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# Reframing the Debate Around State Responses to Infertility: Considering the Harms of Subfertility and Involuntary Childlessness

## Abstract

Many countries are experiencing increasing levels of demand for access to assisted reproductive technologies (ART). Policies regarding who can access ART and with what (if any) support from a collective purse are highly contested, raising questions about what state responses are justified. Whilst much of this debate has focused on the status of infertility as a disease, we argue that this is something of a distraction, since disease framing does not provide the far-reaching, robust justification for state support that proponents of ART seem to suppose. Instead, we propose that debates about appropriate state responses should consider the various implications for health and broader well-being that may be associated with difficulties starting a family. We argue that the harms and disruption to valued life projects of subfertility-related suffering may provide a stronger basis for justifying state support in this context. Further, we suggest that, whilst ART may alleviate some of the harm resulting from subfertility, population-level considerations can indicate a broader range of interventions aimed at tackling different sources of subfertility-related harm, consistent with broader public health aims.

## Introduction

In recent decades, many countries have experienced high levels of demand for assisted reproductive technologies (ART) (Kupka et al, 2010; Mansour et al., 2014). Simultaneously, fertility treatments have become increasingly commercialised due to their profit-making potential (Kamphuis et al., 2014; Frith, 2014). Governmental and other healthcare regulators, funders and providers have developed diverse policies regarding who can access ART, in what circumstances and with what (if any) support from a collective purse (NICE, 2004, 2013; Andrews and Elster, 2000).<sup>i</sup> This policy diversity is met with similarly diverse complaints (McMillan, 2003; Vayena et al., 2002): where ART is relatively readily available, critics argue that state or other collective funding for treatment is inappropriate given other unmet health needs; where ART is less readily available, people (and increasingly organised groups) who want to access or provide treatment object that their needs are being unfairly neglected or their freedoms inappropriately curtailed (Dyer et al., 2013; Donchin, 2011; Mladovsky and Sorenson, 2010).

In the context of the burgeoning possibilities and costs of ART, the question as to how states should respond to citizens who experience difficulties (and seek help) conceiving is not only practically and politically pressing, it is complex and in many ways philosophically challenging. In this paper, we highlight the problematic way the debate about state funding is often biomedically framed, illustrating the limitations of this and suggesting alternative potential justifications for state support. These link to broader, population-level strategies for tackling the problems stemming from conditions variously referred to as infertility, subfertility or involuntary childlessness. Debates about the provision of ART often focus on the disease status of infertility as central to justifying support. We think there are good reasons for preferring the term subfertility to infertility,<sup>ii</sup> and argue that the question of whether or not subfertility is considered a disease is a distraction, since it fails to track practical concerns about who can access ART, whilst generating ambiguities in practice that can be exploited by those with vested interests. Moreover, since being a disease is neither necessary nor sufficient to guarantee state funding, showing subfertility to be a disease will not be decisive in debates about what state support is justified.

Rather than seeking to provide a definition of subfertility or argue that it should or should not be considered a disease, we suggest that it will be more productive to focus on the harms resulting from subfertility, in particular the quality and extent of suffering it can cause, and how it affects individuals' opportunities to pursue valued life projects. Framing the harms of subfertility in this broader way, not tethered to a particular conceptualisation of it as a disease, may expand the range of potential responses to subfertility beyond ART and the narrowly biomedical. Further, attending to the broader social significance of subfertility, including its interaction with other areas of public life in which states have legitimate interests, may help formulate more nuanced policy responses in this area, and greater integration with other initiatives to improve public health and social well-being.

A discussion of the appropriateness of state responses to any health issue requires explication of some key background assumptions about the legitimate scope of state interest and action. We intend our comments to have reasonably broad application (not restricted to any particular countries or healthcare systems), although this discussion is largely predicated upon a roughly ‘western’ liberal political philosophy that assumes some form of (democratic) state governance is legitimate and justified, and that states have some (constrained) role in protecting and promoting the well-being of citizens, including their health (Jones, 1983; Lomasky, 1981). As such, we assume state intervention to support those with subfertility can, in principle, be justified, although we do not attempt to provide such a full justification here.

### Subfertility and the Disease Frame

In this section, we indicate some of the reasons why much of the debate about state support for ART has focused on whether or not subfertility (usually discussed as infertility) should be considered a disease. Variety in both the forms subfertility can take and the way diseases are conceptualised generates significant ambiguity here, leaving room for exploitation by those with vested interests in keeping subfertility within a medical setting. We argue, however, that recognition of subfertility as a disease is likely to be a poor guide as to who might benefit from ART, and is not necessary (nor likely to be sufficient) to obligate (or perhaps even justify) state funding for ART.

Since at least the late 1980s, people who wish to provide or receive fertility treatment have sought recognition of subfertility as a disease (Rosenberg, 1989; Becker and Nachtigall, 1992). The perceived advantages of this include social recognition of the severity and importance of the condition, together with the potential to access the considerable resources of healthcare.<sup>iii</sup> Recognising subfertility as a disease is thus seen as a means of ensuring ART is made widely available (Rosenberg, 1989).

The World Health Organisation (WHO) and several national health bodies have now recognised infertility<sup>iv</sup> as a disease, with the WHO describing it as “a *disease* of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (emphasis added) (WHO [online], 2015). Yet such proclamations still leave room for interpretation and dispute (for example, how frequent is ‘regular’ intercourse?). As such, subfertility retains a rather confused status both as a disease and within healthcare practice (van Balen and Inhorn, 2002). This ambiguity contributes to controversies surrounding state policies for supporting fertility treatment provision and creates opportunities for those individuals and groups who stand to benefit to manipulate understandings, concepts, definitions and categories to their advantage. For instance, stipulating a shorter time frame within the diagnostic criterion serves to broaden the definition of

subfertility, thereby making more people eligible for treatment, while emphasising biomedical causes of subfertility may mandate treatment for some while excluding those with non-biomedical subfertility.

Some of the confusion about the status of subfertility may be traced back to the lack of a single dominant concept of disease within the philosophy of medicine. The two leading approaches are the naturalist / objectivist and the normative / constructivist, and these have differing consequences for thinking about subfertility. In the remainder of this section we illustrate how the disease status of subfertility alters depending upon the underlying concept of disease in use, and the implications of this for regulating access to treatment.

Healthcare is largely, albeit implicitly, premised on objectivist accounts of disease. Christopher Boorse's account has been particularly influential, defining disease as "a type of internal state which impairs health, i.e. reduces one or more functional abilities below typical efficiency" (1977: 555). A condition counts as a dysfunction when it "falls more than a certain distance below the population mean" (1977: 559). Exactly where the line is drawn below which functional ability counts as diseased is, on Boorse's account, arbitrary and conventionally decided. Some forms of subfertility would certainly count as disease on this account, such as cases of congenital absence of the uterus, damaged fallopian tubes, or lack of viable sperm, where internal states clearly reduce functional abilities to reproduce below 'typical' efficiency.

Not all forms of subfertility, however, are linked to purely internal or clearly identifiable forms of dysfunction, and some would therefore fail to meet Boorse's criterion. Lifestyle and environmental influences can affect fertility in the absence of specific dysfunctions; and no cause can be found in approximately a quarter to a third of couples who seek help (described as 'unexplained subfertility') (Cahill and Wardle, 2002; Pandey et al., 2014; Hull et al., 1985; Maheshwari et al., 2008).<sup>v</sup> If eligibility criteria for state support for ART were based upon a narrow objectivist understanding of disease, treatment would likely extend only to a small subset of those deemed clinically subfertile.<sup>vi</sup> This approach may also identify as diseased those who do not consider their lack of fertility problematic (for instance, because they don't want to have children), whilst excluding many (including some same sex couples and single women) who currently seek access to fertility treatment.

A further problem for objectivist accounts relates to the non-binary nature of subfertility. Boorse defines disease in opposition to health, such that an individual is either diseased or healthy. However, people generally fall on a spectrum of being more or less fertile, where this can be affected by a number of factors varying across time, such as age and weight (McLernon et al., 2014). Some who do not conceive within a specified time period do not have any underlying biological dysfunction, while some who do have biological indicators of subfertility may nonetheless successfully conceive. In addition, a woman or man who is subfertile with one partner may not be so with another, despite the absence of any identifiable

cause of subfertility in either partner (Meniru et al., 1997). It seems curious to consider subfertility a disease if it can be 'cured' by changing sexual partner. As mentioned above, a narrow objectivist might well exclude cases like this from the category of disease, but then the problem arises that this conception fails to track common (and medical) understandings and risks seeming arbitrary, making it potentially unacceptable as the basis for justifying or allocating resources to ART.

Constructivists hold disease to be an evaluative, normative, practical concept that tracks the ways that societies value or disvalue certain conditions (Engelhardt, 1976; Margolis, 1976; Nordenfelt, 1995, 2007). Thus, it is only when people have distressing subfertility that the notion of disease arises, and arguably, it is only because we have relevant medical interventions to cure or overcome subfertility that it is counted as a disease rather than a social problem to be resolved outside the medical arena. Constructivist accounts may include a descriptive biomedical component, but emphasise the undesirability of conditions or experience, and social acceptance of this viewpoint.

A constructivist account of subfertility as a disease will not necessarily identify those with particular biomedical dysfunctions as being diseased, or at least will not encourage those with undistressing subfertility to consider themselves diseased. Instead, a constructivist account may identify as diseased all of those who are distressed by their experienced lack of fertility, irrespective of origin. Such an account is thus likely to collapse distinctions between 'biomedical' and 'social' subfertility, where the former is attributed to biomedical factors (blocked tubes, low sperm count, etc.) and the latter to social circumstances, relationship status, sexual orientation, and so on (Ashcroft, 2006; Weston and Vollenhoven, 2002). Essentially, constructivist accounts erode the distinction between medicalised and non-medicalised concepts of subfertility.

At least some who identify as subfertile resist this erosion. Overtly adopting a constructivist account of disease risks diminishing the apparent (or desired) legitimacy that may be conferred by holding disease status. That is, if subfertility is defined absent biomedical criteria (particularly through the inclusion of single people or same sex couples as subfertile) it may seem unlike other more familiar diseases (which have what may be perceived as 'objectively identifiable' biomedical markers), and thus less deserving of healthcare funding. Such thinking may be misguided, but adopting a constructivist account of subfertility may undermine attempts to garner sympathy, respect and public funding for its treatment.

In summary, objectivist accounts of disease significantly narrow the diagnosis of subfertility to those with specific identifiable forms related to biological dysfunction. As a result, they are unlikely to be accepted by many of those seeking treatment. Constructivist accounts, meanwhile, broaden the concept to the extent that it fails to map commonsense understandings of disease, and thereby diminish the potential for

securing health resources on this basis. Although defining something as a disease is sometimes used as a shortcut to answering the question of what, if any, state support is required, this works only because disease status serves as a heuristic device to indicate the presence of factors that justify (or obligate) state support. Where disagreement and controversy about the appropriate extent of state support persists, use of disease status as a surrogate marker seems inappropriate, especially given the implications of competing conceptions of disease discussed above. Therefore, alternative rationales to guide state action in response to subfertility should be sought. Further, as we argue below, the harms of subfertility from identifiable biomedical causes are not clearly distinguishable from those where such causes cannot be identified, rendering this distinction unhelpful in terms of tracking what is morally salient about subfertility.

### Involuntary Childlessness, Harm and State Support

#### *Suffering and disruption to valued life projects*

We propose that subfertility leads to two sorts of (interlinked) harm, which might, together or independently, justify state support. The first is suffering, and the second is thwarting of valued life projects. We argue that the particular forms of suffering and disruption to valued life projects associated with subfertility may justify some degree of state support, although the form such support takes need not be medicalised (and other approaches, such as facilitating alternative forms of child-rearing relationships, tackling the stigma attached to childlessness, and so on, may have additional benefits). Further, we suggest that justifications for state support based on the harm resulting from subfertility are inconsistent with the use of a biomedical / objectivist conception of subfertility to restrict support: similar harm can occur equally amongst those who are childless due to biomedical factors and those whose childlessness arises from their social context. As such, we propose using the term ‘involuntary childlessness’ in place of subfertility, since the former lacks the medicalised overtones of the latter, and better reflects the symmetry with which involuntary childlessness, no matter the cause, should be treated.

Much research has sought to describe both quantitatively and qualitatively what it means to wish for, but be unable to have children. Subsequently, arguments have been provided both in favour of and against the increased provision of ART as one means of relieving the associated suffering.<sup>vii</sup> Space does not permit a full consideration of this evidence here, but we summarise some of the key points in what follows.

Personal, social, cultural and economic factors can all play an important role in affecting the type and extent of suffering the involuntarily childless experience. The practical disadvantages and social stigma of childlessness can be acute. In some contexts, especially those where younger family members typically take responsibility for caring for older relatives, having children is a strongly engrained norm. Childlessness can therefore lead to social alienation, abuse, poverty, humiliation and other harms that can, on occasion, be life-ending. Women typically experience more of these negative effects than men,

reflecting and perpetuating gender inequalities (Dyer et al, 2002, 2005; Daar and Merali, 2002; McLeod and Ponesse, 2008).

At the individual level, thwarted attempts to establish parental relationships may damage a person's social identity and sense of self. The extent of this varies between individuals, and whilst, for some, not having children will be something that they are able to accept in time, for others, the idea of becoming a parent may be central to their conception of living a good life. For those people, it may be very difficult to accept that they will not be able to found a family as anticipated, leading to severe and long term distress (Herrmann et al, 2011; Downey and McKinney, 1992; Dyer et al., 2005). Thus, as well as the harm of acute suffering resulting directly from childlessness, there may be broader, more pervasive harms in terms of lost opportunities to pursue valued life projects.

The language people use to describe their sense of failure and disappointment in the context of involuntary childlessness can be powerful: bereavement, guilt, loss, and grief feature frequently amongst the expressions used to explain how it feels to be missing the desired child / children (Guerra et al, 1998; Myska [Online], 2014; May, 1995; Greil, 1997; Cousineau and Domar, 2007; Carter et al., 2013).<sup>viii</sup> Affected individuals describe struggling to maintain good relationships with others or even to venture out from home because the sight of families with children is so painful. There are also many accounts of people spending vast sums of money and years of their lives trying to conceive, indicating the depth and strength of their desire (Coles, 2010; Hale and Bracchi, 2012; Ferguson, 2014; Spar, 2013).

For those who do suffer, the impact of involuntary childlessness can be devastating, chronic and pervasive. Clearly not all people will suffer to the same extent or in the same way, and variations can depend on individual circumstances and character, as well as on socio-cultural factors (including the response of wider communities). The multi-faceted nature of suffering may be associated with inability to conceive genetically related offspring, or missing out on other aspects of starting a family, such as pregnancy, childbirth, meeting familial / cultural expectations about what is 'normal,' and so on. This makes it difficult to generalise, or to judge the type and extent of suffering in specific cases.<sup>ix</sup> Yet the fact that not all those who remain childless suffer, or suffer for the same reasons, should not lead us to conclude that *none* suffer from childlessness, or that the suffering is never extensive and profound.

Two key points may be drawn from the literature on childlessness-related suffering: first, the nature of the suffering is often wrapped up in (relational) notions of personal identity (regarding personal expectations and social roles), forming special relationships, pursuing valued life projects, and so on. Second, the experience of suffering does not seem to depend upon there being any particular cause of involuntary childlessness, although the specific reasons why people suffer may vary.<sup>x</sup> Suffering can result whether biomedical or social factors are the cause of involuntary childlessness, and thus, a suffering-



based justification for state support should apply equally to the involuntarily childless in general, irrespective of any diagnosis or not of disease.

The suffering associated with involuntary childlessness is linked to what we identify as the second harm: thwarting of valued life projects. It seems reasonable to say that involuntary childlessness represents a significant obstacle to some people's ability to pursue what matters to them in life. The effects sometimes resulting from involuntary childlessness - grief, humiliation, shame, loss, depression, social alienation, loss of identity, damage to relationships - are bound up in day-to-day lives as well as future plans, and can have a corrosive impact on all aspects of an individual's life.

We do not wish to strictly delineate between the harm resulting from suffering and that from disruption to valued life projects, since the two are closely linked. Experiencing suffering, whatever the cause, is likely to significantly impact upon the ability to pursue valued life projects. Additionally, being frustrated in attempts to pursue valued life projects is likely to contribute to experiences of suffering.

#### *Legitimate State Support: Suffering and Valued Life Projects*

Above, we have sought to outline the kinds of harm experienced by some of those who are childless, in particular, those who remain childless despite (sometimes considerable) efforts on their part to bear children. In this section, we will argue that this harm can be of the appropriate sort to justify and guide state support. We do not propose that *any particular* kind of support is (all things considered) justified, since this will depend on whether the intervention itself is appropriate (taking into account efficacy, invasiveness, cost, implications for fairness, safety, and so on). Nor does it preclude other relevant factors from countering this justification and guidance. We suggest that a 'public health'-type approach (by which we mean an approach informed by the methods and framing adopted in public health research, and focusing on population-level interventions and effects), may usefully guide legitimate state action. This need not be strictly concerned with promoting health in a narrow sense (especially since we argue the problematic nature of involuntary childlessness extends beyond being a disease), but could more broadly seek to promote well-being and foster other social values.

What constitutes an appropriate justification for state support is contested. There is no single, settled account of legitimate political influence with which all reasonable people agree (and nor is there any prospect of one). Yet there is at least a degree of convergence within the broadly dominant 'western' political liberalism which may permit some agreement at the level of specific actions even where there is disagreement about the guiding principles used to justify actions.<sup>xi</sup> Accordingly, we suggest that a range of popular political philosophies could uphold supportive state responses to involuntary childlessness justified on the basis of relieving suffering or facilitating valued life projects. None of these positions

involve a commitment to the position that state support is justified *only* in the case of disease, and so we maintain that disease status remains the wrong focus for such justificatory enterprises.

State intervention may be justified on the basis of the relief of the suffering directly resulting from involuntary childlessness. Focus on the relief of suffering can form one element of a 'piecemeal' account of what states are justified in doing. In this case, relieving suffering in others may generally be seen as desirable as a form of exercising compassion, solidarity, beneficence, empathy, or a number of other social values. Such motivation for action will be unobjectionable, though full justification will depend (as ever) on the action proposed.

Ensuring that people have (equal) opportunities to pursue valued life projects, understood in reasonably broad terms, is seen as a legitimate basis for state action on many accounts of political philosophy. For instance, Rawlsian liberalism posits that a just state (formed of justly operating institutions) should not provide advantages to some citizens over others on the basis of their conceptions of the good life; capabilities approaches emphasise the need to ensure people have both negative freedoms and genuine positive opportunities to be or do what they have reason to value (Rawls, 1971; Sen, 2009).<sup>xii</sup> On any broadly 'western' liberal political philosophy it is likely that justification for state intervention will relate more or less directly to the facilitation of people's pursuing good lives (as judged by themselves, but with certain limitations). Of course, one need not accept any such position, and there will be plenty who think the state's scope for action should be much more restricted. Our aim here is not to support any particular political theory. Rather, our contention is only that, for those who think that states do have some role in facilitating people's valued life projects, ameliorating involuntary childlessness may be justified within that role.

The above justifications for state support do not suggest differential entitlements to support for those who struggle to bear children as a result of biological dysfunction as opposed to those for whom social factors are more influential. To the extent that the harms experienced across all forms of involuntary childlessness are comparable, it is not justifiable to discriminate between different groups. This is not to say that all people should receive *exactly the same* treatment, however, since potential for therapeutic benefit may differ according to what is contributing to the suffering associated with childlessness. Interestingly, some may derive benefit just from having access to therapy, even where this does not increase their prospects for conception or a live birth (Pandian et al, 2012; Ryan, 1999). Careful thought must therefore be given to the expected utility of treatment, which might relate to a variety of valued experiences.

A salient concern here relates to the distribution of state funds across society, including for tackling other causes of suffering and supporting other valued life projects. This distribution will depend on resources available to particular states and other budget pressures. As such, we cannot provide specific

suggestions as to how much any state should spend on addressing involuntary childlessness, but instead make some more general points regarding what ought to be borne in mind when making judgements about the relative priority of fertility treatment in resource allocation.

Essentially, our contention is that different causes of suffering and life project disruption should be treated symmetrically in terms of state support, according to their magnitude. While there are no agreed metrics for measuring suffering or incommensurate forms of harm, it is plausible to postulate that involuntary childlessness may cause harm of a similar nature and / or degree as other threats to valued life projects, such as homelessness, lack of education, unemployment, ill health, loss of loved ones and relationship breakdown. The list goes on, and it will be for states / societies to negotiate the extent to which such factors are thought to cause significant harm and warrant state responses. There are significant differences globally between the sphere of legitimate influence allocated to states, relating to local socio-cultural norms for what is expected / accepted of the state.<sup>xiii</sup> As such, norms may operate to restrict the domain of state activity to relieve suffering or facilitate life projects in areas that would otherwise be legitimate targets for intervention. This is likely to mean that factors which equally affect individuals' life projects and suffering are not, in practice, addressed to the same extent. We claim however, that the appropriateness of the influence of these norms should always be open to question.

#### Population-Level Considerations

We suggest that there is no reason to expect the forms of suffering and disruption to valued life projects will be significantly and consistently different depending on the causes of involuntary childlessness.<sup>xiv</sup> If it is generally accepted as legitimate for states to use resources to relieve suffering and facilitate valued life projects, at first look it is legitimate to do so in cases of involuntary childlessness.

We now propose that, in justifying intervention on the basis of relieving suffering and facilitating valued life projects, state support for the involuntarily childless is more akin to broader state action to promote well-being across domains, rather than any narrower role in healthcare. This is consistent with the public health-type approach we endorse: keeping in mind the 'bigger picture,' population-level effects and trade-offs between different costs and benefits across public life, and not restricted to promoting 'health' in a narrow sense. Whilst we think the activities states might engage in to tackle involuntary childlessness will often be readily recognisable as public health interventions, we do not think they should be restricted only to interventions with a direct impact on health, since (as we have shown) the problematic nature of involuntary childlessness extends beyond narrow conceptions of health and disease.

Whilst ART and other fertility treatments may provide solutions for some, they leave a considerable amount to be desired in terms of efficacy and safety (Bhattacharya et al., 2008; Dapuzzo et al., 2011; Pandian et al., 2012). Adopting a medicalised conception of subfertility encourages a focus on refining our clinical definition (and subsequent identification) of the subfertile, and ensuring ART is made available to only and all within this group. Yet this could simply increase demand for ART (whether or

not provision is increased to match) and will likely result in many people remaining childless either through lack of access to ART or due to its inefficacy. A particular concern is that any widened eligibility criteria for state-funded ART could increase demand from (and uptake in) groups who are less likely to be well served by these technologies (such as older people, those who are outside a healthy weight range, and couples with no apparent cause of subfertility who may still conceive naturally).

A population-level, 'public health'-type approach could encourage consideration of the wider effects of efforts to address the harms associated with involuntary childlessness, looking beyond individual-level interventions (Lemoine and Ravitsky, 2015).<sup>xv</sup> For instance, education to promote social capital and empowerment (particularly amongst women), as well as tackling social problems such as poverty and poor healthcare provision in general, may have both direct and indirect effects on involuntary childlessness. Since a significant global cause of involuntary childlessness results from sexually transmitted infections (STIs) (Vayena et al., 2002), safe sex education and condom provision can tackle some biomedical causes of subfertility. Encouraging awareness and discussions of sexual health and fertility can also challenge taboos surrounding childlessness and reduce social stigma and alienation which drive psychological and physical abuse, shame, guilt, depression and other damaging effects which can result from childlessness.<sup>xvi</sup> Altering such deeply embedded norms and traditions may be both difficult and contentious, yet without tackling the underlying prejudices against childlessness, potential to limit the suffering of those who are childless (both voluntarily *and* involuntarily) will be restricted.

There are also opportunities for child-rearing and establishing a family which do not involve ART, genetically related children, or direct experience of pregnancy and childbirth. Fostering, adoption and engagement in other forms of childcare may provide some people with the chance to experience the kinds of parenting and nurturing relationships they may typically seek through 'natural' methods of conception and child-bearing (Friedrich, 2013). Although such alternatives may be unavailable to some and rejected by others, they can present opportunities for family building and loving relationships which may relieve suffering and enable people to lead fulfilling lives. Once again, in order for adoption and other opportunities for child-rearing to be recognised as valued alternatives, social prejudices and assumptions may need to change. In particular, whilst some currently see a lack of genetic kinship as a significant loss, such beliefs could shift along with changing norms and practices.<sup>xvii</sup> There may also be a need to make processes such as adoption less onerous, while maintaining regulations to ensure the safety and well-being of both children and parents.

Activities enabling alternative ways of experiencing (quasi) parental relationships may tackle the harmful effects resulting from involuntary childlessness both directly and indirectly. As discussed, education (particularly regarding sexual behaviours) can reduce STIs as well as foster social capital, help to combat poverty and challenge gendered power imbalances; public health programs to promote healthy lifestyles

may reduce lifestyle-related subfertility as well as promote general health and wellbeing (Lemoine and Ravitsky, 2013); and state facilitation of fostering and adoption (particularly for same sex couples) may undermine narrow cultural stereotypes of traditional family forms, promoting inclusivity (McTernan, 2015). Some structural factors affecting involuntary childlessness may only be tackled through state action, including factors that affect (particularly women's) opportunities to bear children during their most fertile years, such as parental benefits and secure employment (including flexible working, parental leave and prospects for promotion). Greater security at home and work may also enable people to start trying to conceive at a younger age when their fertility is likely to be higher (Haan and Wrohlich, 2011; Vos, 2009; D'Addio and D'Ercole, 2005).

All of these areas of action could fall within the state's legitimate scope of activity, although the extent of expenditure will, as discussed, be a vital and decisive factor in determining what action is justified. Our intention is to show that involuntary childlessness, when viewed not only (or primarily) as a 'disease,' but rather as a cause of suffering and lost opportunities to pursue valued life projects, linked to a complex array of norms, cultures, expectations, biological factors and social structures, can be tackled through a diverse range of interventions. Further, it is likely that only state action in the form of population-level interventions will be able to alter structural factors in ways necessary to significantly reduce both involuntary childlessness and its associated harm.

### Concluding Remarks

This paper has considered how states ought to respond to (increasing) demands for fertility treatment. Debate in this area has typically focused on whether or not subfertility should be recognised as a disease (and treated through health services alongside other diseases). We have argued that, although such a focus is understandable, it is ultimately unhelpful since it simply leads to further disagreements and fails to resolve questions regarding justified state action. Instead, we argue for a careful consideration of the harms resulting from involuntary childlessness, without restricting this consideration to the domain of health and disease. We outline two sources of harm - suffering directly resulting from involuntary childlessness, and related disruption to valued life projects - which we propose are a more promising basis for justifying state support. In considering justified state support, harms resulting from involuntary childlessness should be considered symmetrically with comparable harms from other sources. Further, harm-based justifications provide no basis for discriminating between involuntary childlessness resulting from different causes (i.e. the biomedical / social subfertility distinction).

Although we cannot make recommendations regarding the magnitude of state support for involuntary childlessness that would be appropriate on this account, we do suggest that re-focusing activities towards population-level and public health interventions (rather than upscaling provision of ART) may offer advantages. Such strategies would aim to alter background conditions in order to both

reduce incidence of involuntary childlessness (for example, by reducing STIs), and to reduce the harms resulting from childlessness (for example, by tackling negative stereotypes and stigmatisation of childless women).

This move away from a medicalised concept of subfertility and methods of treatment, and towards a more holistic understanding of the harms of involuntary childlessness and how these may be tackled in tandem with other factors affecting public health and social well-being may have potentially controversial implications (Lemoine and Ravitsky, 2015). For instance, since justification for state support does not rely upon restoring 'natural' (healthy) function, it will be equally important to support homosexual couples and single people in their efforts to have children as heterosexual couples. Whilst some will find this departure from the medicalised, health-restorative approach objectionable, we believe it to be more consistent with robustly justifiable grounds for state provision of support to the involuntarily childless.

## References

- D'Addio, A. C. and D'Ercole, M. M. (2005). 'Policies, Institutions and Fertility Rates: a Panel Data Analysis for OECD Countries'. *OECD Economic Studies*, 41(2): 7–43.
- Andrews, L. B. and Elster, N. (2000). 'Regulating Reproductive Technologies'. *Journal of Legal Medicine*, 21(1): 35-65.
- Ashcroft, R. (2006). 'Fair Rationing is Essentially Local: An Argument for Postcode Prescribing'. *Health Care Analysis*, 14: 135-144.
- van Balen, F. and Inhorn, M. C. (2002). 'Introduction: Interpreting Infertility: a View From the Social Sciences'. in F. van Balen and M. C. Inhorn (eds.) *Infertility Around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*. Berkley: University of California Press.
- Becker, G. and Nachtigall, R. D. (1992). 'Eager for Medicalisation: the Social Production of Infertility as a Disease'. *Sociology of Health and Illness*, 14(4): 456-471.
- Bhattacharya, S.; Harrild, K.; Mollison, J.; Wordsworth, S.; Tay, C.; Harrold, A.; McQueen, D.; Lyall, H.; Johnston, L.; Burrage, J.; Grossett, S.; Walton, H.; Lynch, J.; Johnstone, A.; Kini, S.; Raja, A. and Templeton, A. (2008). 'Clomifene Citrate or Unstimulated Intrauterine Insemination Compared with Expectant Management for Unexplained Infertility: Pragmatic Randomised Controlled Trial'. *British Medical Journal*, 337(7666): 387–390.
- Boorse, C. (1977). 'Health as a Theoretical Concept'. *Philosophy of Science*, 44(4): 542-573.
- Cahill, D. J. and Wardle, P. J. (2002). 'Management of Infertility'. *British Medical Journal*, 325(7354): 28-32.
- Carter, D.; Watt, A. M.; Braunack-Mayer, A.; Elshaug, A. G.; Moss, J. R. and Hiller, J. E. (2013). 'Should There Be a Female Age Limit on Public Funding for Assisted Reproductive Technology? Differing Conceptions of Justice in Resource Allocation'. *Journal of Bioethical Inquiry*, 10(1): 79-91.

- Coles, S. (2010). 'The True Cost of IVF Treatment'. *Moneywise* [online]. Available at: <http://www.moneywise.co.uk/cut-your-costs/family-life/the-true-cost-ivf-treatment>. [Accessed 07/05/2015].
- Cousineau, T. M. and Domar, A. D. (2007). 'Psychological Impact of Infertility'. *Best Practice and Research Clinical Obstetrics and Gynaecology*, 21(2): 293-308.
- Daar, A. S. and Merali, Z. (2002). 'Infertility and Social Suffering: the Case of ART in Developing Countries'. pp. 15-21 in Vayena, Rowe and Griffin (eds.) *Current Practices and Controversies in Assisted Reproduction*. Geneva: World Health Organisation.
- Dapuzzo, L.; Seitz, F. E.; Dodson, W. C.; Stetter, C.; Kunselman, A. R., and Legro, R. S (2011). 'Incomplete and Inconsistent Reporting of Maternal and Fetal Outcomes in Infertility Treatment Trials'. *Fertility and Sterility*, 95(8): 2527-2530.
- Donchin, A. (2011). 'In Whose Interest? Policy and Politics in Assisted Reproduction'. *Bioethics*, 25(2): 92-101.
- Downey, J. and McKinney, M. (1992). 'The Psychiatric Status of Women Presenting for Infertility Evaluation'. *American Journal of Orthopsychiatry*, 62(2): 196-205.
- Dyer, S. J.; Abrahams, N.; Mokoena, N. E.; Lombard, C. J. and van der Spuy, Z. M. (2005). 'Psychological Distress Among Women Suffering From Couple Infertility in South Africa: a Quantitative Assessment'. *Human Reproduction*, 20(7): 1938-1943.
- Dyer S. J.; Sherwood, K.; McIntyre, D. and Ataguba J. E. (2013). 'Catastrophic Payment for Assisted Reproduction Techniques with Conventional Ovarian Stimulation in the Public Health Sector of South Africa: Frequency and Coping Strategies'. *Human Reproduction*, 28(10): 2755-2764.
- Engelhardt, T. (1976). 'Ideology and Etiology'. *Journal of Medicine and Philosophy*, 1: 256-268.
- Ferguson, D (2014). 'IVF and the NHS: the Parents Navigating Fertility's Postcode Lottery'. *The Guardian* [online]. Available at: <http://www.theguardian.com/money/2014/may/10/ivf-nhs-fertility-postcode-lottery-cut-costs>. [Accessed 07/05/2015].
- Friedrich, D. (2013). 'A Duty to Adopt?'. *Journal of Applied Philosophy*, 30(1): 25-39.
- Frith, M. (2014). 'You're Big Business Now, Baby'. *The Telegraph* [online]. Available at: <http://www.telegraph.co.uk/women/womens-health/11171311/Youre-big-business-now-baby.html>. [Accessed 14/01/15].
- Greil, A. L. (1997). 'Infertility and Psychological Distress: a Critical Review of the Literature'. *Social Science and Medicine*, 45(11): 1679-1704.
- Guerra, D.; Llobera, A.; Veiga, A. and Barri, P. N. (1998). 'Psychiatric Morbidity in Couples Attending a Fertility Service'. *Human Reproduction*, 13(6): 1733-1736.
- Haan, P, and Wrohlich, K. (2011). 'Can Child Care Policy Encourage Employment and Fertility?: Evidence From a Structural Model'. *Labour Economics*, 18: 498-512.

- Hale, B. and Bracchi, P. (2012). 'The Couples Crippled by the Cost of IVF'. *The Daily Mail* [online]. Available at: <http://www.dailymail.co.uk/femail/article-2085356/The-couples-crippled-cost-IVF.html>. [Accessed 07/05/15].
- Harris, J. (2003). 'Assisted Reproductive Technological Blunders (ARTBs)'. *Journal of Medical Ethics*, 29(4): 205-206.
- Health Talk (2015) 'People's Experiences: Infertility'. *Health Talk* [online]. Available at: <http://www.healthtalk.org/peoples-experiences/pregnancy-children/infertility/topics>. [Accessed 07/05/2015].
- Herrmann, D.; Scherg, H.; Verres, R.; von Hagens, C.; Strowitzki, T. and Wischmann, T. (2011). 'Resilience in Infertile Couples Acts as a Protective Factor Against Infertility-Specific Distress and Impaired Quality of Life'. *Journal of Assisted Reproduction and Genetics*, 28(11): 1111-1117.
- Hull, M. G.; Glazener, C. M.; Kelly, N. J.; Conway, D. I.; Foster, P. A.; Hinton, R. A.; Coulson, C.; Lambert, P. A.; Watt, A. M. and Desai, K. M. (1985). 'Population Study of Causes, Treatment, and Outcome of Infertility'. *British Medical Journal*, 291(6510): 1693-1697.
- Jones, G. E. (1983). 'The Right to Health Care and the State'. *The Philosophical Quarterly*, 33(132): 279-287.
- Kamphuis E. I.; Bhattacharya S.; van der Veen, F.; Mol, B. W. and Templeton, A. (2014). 'Are We Overusing IVF?'. *British Medical Journal*, 348: g252-g256.
- Kupka, M. S.; Ferraretti, A. P.; de Mouzon, J.; Erb, K.; D'Hooghe, T.; Castilla, J. A.; Calhaz-Jorge, C.; De Geyter, C. and Goossens, V. (2014). 'Assisted Reproductive Technology in Europe, 2010: Results Generated from European Registers by ESHRE'. *Human Reproduction*, 29(10): 2099-2113.
- Lemoine, M. and Ravitsky, V. (2013). 'Toward a Public Health Approach to Infertility: the Ethical Dimensions of Infertility Prevention'. *Public Health Ethics*, 6(3): 287-301.
- Lemoine, M. and Ravitsky, V. (2015). 'Sleepwalking into Infertility: The Need for a Public Health Approach Towards Advanced Maternal Age'. *American Journal of Bioethics*, 15(11): 37-48.
- Lomasky, L. E. (1981). 'Medical Progress and National Health Care'. *Philosophy & Public Affairs*, 10(1): 65-88.
- Maheshwari, A.; Hamilton, M. and Bhattacharya, S. (2008). 'Effect of Female Age on the Diagnostic Categories of Infertility'. *Human Reproduction*, 23(3): 538-542.
- Maheshwari, A.; Griffiths, S. and Bhattacharya, S. (2011). 'Global Variations in the Uptake of Single Embryo Transfer'. *Human Reproduction Update*, 17(1): 107-120.
- Mansour R.; Ishihara, O.; Adamson, G. D.; Dyer, S.; de Mouzon, J.; Nygren, K. G.; Sullivan, E. and Zegers-Hochschild, F. (2014). 'International Committee for Monitoring Assisted Reproductive Technologies World Report: Assisted Reproductive Technology 2006'. *Human Reproduction*, 29(7): 1536-1551.
- Margolis, J. (1976). 'The Concept of Disease'. *The Journal of Medicine and Philosophy*, 1: 238-255.



- May, E. T. (1995). *Barren in the Land of Promise: Childless Americans and the Pursuit of Happiness*. Cambridge (MA): Harvard University Press.
- McLeod, C. and Ponesse, J. (2008). 'Infertility and Moral Luck: the Politics of Women Blaming Themselves for Infertility'. *International Journal of Feminist Approaches to Bioethics*, 1(1): 126-144.
- McLernon, D. J.; te Velde, E. R.; Steyerberg, E. W.; Mol, B. W. J. and Bhattacharya, S. (2014). 'Clinical Predication Models to Inform Individualized Decision-Making in Subfertile Couples: a Stratified Medicine Approach'. *Human Reproduction*, 29(9): 1851-1858.
- McMillan, J. R. (2003). 'NICE, the Draft Fertility Guideline and Dodging the Big Question'. *Journal of Medical Ethics*, 29(6): 313-314.
- McTernan, E. (2015). 'Should Fertility Treatment be State Funded?'. *Journal of Applied Philosophy*, 32(3): 227-240.
- Meniru, G. I.; Brinsden, P. R. and Craft, I. L. (1997). *A Handbook of Intrauterine Insemination*. Cambridge: Cambridge University Press.
- Mladovsky, P. and Sorenson, C. (2010). 'Public Financing of IVF: a Review of Policy Rationales'. *Health Care Analysis*, 18(2): 113-128.
- Myska, S. (2014) 'When Childlessness isn't a Choice'. *BBC* [online]. Available at <http://www.bbc.co.uk/news/magazine-28785054>. [Accessed 14/04/2015].
- NICE (2004). *Fertility: Assessment and Treatment for People with Fertility Problems*. London: RCOG Press.
- NICE (2013). *Fertility: Assessment and Treatment for People with Fertility Problems*. Manchester: NICE.
- Nordenfelt, L. (1995). *On the Nature of Health: an Action-Theoretic Approach*. Dordrecht: Kluwert.
- Nordenfelt, L. (2007). 'Establishing a Middle-Range Position in the Theory of Health: A Reply to My Critics'. *Medicine, Health Care and Philosophy*, 10: 29-32.
- Pandey, S.; McLernon, D. J.; Scotland, G.; Mollison, J.; Wordsworth, S. and Bhattacharya, S. (2014). 'Cost of Fertility Treatment and Live Birth Outcome in Women of Different Ages and BMI'. *Human Reproduction*, 29(10): 2199-2211.
- Pandian, Z.; Gibreel, A. and Bhattacharya, S. (2012). 'In Vitro Fertilisation for Unexplained Subfertility'. *Cochrane Database of Systematic Reviews*, 4.
- Powers, M. and Faden, R. (2008). *Social Justice: The Moral Foundations of Public Health and Health Policy*. Oxford: Oxford University Press.
- Rawls, J. (1971). *A Theory of Justice*. Oxford: Oxford University Press.
- Robertson, J. A. (1994). *Children of Choice: Freedom and the New Reproductive Technologies*. Chichester: Princeton University Press.
- Rosenberg, C. E. (1989). 'Disease in History: Frames and Framers'. *The Milbank Quarterly*, 67: 1-15.

- Ryan, M. (1999). 'Using Conjoint Analysis to Take Account of Patient Preferences and Go Beyond Health Outcomes: An Application to In Vitro Fertilisation'. *Social Science & Medicine*, 48(4): 535-546.
- Sen, A. (2009). *The Idea of Justice*. Cambridge MA: Harvard University Press.
- Spar, D. (2013). *The Baby Business: How Money, Science and Politics Drive the Commerce of Conception*. Cambridge MA: Harvard Business Review Press.
- Sunstein, C. R. (1998). 'Practical Reason and Incompletely Theorized Agreements'. *Current Legal Problems*, 51(1): 267-298.
- Vayena, E.; Rowe, P. J. and Griffin, P. D. (2002). *Current Practices and Controversies in Assisted Reproduction: Report of a meeting on 'Medical, Ethical and Social Aspects of Assisted Reproduction' Held at WHO Headquarters in Geneva, Switzerland, 17-21 September 2001*. Geneva: World Health Organisation.
- Vos, A. E., (2009). 'Falling Fertility Rates: New Challenges to the European Welfare State'. *Socio-Economic Review*, 7: 485-503.
- Weston, G., and Vollenhoven, B. (2002). 'Is IVF Becoming a Band Aid for Social Infertility?'. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 42(5): 476-477.
- WHO (2015). 'Infertility Definitions and Terminology'. *World Health Organisation* [online]. Available at: <http://www.who.int/reproductivehealth/topics/infertility/definitions/en/>. [Accessed 07/05/2015].

Notes

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<sup>i</sup> See also Maheshwari et al., 2011 (and references contained within) for discussion of different approaches to regulation of various aspects of ART and factors affecting this.

<sup>ii</sup> A note on terminology: throughout this paper we often refer to ‘subfertility’ rather than the more widely used ‘infertility.’ The latter has connotations of permanence and irreversibility (sterility), whilst subfertility seems better able to capture the non-binary nature of fertility (i.e. people may have reduced fertility for a range of reasons, and may conceive spontaneously or with intervention).

<sup>iii</sup> Identifying subfertility as a disease may also help to establish what some see as a ‘right to have children’ by aligning it with a ‘right to healthcare.’

<sup>iv</sup> In the WHO definition, ‘infertility’ rather than ‘subfertility’ is used, although as discussed earlier, they do not mean anything radically different by using one term rather than the other.

<sup>v</sup> These data refer to heterosexual couples where subfertility is identified according to the widely used criterion of at least one year of unprotected heterosexual intercourse without conception.

<sup>vi</sup> A narrow understanding that requires an identifiable internal dysfunction in order to admit subfertility as a disease may be too demanding, as Boorse allows that dysfunction may occur at any level up to that of the organism. Thus it is possible that on a broader objectivist account, many of the (clinically) subfertile would count as having a disease.

<sup>vii</sup> This includes philosophical consideration of the (alleged) importance of bearing (genetically related) children (see, for example, Harris, 2003; Robertson, 1994).

<sup>viii</sup> Alongside academic reports on the effects of subfertility, there are numerous accounts of people’s experiences of subfertility on blogs, social networking sites and online support groups / web forums. Health Talk also hosts a set of interviews with people who have suffered from fertility problems, describing their experiences (Health Talk [Online], 2015).

<sup>ix</sup> Particularly given a reliance on people’s self-reporting.

<sup>x</sup> This inference must be somewhat tentative, since we are not aware of any literature that seeks to directly compare the suffering resulting from childlessness of people who are involuntarily childless for different reasons.

<sup>xi</sup> Sunstein describes this process as ‘incompletely theorised agreements.’ (Sunstein, 1998)

<sup>xii</sup> Further examples could be given here, including Powers and Faden’s (2008) ‘Social Justice’ approach to public health.

<sup>xiii</sup> For instance, in cultures where community-based support networks are central to the way of life, states may not be expected to provide care for the sick or elderly. Yet in other countries, it may be seen as the state’s job to ensure all sick and elderly people are cared for through taxation and publicly provided facilities.

<sup>xiv</sup> Whilst evidence is lacking, the etiology of different forms of childlessness could result in systematic differences of suffering, for instance, if the preservation of hope is more likely in heterosexual couples with unexplained subfertility, or if social stigma is more acute in some causes of childlessness than others. However, it is not clear that differences in suffering will map onto the medicalised subfertility / non-medicalised involuntary childlessness distinction, but rather will depend on a much broader range of factors. As such, potential differences here do not justify differential state support dependent on general judgements about the cause of childlessness.

<sup>xv</sup> Not discussed here are a range of other, population-level / public health interventions which states might introduce in order to maintain a sustainable population size. These may relate to migration policies as well as policies to encourage or

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discourage reproduction. There will be specific concerns associated with population control mechanisms which, though relevant to this discussion, we are unable to consider here.

<sup>xvi</sup> This may be particularly pertinent where background social conditions involve strong pronatalist assumptions. We cannot consider the status of such beliefs here, but they are widespread, and likely to implicitly and explicitly shape policy relating to fertility.

<sup>xvii</sup> More substantive claims regarding the value of genetic kinship are made, though they are quite contentious and not, we think, persuasive (Harris, 2003; Robertson, 1994).