Accessing Assisted Reproductive Technologies: Issues of Culture and Diversity in the Third Phase

Kate Hampshire and Bob Simpson [eds]

Series Title: Fertility, Reproduction, and Sexuality
Table of Contents

Introduction

Assisted Reproductive Technologies: A Third Phase? ??

Bob Simpson and Kate Hampshire

Section One: (Islamic) ART Journeys and Moral Pioneers

Introduction: ART Journeys and Moral Pioneers ??

Marcia C. Inhorn

‘Islamic Bioethics’ in Transnational Perspective ??

Morgan Clarke

Moral pioneers: Pakistani Muslims and the take-up of assisted reproductive technologies in the North of England. ??

Bob Simpson, Mwenza Blell and Kate Hampshire

Whither Kinship? Assisted Reproductive Technologies and Relatedness in the Islamic Republic Iran ??

Soraya Tremayne

Commentary: ‘ART journeys and Moral pioneers’ ??

Farouk Mahmoud

Section Two: ARTs in Developing Countries.

Introduction. ARTs in Resource Poor Areas: Practices, Experiences, Challenges and Theoretical Debates
Trudie Gerrits

Global Access to Reproductive Technologies and Infertility Care in Developing Countries

Willem Ombelet

Childlessness in Bangladesh: Women’s Experiences of Access to Biomedical Infertility Services

Papreen Nahar

Ethics, Identities, and Agency: ART, Elites and HIV/AIDS in Botswana

Astrid Bochow

A child cannot be bought? Economies of Hope and Failure When Doing ARTs in Mali

Viola Hörbst

Viola Hörbst

ARTS and the Low-Income Threshold: An overview from Sri Lanka.

Thalina S. Palihawadana and H.R. Seneviratne
Section Three: ARTs and Professional Practice

Introduction: Ethnic Communities, Professions and Practices

Alison Shaw

Reproductive Technologies and Ethnic Minorities: Beyond a Marginalising Discourse on the Marginalised Communities

Sangeeta Chattoo

Knock knock, ‘You’re my mummy’: Anonymity, Identification and Gamete Donation in British South Asian Communities

Nicky Hudson and Lorraine Culley

Practitioner perspective

Miriam Orcutt and Ana Liddie Navarro

Bibliography

Notes on Contributors

Index
ASSISTED REPRODUCTIVE TECHNOLOGIES: A THIRD PHASE?

Bob Simpson and Kate Hampshire

Introduction

The story of assisted reproductive technologies (ARTs) is a remarkable one.¹ That sperm and ova can be taken from a man and a woman, brought together in a petri dish to achieve conception and then implanted back into the womb of a woman where the early-stage embryo will come to term, was a technical feat that was to have profound consequences. With the birth of Louise Brown in 1978 the era of the ‘test-tube baby’ had begun and with it the emergence of a powerful confluence of biomedical, social and economic interests. Coupling the desires of those who are involuntarily childless with medical and pharmaceutical interests has led to an inexorable rise in the visibility and availability of ART services. Moreover, it has propelled their assimilation and acceptance into everyday worlds of family formation; the exceptional has become ordinary, or at least as ordinary as any human conception can ever be. It was reported at the European Society of Human Reproduction and Embryology’s annual meeting in Istanbul in 2012 that some five million babies had been born around the world with the aid of ARTs (ESHRE 2012, Franklin 2012).

Echoing an earlier prediction made by Paul Rabinow in relation to the new genetics, the power of ARTs to re-shape ideas of identity and relationality is such because developments of this kind ‘will be embedded throughout the social fabric at the micro-level’ (Rabinow 1996:100). But, the diffusion of ARTs has other consequences. Beyond the elementary assistance offered to a husband and wife using their own gametes to achieve conception are a plethora of other possibilities. Third party provision of sperm, ova or
fertilised embryos used with techniques such as in-vitro fertilisation (IVF), intra-uterine injection (IUI) and intra-cytoplasmic sperm injection (ICSI) bring novel relational possibilities. For example, mothers may donate eggs to their daughters thereby creating children who are both their ‘grandchildren’ and ‘children’ at the same time, as in the Melanie Boivin case. Male couples may employ the services of surrogates and egg donors to produce offspring that are biologically, socially and economically their own, as in the case of Tony Barlow and Barry Drewitt. Further possibilities are added given that gametes and embryos can be cryopreserved for use at some point in the future, enabling posthumous conception to take place, as in the case of Diane Blood. These combinations take reproduction and parenthood beyond existing norms and expectations. As such, they pose significant challenges to prevailing ethical, legal and religious orthodoxies. Not least of these challenges is the potential for commoditisation of gametes and embryos which threatens to dislodge these substances from their positions within existing schemes of meaning and value.

The anthropological literature on ARTs in the UK and the US has provided ground-breaking accounts of these encounters between novelty and convention in the realms of kinship, family and reproduction (Strathern 1992a, 1992b; Franklin 1997; Edwards 1993; Thompson 2005). These accounts described what we might think of ARTs in their first phase, a period approximating the 1980s and 1990s, in which extra-corporeal conception became available to a relatively small number of people in Europe, America and the Middle East. Services were available, but mostly in the private sector for those able to pay substantial sums for their own treatment.

The second phase of ARTs, from the late 1990s on, saw the spread of IVF across the globe with take up mostly by elites through private sector provision. A ‘Euro-American’ perspective on ARTs was soon augmented by accounts of IVF in a wide range of country settings. Accounts of IVF-cultures around the world include those for Israel (Kahn 2000;
Nahman 2013, Italy (Bonnacorso-Rothe 2009), Spain (Orobitg and Salasar 2005), China (Handwerker 2002), Ecuador (Roberts 2006), Egypt, (Inhorn 1994), Lebanon (Clarke 2011), Iran, (Tremayne 2006, 2009), India (Bharadwaj 2008) and Sri Lanka (Simpson 2001a, 2004a, 2004b, 2004c, 2005). These ethnographies illuminate the distinctive forms that parenthood, and relationality take when ARTs become available in diverse cultural settings. With the exception of Israel, where publically-funded fertility services sit within a wider policy of state-supported pro-natalism, access to ARTs in the countries listed above is mostly the preserve of those who can afford to pay for services. The commercial orientation of ART provision has rendered these services an important site of inequality in terms of class, race, ethnicity and gender and as such an important contributor to what Colen earlier identified as ‘reproductive stratification’ (Colen 1986). To date then, the study of ARTs in the second phase has mostly focussed on a relatively small number of global elites accessing services commercially, either in their own countries or following travel abroad (Ginsberg and Rapp 1995, Culley et al 2011). Set against the global burden of infertility, one could argue that this focus has produced a disproportional effect. ARTs, accessed by the few, have influenced the reproductive desires of the many both as an icon of technologically-assisted reproduction and as a source of powerful rhetorics about medicalised reproduction. Media coverage plays a major part in this process, continuing to ‘shape reproductive expectation and desires, particularly when reproductive “miracles” become the focus of media frenzy’ (Inhorn and Van Balen 2002:5).

Yet, this picture is changing and it is aspects of this change that we explore in this volume. Although at an early stage, it appears that delivery of ARTs is spreading beyond the private sector, both in first world and third world settings, as these technologies become increasingly recognised as part of a standard repertoire of medical assistance for infertility. Increasing accessibility and acceptability mean that far from being rare and exceptional,
ARTs are, for an ever widening constituency becoming part of routine expectation. This we refer to as ARTs in their third phase; an extension of access and availability which further integrates ARTs into infertility treatment across the globe. We have identified two stepping off points for our interest in this important phase in the development of ARTs. The first concerns publicly-funded access to ARTs in the UK and the second, the move to recognise infertility as a disease (rather than mere misfortune) and to mobilise treatments to address it as such in developing world settings.

Stepping Off Point One: Publicly Funded Access to ARTs in the UK

In recent decades, infertility and its consequences have become increasingly visible in the UK. In the 1980s it was estimated that one in six British couples who wished to have children were unable to do so (Hull et al. 1985). More recent estimates have resulted in predictions of an ‘infertility time bomb’ with as many as one in three couples having difficulty conceiving. Amongst the growing list of contributory factors are later age of first pregnancy (often blurring the distinction between voluntary and involuntary childlessness), an increase in sexually transmitted diseases, childhood obesity and a consequent rise of conditions such as polycystic ovary syndrome. Involuntary childlessness is a cause of major distress, bringing significant physical, emotional and social consequences. Failing to conceive when there is an explicit desire to do so is also a condition with which others easily identify and is often construed in terms of desperation and tragedy (Franklin 1997). Furthermore, a widespread response to this condition is a willingness to go to considerable physical, emotional and economic lengths to achieve a pregnancy that will result in a child that might be thought of in some way as one’s own.
With the development of ARTs there has been a growing recognition that infertility is not merely an unfortunate personal circumstance but a recognised condition for which a growing range of treatment options exist and, furthermore, that policies should be formulated and resources committed to its alleviation. As a consequence, in the UK over the last twenty years, the use of assisted reproductive technologies has gone from being something that was exceptional and rare to being relatively commonplace, with points of access available across a range of National Health Service (NHS) and private clinics. To this end, in 2004 the UK’s National Institute of Clinical Excellence (NICE) issued guidelines for NHS hospitals on the provision of fertility treatments. If certain conditions were met then patients could expect up to three cycles of IVF to be provided and funded by the state.

This move can be seen as part of a wider pan-European trend to support infertility services through the public purse. A recent survey by the European Society of Human Reproduction and Embryology (ESHRE) reported that 1051 clinics operating in 36 European countries (3 more than compared with 2007) reported 532,260 treatment cycles, representing a 7.9% increase in the activity since 2007, (Ferraretti et al. 2012). Furthermore, monitoring by ESHRE suggests that more ART cycles per million population were performed in countries where public funding was more easily available. For example, in Belgium and Denmark, where state funding is most generous, 2479 and 2450 ART cycles per million population were recorded in 2008. In Germany, Italy and UK, where state funding is less generous, the number of cycles per million were 801, 807 and 825 respectively. These figures have led health economist Mark Connelly to suggest that state policies for the funding of fertility treatment through public reimbursement has a direct influence on national birth rates. At a time when total fertility rates (TFR) have declined below replacement levels across Europe, these findings have important consequences, suggesting that ARTs may have
a role to play in maintaining national fertility rates by addressing unmet need for fertility treatment.

Our interest in the specifics of these broader demographics of infertility began with an ESRC-funded project which set out to investigate the ways in which British Pakistani Muslims understand and negotiate involuntary childlessness with particular reference to the solutions offered by the ARTs. In this research, we considered how the explicit intention to provide greater access to infertility treatments was received and acted upon by ethnic minority groups and specifically those from the Pakistani Muslim community. As a culturally distinct community, Pakistanis are typically characterised as conservative in their patterns of kinship and community, family formation and reproductive behaviour and their ideas about the place of children in the family (Berthoud 2000, Thapan 2005). Most Pakistanis also have a strong relationship with Islam as a guide to action generally, but particularly when faced with adversity. We were interested to learn more about the reproductive problems experienced by couples from this community, their ways of dealing with them and the issues faced by service providers in ensuring equal and appropriate access to treatments.

The research was carried out at a time when, despite a small upturn, low and late fertility looks set to be sustained in the UK, along with the rest of Europe (Goldstein et al. 2009). However, along with British Bangladeshis, British Pakistanis continue to have much higher fertility rates than the national average: close to three children per woman (Coleman and Dubuq 2010). British Pakistanis in particular have low levels of childlessness and higher progression to third and higher-order births than the general British population (Penn and Lambert 2002; Sobotka 2008; Modood 1997). These levels of fertility persist despite a particularly high prevalence of polycystic ovary syndrome-related infertility reported among South Asian populations in the UK (Rodin et al, 1998). Maintenance of high fertility rates in the face of rising infertility is often attributed to a strongly pronatalist ideology and normative
pressures to bear children. However, generally high levels of fertility do not equate with uniform fertility and where pronatalism is strong, the consequences of impaired or delayed fertility can be all the greater for individuals who experience reproductive disruption (Inhorn, 2003c; Hampshire et al. 2012a, 2012b). For couples who find themselves in this situation, the suffering that ensues can be acute. As we go on to demonstrate, the quest for resolution is not merely biomedical but connects with a tangle of interests that are cultural, moral and economic.

Stepping off Point Two: ARTs in Developing World Contexts

The second stepping off point is, on the face of it, a long way from the first. At the workshop held at the end of our Pakistani Muslims and ARTs project, it was apparent from the contributions of Frank Van Balen, Johanne Sundby and Willem Ombelet regarding reproductive technologies in lower income countries that there were important connections. These presentations led us to think more carefully about the availability of ARTs in the economically developing world and a growing recognition of ‘the reproductive desires and dilemmas of infertile women and men living outside the West’ (Inhorn and Van Balen, 2002:6; see also Vayena et al 2009). The discussions which followed, particularly with the UK fertility consultants present, suggested that many of the problems of infertility and likely solutions in resource poor communities were ones that had resonances in their own practice in the UK. Suffice it to say that similar challenges and issues emerged in both contexts despite some very different drivers for ARTs operating in better resourced settings in the global north. A key difference is the exceptionally high levels of infertility found in many resource-poor settings (Inhorn, 2009). Fertility impairment is in turn caused by the prevalence of sexually transmitted diseases, high numbers of unsafe abortions, frequent
postpartum pelvic infections and rates of tubal factor infertility that are 2 to 4 times higher than in the rest of the world (Inhorn 2009). Many of the conditions prevalent in the developing world could be avoided through improved public health measures. However, once these conditions are in place they are difficult to treat; prevention is infinitely better than cure. ARTs offer one of the few solutions should fertility be disrupted by one of these conditions and much work has been carried out recently into the development of low cost treatments (Ombelet and Campo 2007, also see this volume). The issue of low-cost IVF was of particular interest to the UK consultants attending the workshop when considering access to services in the UK.

An important event in recognising the importance of affordable access to fertility treatments in resource poor settings was the conference organised by the ESHRE Special task Force on Infertility in Developing Countries held 2008 in Arusha, Tanzania (Ombelet and Van Balen 2010). This multidisciplinary conference brought together representatives of the most significant organisations operating in the infertility field along with practitioners and academics. One of the outcomes of the meeting was the setting up of a series of pilot studies in which affordable treatment for infertility were trialled in Genk, Belgium with the eventual aim of introducing these into resource poor areas (Johnson et al, 2014, Ombelet 2014, Van Blerkon et al 2014).

The project of providing assistance to those experiencing reproductive disruption in developing world settings has elicited concerns and criticism throughout its history. It is argued that ARTs are not a priority in resource-poor settings, where population pressures are high and there is likely to be poor medical infrastructure, regulation and quality control (Macklin 1995; Okonofua 1996; Vayena et al. 2009). Combined with the low success rate of ARTs, there is likely to be major disappointment for those facing infertility given that expectations will be high and results sparse (Edouard and Olatunbosun 1997). Finally,
feminist concerns identify a continuing focus on women’s procreative roles in ARTs as symptomatic of an abiding patriarchy and the exploitation and appropriation of women’s bodies (Rapp 2001). Nonetheless, the pressure to recognise the plight of those with reproductive difficulties continues to rise up the international agenda. The International Conference on Population and Development (ICPD) held in Cairo lead to a United Nations Programme of Action 1995 which recognised ‘the rights of men and women to choose the number, timing and spacing of their children by calling for reproductive health programmes to include the prevention and appropriate treatment of infertility’ (ICPD 1994, also see Nachtigall 2006:871)

Three Themes in the Third Phase of ARTs

Both of the above stepping-off points suggest the beginning of an opening up of ARTs to new constituencies in terms of ethnicity, education and class. With this widening of access, reproductive ‘assistance’ is summoned in very diverse settings in terms of lay beliefs about procreation, body and relationships. Here we see the biomedical responses to frustrated reproductive desire framed within ever more diverse notions of family, kin and community and shaped by distinct configurations of morals and values. In this respect, we might simply record that ARTs become even further embedded in day-to-day life. However, we would like to draw attention to three themes which provide significant points of overlap between the two very different stepping off points identified above. These are the fertility-infertility dialectic, globalisation and, a form of moral pioneering that entails what we have termed, the bricolage of bioethics.
The Infertility Dialectic

A key feature of many of the groups and communities that are being reached in a third phase of ARTs is that they already appear to have high levels of fertility. This may well be true at a population level but, for those who have the misfortune to encounter ‘‘barrenness amid plenty’’ (Van Balen and Gerrits 2001), the consequences of infertility can be seriously amplified, by what Inhorn has referred to as the fertility-infertility dialectic: a situation in which the prevalence of infertility is often greatest where fertility is the highest. (Inhorn 1996, 2003b, 2003c, 2007b). The problem is further compounded by the fact that many of the steps taken to increase fertility are the very things that might impair it (for example, unprotected sex and sex with multiple partners increasing the likelihood of infertility linked with sexually transmitted infection). Where there are strong expectations surrounding fertility, the occurrence of infertility can be particularly catastrophic, leading couples into a relentless ‘quest for conception’ (Inhorn 2003c:1838). Furthermore, experiences of infertility may be structured by gender, social class, age and ethnicity which can interact to compound the suffering and disempowerment of childless women (Inhorn 1996:2; Riessman 2000, 2002).

A perception which emerges from this paradox in both the UK Pakistani Muslim context (and in many other contexts, particularly in the ‘developing world’) concerns the issue of fertility control in populations that are already seen as over-producing. The attribution of ‘hyper-fertility’ to some populations means that infertility is either ignored or even welcomed by policy-makers as a ‘solution’ to over-population (Greil et al. 2010; Van Balen and Inhorn 2002, Ombelet this volume). The use of ARTs in these contexts is also seen as an unhelpful distraction from other more pressing health priorities that may afflict such communities such as high rates of maternal and child mortality, and a heavy burden of infectious diseases like HIV and Malaria (Macklin 1995 and Okonofua, 1996): ‘infertility is
relatively unimportant in low-resource settings where fatal and contagious diseases remain uncontrolled’ (Vayena et al. 2002:13, also see Van Zandvoort et al. 2001). Measures aimed at increasing fertility in such settings would appear to be counter-intuitive when population control and lack of effective contraception pose serious challenges to public health and well-being.

Such views are further reinforced in the UK when set against demographic concerns about the rates at which different groups reproduce. Anxieties have recently been further raised by suggestions that there is a close link between religion, ethnicity and fertility such that those who are most strongly affiliated to a religious way of life are also more likely to have the biggest families – secularists it would seem do not reproduce terribly well (Kaufman 2010). In other words, ‘society’, and prevailing views of fertility therein, provide an important context within which to situate discussions about infertility among ethnic minority communities in western countries, as well as among the poor in developing-world ones.

Yet, in both these contexts it is clear that what is the subject of erasure when viewed at the level of populations and demography is all too visible when viewed at the level of families and individuals (Vayena et al. 2002). The social, psychological and economic impacts of infertility are considerable. In otherwise ‘high-fertility’ settings, these impacts are both significant and disproportionate (Bharadwaj 2003; Bhatti et al. 1999; Gerrits 1997, Nahar 2010; Riessman 2000; Van Balen and Bos 2009). In this volume we explore the finer grain of these contradictions and the ways in which ARTs become woven into prevailing ideas about fertility and infertility in settings which fall outside of ‘two-will-do’ norms and practices.

Reproductive Technologies as Global Form
In December 2008, seventy-two clinicians, scientists, epidemiologists and social scientists gathered together at the WHO headquarters in Geneva, Switzerland to work out an agreed vocabulary to be deployed worldwide when using ARTs (Zegers-Hochschild et al. 2009). The driver for this initiative was the need to ‘benchmark’ and ‘standardise’ terms and definitions used in ART delivery and evaluation. Having a common terminology is seen as crucial to ‘monitoring the availability, efficacy, and safety of assisted reproductive technology’ (Zegers-Hochschild et al. 2009: 1521). The application of ARTs in increasingly diverse social, cultural and economic settings makes ever more pressing the need to establish a backdrop of standardised definitions. Without this lingua franca, the mutability of ARTs and their adaptation to different settings will be impeded. Yet, the work of standardisation encompasses far more than mere vocabulary and extends into training, clinical procedures, appliances, techniques and the drugs used to overcome involuntary childlessness.

In short, the field of ART research, development and delivery is presently characterised by the increasing mobility of personnel, technologies and information. In considering these developments, Kneckt and colleagues draw attention to ‘reproductive technologies as global form’ (Kneckt et al. 2012). In so doing, they move beyond local cultures of ARTs and bring into focus an assemblage that is both global and highly influential (Ong and Collier 2005). As this assemblage extends and consolidates, a third phase in the development of ARTs becomes increasingly visible. Speed of diffusion and the proliferation of connection mean that ARTs take on a form that is trans-national and distributed with providers and consumers operating outside of state boundaries in the delivery of treatments. Beck, for example, describes the ways in which fertility laboratories in Cyprus are connected by monitors to sites in North America enabling clinicians to consult and seek advice from more experienced colleagues in the US. As such, national boundaries appear permeable and incidental to the operation of IVF delivery (Beck 2012). In the same collection, Simpson
describes how IVF was established in Sri Lanka in collaboration with international fertility teams. Part of the justification put forward by doctors for establishing services in the country was that access would be widened; those in need of treatment would no longer have to travel abroad and pay overseas rates. Nonetheless, oversight by established UK fertility teams and adherence to international guidelines such as those of the HFEA remained essential for claims made about the comparability and hence the quality of local provision (Simpson 2012). These examples point to an ever widening repertoire of possibilities for the take-up of knowledge of how to practice ARTs and the markets for equipment and pharmaceuticals on which this diffusion relies. Standard forms of service delivery are thus taken up against diverse legal, demographic and public policy contexts and distinctively local configurations of kinship, gender and well-being.

Bioethical Bricolage and Moral Pioneering

In recent years, public concerns about the ways in which emergent biotechnologies are entering into private lives is currently captured in the field designated as bioethics. As a quasi-secular and liberal discourse on values and meaning in plural societies, bioethics is used as a framework within which to manage complex and sometimes competing claims as to what constitute progress. In the various contexts that are described in this collection, reproduction emerges as a central pre-occupation and, moreover, one linked fundamentally to human flourishing as expressed existentially through ideas of completeness, connection and continuity (Van der Geest and Nahar 2013). Not to be able to reproduce when there are strong pressures to do so invites both speculation – why me? – and action – what can we do by way of remedy? What actions are permissible and encouraged may be easily read off from custom, belief and tradition. For example, fertility rites and the use of medicines to
achieve conception are common in many societies whilst fostering, adoption, polygamy and other such strategies to acquire children might be resorted to when these fail. Ways of ensuring social reproduction when biological reproduction fails are as old as human society itself. However, where ARTs are concerned, what is forbidden and proscribed is not always clear and is likely to be the subject of debate and negotiation. Evaluating possible courses of action in the face of unwanted fertility invites consideration of multiple reference points of legitimation, engenders novel precedents and stimulates creative interpretations, all of which are likely to be adduced to bring orthodoxy into line with what Inhorn once referred to as ‘immortality desire’ (Inhorn 1994). The result is something akin to the bricolage made famous in Levi Strauss’ account of mythological thought and the human imagination (Levi-Strauss 1966). In this view, the human imagination does not operate with a blueprint made up of rules that are straightforwardly observed, but actively and creatively fashions meaning out of a diverse and readily available sets of symbolic resources. The resultant forms have the character of being cobbled together in the manner of a contraption that mostly functions adequately rather than a well-built machine that is designed for purpose.

In this regard, we are keen to draw attention to the ways in which the reception of ARTs inspires experimentation and pioneering in the quest for meaning. Infertile couples, their wider families, clerics, physicians and other interested parties engage in the deconstruction and reconstruction of meaning in order to arrive at workable models for how to make sense of misfortune and its remedies. The book thus brings into focus examples of the co-production of moral worlds in which the use of ARTs figure as an acceptable strategy for individuals, families and communities to deal with the distress that comes with unwanted infertility. Through a variety of ethnographic approaches we examine the kaleidoscope of influences that feature in a quest, not merely for conception, but for a morally-situated conception.
In focussing on the ways in which ARTs are coming within the reach of new constituencies as defined by socio-economic status, ethnicity and geography, we thus seek to move beyond a model which posits a backdrop of standardised delivery in front of which cultural diversity is widely and often problematically acted out. In considering new and emerging arena of engagement with ARTs throughout the world we draw attention to the flow of ideas in both directions. Beliefs and practices designated as ‘traditional’ or ‘cultural’ are rendered permeable and labile when individuals are faced with reproductive challenge and the novel solutions on offer. Conversely, medical practices are subject to variation and modification in ways that belie the standard models of clinical and ethical practice when rolled out in culturally and economically diverse contexts.

The Book

The book is divided into three sections each of which begins with an analytical commentary on the content and cross cutting themes of the chapters. A novel experiment in the book is to conclude each section with a commentary from those practicing in the fields that we have described. The first section takes up the theme of engagement with ARTs not just as a therapeutic encounter but as a kind of moral journey. Consistent with the metaphor of journeying is the idea of people moving into new conceptual terrains as ‘pioneers’ for whom techno-scientific innovation initiates decision making that, in cultural terms, is as risky as it is novel (Rapp 1988). ARTs in the third phase operate in settings in which frameworks of meaning are typically partial, contradictory and emergent. The chapters in this first section illustrate the nature of the quest for accommodation and legitimation of ARTs within the context of Islam in the broadest sense. However, detailed expositions of the practice of ARTS in religiously plural Lebanon (Clarke), among Pakistani Sunni Muslims in England
(Simpson, Blell and Hampshire) and among Shias in Iran and the UK (Tremayne) highlight the variability that underlies any simple claims to an Islamic Bioethics or intra-national, let alone inter-national public consensus. Each of the pieces throws light on the ways in which religious, legal and customary authority is woven into debate, consultation, opinion and decision-making to produce workable legitimation of present and future actions regarding family formation. In their effects, ARTs are not simply grafted onto stable forms of family and kinship but are themselves part of the shifting mosaic of relationality in everyday life. This point emerges most strikingly in terms of gender relations, and specifically the ways in which ARTs draw men, albeit sometimes reluctantly and often unsuccessfully, into the domain of reproduction, both economically and emotionally. Our intention in bringing these chapters together is thus not to essentialise or exceptionalise Islam in relation to the ARTs; indeed, quite the opposite. By juxtaposing pieces on groups of people who all define themselves broadly as Muslims, we see the variation and negotiation that emerges as individuals, couples, families and others encounter and navigate newly-emerging and local moral worlds.

In the second section, attention turns to ARTs and infertility in resource poor areas with examples drawn from Bangladesh (Nahar), Botswana (Bochow) and Mali (Hörbst). The section opens with a reflection on the politics of access to ARTs in the developing world by Willem Ombelet, who argues that it is no longer acceptable that ARTs remain the preserve of those that can afford them. Considering the burden of involuntary childlessness in low income settings, Ombelet contends that infertility should no longer be seen as an individual medical problem but be recast as a major public health issue and accompanied by a global campaign to alleviate it. His arguments are clearly articulated in terms of reproductive autonomy, social justice and equity as enshrined in World Health Organization strategy regarding family planning. The ethnographic chapters which make up
this section each describe ARTs within broader cultural, economic and historical trajectories and specifically the very contexts in which Ombelet envisages a widening access to ARTs. Papreen Nahar describes how knowledge of infertility treatments in Bangladesh circulate between rural and urban contexts with ARTs featuring as an important imaginary when dealing with infertility, that is, thought about by many but accessed by only a few. The account of ARTs in Gaborone, Botswana by Astrid Bochow draws on biographies of women of different ages to plot how infertility treatment and ARTs have become established over time. Similarly, Viola Hörbst analyses detailed ART-stories of women in Bamako, Mali to reveal the relationship between the social and financial status of women and their strategies for accessing fertility treatment. In both chapters, the pattern of ART use is initially one of elites accessing treatments outside of the country followed by the development of local provision for such elites and, subsequently, a blending of ART treatments with a range of local provisions. The twist in the tail in Hörbst’s account however is the loss of confidence in local providers and a shift back into the global marketplace of fertility treatment and away from Malian providers. Both studies highlight the ways in which financial and familial interests shape individual strategies for engagement with ARTs and in so doing provide important contextual detail regarding the reshaping of reproductive relations in the third phase of ARTs.

The extension of ARTs to new populations and new subgroups (ethnic, socio-economic) within populations raises many questions about interactions between healthcare professionals and increasingly diverse recipients of these technologies. The third and final section of this book explores the ethics of care from the perspective of ethno-religious communities. Here novel reproductive interventions are taken as the focal point in thinking about professional response to ARTs in diverse cultures and socio-economic settings. The notion of discrete moral worlds which map neatly onto group or community is brought into
question in chapters by Sangeeta Chattoo and Nicky Hudson and Lorraine Culley in ways that are illuminating for the notion of ARTs in the third phase. Both pieces reflect on the place of ethno-religious communities in the context of UK society in general and health policy in particular. Each sounds a cautionary note when it comes to over-investing in the idea of bounded ‘cultures’ within which a discrete and ordered morality prevails. Each piece extends the arguments made in the preceding sections, drawing attention to the permeability and scalability of the categories and classifications likely to be in circulation at the interface between health care providers and the communities they serve. Chattoo goes beyond ‘minority’ groups in order to examine the way that the category ‘South Asian’ is used by medical professionals in relation to questions of infertility, privacy and autonomy among such groups. Central to her concerns are questions of just what constitutes ‘culturally competent care’ in the context of NHS delivery, what this tells us about difference and how in political and ideological terms it is currently being managed? In similar vein, Hudson and Culley explore the perceptions of Muslims, Sikhs and Hindus on questions of anonymity, inheritance and knowledge of the donor in third party ART transactions. In reflecting on the meaning of a ‘community view’, Hudson and Culley are able to show important areas of cross-community consensus and difference with regard to questions of relatedness in ARTs.

In this collection we bring into focus a third phase in the development of ARTs in which access to these extraordinary technologies is beginning to move beyond global elites and is accessed by ever more diverse cultural and socio-economic constituencies using ever more novel strategies. In sketching out the contours of what this development looks like we highlight some of the ethical and practical complexities that arise in the quest for parenthood in the twenty first century.

Notes
1. The preferred acronym throughout this piece is ART rather NRT as we wish to emphasise the increasing routinisation of assistance in reproductive failure rather than novelty per se.

2. In this case a Canadian women secured legal permission for a future donation of her eggs to her daughter who was rendered infertile as a result of being born with Turner Syndrome (Edwards 2009). Received on 8 August 2011 from http://www.nature.com/news/2007/070702/full/news070702-5

3. In this case, two gay men have formed a family of five children using their own sperm and the services of egg donors and surrogates. Received on 8 August 2011 from http://www.guardian.co.uk/lifeandstyle/2010/jul/17/gay-fathers-drewitt-barlow. Also see Simpson 2004b for a novel South Asian reading of this case.

4. In the case of Diane Blood, sperm was extracted posthumously from her husband and using cryo-preserved sperm she was able to produce two children over a period of years who were the biogenetic offspring of her dead husband (Simpson 2001).

5. 'Infertility time bomb' warning given at a 2005 European fertility conference by Professor Bill Ledger of the University of Sheffield. Received on 1 June 2011 from http://news.bbc.co.uk/1/hi/health/4112450.stm


7. The UKs Human Fertilisation and Embryology Authority reports that in 1991, when the Authority was established and data collection began, there were 6146 IVF patients who underwent 6609 cycles. By 2006 these figures had risen to 18,183 and 22,343 respectively (HFEA 2007). The figure reported by the HFEA for 2010 was 45,246 patients undergoing 57,652 cycles. Received on 12 July 2012 from http://www.hfea.gov.uk/ivf-figures-2006.html#1278
8. The target of three cycles on demand has mostly become an aspiration, with many
   Trusts being unable to afford any treatments at all (for example see: Rationaing
   Babies: IVF is Still a Postcode Lottery. Received on 30 May 2014 from
   http://www.independent.co.uk/life-style/health-and-families/health-news/rationing-
   babies-ivf-is-still-a-postcode-lottery-1682308.html)

9. BBC news ‘Funding IVF in the UK is feeble’ report on comments made by Dr Mark
   Connelly at ESHRE conference in July 2012. Received on 21 May 2013 from
   http://www.bbc.co.uk/news/health-18675858

10. The Pakistani Muslim research was carried out with the aid of a grant from the UK’s
    Economic and Social Research Council (RES-000-23-1488).

11. For example see article headlined ‘Whites will be an ethnic minority in Britain by the
    end of the century’ reported Anthony Browne in The Observer on 3rd September,
    2000.