was a call for research on psychosomatic issues in couples with an unfulfilled desire for a child, particularly for the male partner who has long been regarded as “the patient’s companion”. Recent changes in perspective means fertility research is no longer "women centred", and instead a “dyadic focus” is utilised [6]. The novel approach has revealed that the coping strategies of both partners with fertility problems are interrelated and that unfavourable strategies in one partner can influence the psychological risk profile of the other [7].

The profound psychological effect of diagnosis and therapy in reproductive medicine on men is now acknowledged [8]. Men with male factor infertility suffer as much as women diagnosed with female factor infertility, and this suffering is caused in part by the fact that male factor infertility seems to be more stigmatized than other infertility diagnoses. In many areas there is an absence of studies on the psychological impact of invasive reproductive treatment measures on infertile men. The counselling needs of men and women after successful – and especially after unsuccessful – treatment also warrants further investigation. The same applies to the counselling needs of sperm donors, of families after donor insemination, and to the development of children conceived in this manner [9].

A global effort is required to perform psychosomatic research on men with fertility problems that addresses the counselling needs of those men who seek medical treatment and also for those who do not. Cultural differences also need to be explored. This “underexplored territory” in psychosomatic research demands a global collaborative approach.

### Care provision following birth trauma

The third area identified for global collaboration was to evaluate care provision after birth trauma. A traumatic birth has been defined as *‘the emergence of a baby from its mother in a way that involves events or care that cause deep distress or psychological disturbance, which may or may not involve physical injury, but results in psychological distress of an enduring nature’* [10]. Evidence suggests that up to 30% of women can experience their birth as traumatic, and approximately 4% of women in general community samples and 19% in high-risk populations develop post-traumatic stress disorder (PTSD) following childbirth [11]. While antenatal and intrapartum risk factors for birth-related PTSD have been identified, women’s subjective perceptions are considered the most important as birth trauma can occur irrespective of how the baby is born. A traumatic birth may be associated with negative short and long-term impacts for women including PTSD symptoms such as flashbacks, nightmares, hypervigilance, and also reduced self-confidence and self-esteem, mother-infant attachment difficulties, relationship difficulties with partners, breastfeeding discontinuation, social isolation, reduced take-up of healthcare and prevention or delay of future conceptions [12]. Birth-related PTSD has also been associated with poor social-emotional development in infants [13].

Currently, there are no international insights into what, when, who and how support is provided to women following a traumatic birth. A recent UK audit showed maternity services tend to offer a listening or debriefing type service where women can review and discuss their care with a maternity professional [14] but data on the availability, use, and efficacy of comparable services in other countries is missing. ~~randomised trials report little or no evidence of a positive or adverse effect of debriefing~~

Further research is needed to review the models of support provided to women following traumatic childbirth and their outcomes. A mapping exercise with heads of services in different countries would obtain global insights into care provision. Surveys to elicit the support women have accessed and need could also be useful. Data could be used to design and develop effective interventions and to inform international and national guidelines related to care/treatment provision.

## Denial of pregnancy

How to best manage women who deny their pregnancy was another topic shortlisted for global input. Pregnancy is only detected after 20 weeks, or even at birth, in up to one in every 500 pregnancies [15]. Due to a lack of prenatal care and pre-existing morbidity, women who deny pregnancy and their babies are at increased risk of adverse medical and psychosocial outcomes including preterm birth, low birth weight, increased mortality and infanticide [16,17].

There is limited research in this field. All studies are small and their methodology divergent, making the identification of common outcomes difficult. An international study in this field has commenced as a pilot hypothesis-generating, explorative study using a qualitative research approach and empirical attachment research to explore the potential psychological factors and unresolved trauma that might be present in affected women [18].

The next step will be to use this data to consider how to adapt maternity care, ensure barriers to accessing antenatal care are removed, and how to help health professionals manage affected women and their babies.

## Cancer survivors who desire children

Another topic identified for global collaboration centred around the management of fertility desires in women who have survived cancer. Advances in cancer diagnosis and treatments have dramatically improved survival rates. Cancer survivors are often of reproductive age and desire children. The advent of new technologies such as egg donation and surrogate motherhood have raised their hopes for pregnancy. However, when they try to bear children, they confront more complex problems than other couples with infertility who have not survived cancer. These complexities can include fears of disease recurrence, limitations on time available for conception, loss of reproductive organs and cost of infertility treatments. These additional burdens can aggravate psychosomatic problems.

The barriers and assistance for cancer survivors seeking fertility assistance vary by country. In some countries in vitro fertilization and embryo transfer and other forms of fertility assistance are common and accessible. In other countries these services are not available to the majority of cancer survivors. Even in high resource countries, there can be barriers to egg donation and surrogate motherhood can be prohibited. This means that in some cases fertility goals are not able to be realised.

Despite the large volumes of work into fertility, this group remain under-researched. A global perspective evaluating the opportunities and barriers for fertility for cancer survivors is an important preliminary step in research. Utilisation of a common questionnaire in multiple countries would achieve important baseline data. This could be followed by a common survey to enquire about available psychosocial support and patient centred solutions to provide care. This could lead to the development of interventions for evaluation.

### Reducing incongruous expectations for childbirth

Another area identified as requiring a global research focus was to identify how to manage incongruous expectations for childbirth. Birth, by definition, involves uncertainty. Women gather information from a variety of sources on pregnancy and childbirth to cope with this uncertainty and prepare for birth. They form expectations of birth and make plans (formal or not) for what they prefer. However, birth is unpredictable and for many women actual birth is different to their plan. Incongruent planned-to-actual birth experiences have been studied in relation to vaginal versus caesarean delivery, the usage of epidural anesthesia, and hospital versus midwifery-led or home birth. Yet incongruence may also occur for other interventions and aspects of birth. Incongruent experiences can have detrimental effects: They have been linked with birth trauma [19], lower satisfaction with birth and care provision and feelings of guilt [20]. In the longer term, they have associated with post-partum depression [21] and PTSD [22].

The cultural image of childbirth in many countries is of a natural event, despite the increasing medicalization. Negative consequences of incongruent birth experience have been more often linked to birth that ended up more medical than desired, though the opposite direction (e.g., desiring a caesarean delivery or an epidural and not receiving them) can be just as detrimental. These findings raise two important questions: *Can we identify the factors that increase or lower the chances of incongruence between planned and actual birth?* To what extent are these factors related to the socio-cultural context, which shapes women's images of birth, perceptions of their body and expectations of themselves as a mother-to-be? Or, to institutional practices and constraints? Secondly, knowing that incongruent birth experiences cannot always be prevented, *which factors can decrease the detrimental effects of incongruent birth experience?*

Both expectations and experiences of childbirth are known to be affected by women's personal characteristics and beliefs [23], the socio-cultural context, provider attitudes and behaviours, and institutional characteristics. Since these are all potentially modifiable, it may be possible to identify ways to reduce the incongruence and its effects. Future research could continue to investigate these questions within countries and cultures and, most importantly, across cultures, to identify universal and culture-specific targets for interventions to reduce such incongruence and minimize its detrimental effects on women's perinatal mental health.

## Journal impact factor rising

Finally, it is with pleasure that we report that JPOG has continued its constant rise in Impact Factor, growing from 1.065 in 2015 to 2.327 in 2018. There has been a corresponding increase in article downloads with a 23% increase observed in 2018 compared to 2017. Articles were downloaded globally, with Europe and North America the leading regions. The journal continues to receive diverse submissions and authorship is geographically diverse. We hope these positive outcomes will continue into 2020.

## Disclosure statement

No potential conflict of interest was reported by authors.

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This meta-synthesis better reflects the relationships listed in the text

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**Table 1 Top ranked topics for global collaboration**

| **Topic** | **Global co-ordinator** |
|---|---|
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| Care provision following birth trauma | Gill Thomson<br>GThomson@uclan.ac.uk. |
| Denial of pregnancy | Antje Bittner<br>Email: antje.bittner@ukdd.de |
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