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CLINICAL ENCOUNTERS AND CULTURALLY COMPETENT PRACTICE: THE CHALLENGES OF PROVIDING CANCER AND INFERTILITY CARE

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ABSTRACT

This qualitative paper compares how practitioners respond to adults from two ethnic groupings (defined for analytical purposes as South Asian and White), whose fertility is threatened by cancer. Our findings suggest practitioners, in their struggle to offer culturally sensitive care, negotiate various competing ideas, reflecting wider cultural assumptions underpinning notions of ethnicity, gender, fertility and responsible parenthood within the context of premature death posed by a diagnosis of cancer. Wider social and political responses to minority ethnic groups often intersect with personal and professional judgements in influencing what practitioners regard as appropriate care. Our conclusion explores the need for a more pluralistic response to facilitating culturally competent care.

KEYWORDS: Culturally competent care, multiculturalism, cancer, ethnic diversity, infertility, cultural sensitivity.

Despite differences in interpretation and implementation, the idea of culturally competent care has developed sufficient conceptual flexibility to capture a range of initiatives, all of which share a common aim of engaging with cultural differences as a means of ensuring care organisations maximise the effectiveness of their interventions. This flexibility partly explains the idea's popularity, as it simultaneously combines a post-modern concern with reflexive engagement and normative persuasion (Lo and Stacey, 2008) with a more long-standing, instrumental interest, which enables the State to use such insights to collectively manage complex social issues (Beck, 1992). As an illustration, this paper provides an analysis of how health and social care practitioners reflect on the 'messiness' (see Gunaratnam, 2008) of their everyday clinical encounters with patients of white and South-Asian backgrounds, while attempting to provide 'cultural competence' care. The interface between oncology and infertility services is an ideal case study, as the routines of the clinical encounters embody multi-faceted social, cultural and ethical judgements, requiring detailed, sensitive and responsive negotiation (Drew, 2003). While infertility is an area that shows significant ethnic disparities in care (Culley et al., 2006), gender and age introduce additional complexities (Crawshaw and Sloper, 2010), in addition to social-economic status (The Cancer Reform Strategy, 2007); making explanations focusing only on ethnic differences problematic.

Culturally competent care

Culturally competent care is concerned with supporting appropriate interaction between practitioners and their clients (Kymlicka, 2001). It encourages awareness of different cultural practices and values, including one's own assumptions; sensitivity to how these values can mediate the interpretative process; and the development of cross-cultural skills, on the basis of this sensitivity, to ensure effective communication (Betancourt et al., 2002). However, implementing culturally competent care, while reflecting a genuine commitment on the part of health and social care agencies to ensure difference does not become the basis of inequalities, generates various theoretical and practical difficulties. Solutions reflect different interpretations of what the problem is.

There are those who argue for more reified, pedagogically-informed and prescriptive models, as a way of overcoming (ineffective) implementation (see Teal and Street, 2009). Here, the answer

lies in a more particularised and continued refinement in how difference is recognised, categorised and (positively) responded to. Such explanations have a particular attraction for policy makers, who are looking to 'manage' multi-cultural societies, with 'easily' implemented comprehensive protocols of formulaic responses, applicable to a diverse range of contexts and situations. This approach, although having some value, can create the danger of presenting idealised views of cultural norms and practices (Chattoo and Atkin, 2012). This introduces a more critical response, which identifies a reliance on an over-generalised, notion of culture as undermining the potential usefulness of the idea (Lo and Stacey, 2008). Consequently, culturally competent care would be more likely to succeed if, instead of generating standardised protocols, it encouraged practitioners to question the complex relationship between collective norms and individual interpretations (Kymlicka, 2001). Evidence suggests that this can be accommodated by professional practice, although this is far from universal and that any understanding and response has to be part of the larger process of living in a multi-cultural society (Gunaratnam, 2008).

This raises an important conceptual link between health care and ethnicity. 'White' ethnicities, for example, are rarely used to explain people's experiences of health. Whereas, for 'non-white' populations, ethnicity is almost always noted (Karlsen, 2012). This essentialising view of ethnicity, in which ethnic minorities are seen as the 'other', has been repeatedly challenged. Debates about infertility suggest gender as much as ethnicity explains experience (Mirza, 2009). Feminist writings, for example, have brought the agency of women to the forefront of discussion, specifically in how infertility and its treatments compromise aspects of womanhood (Inhorn and Balen, 2001; Throsby, 2004). Similarly, infertility in men is associated with greater stigma and secrecy and connected to impotency and emasculation (Simpson, 2004). Hence certain experiences of infertility, even though rooted in local cultures within an ethnic group (for instance, Mirpuri, Gujarati-Hindu or Bangladeshi Muslim) might highlight the role of gender, age or socio-economic position across ethnic groups (white-British, White-Cypriot and South Asian).

The clinical encounter

Culturally competent care does not occur in a void but represents one communicative strategy among many, available to health and social care practitioners; each fundamental to the context of care, reflecting broader professional vulnerabilities and the need to manage social encounters, to achieve desirable outcomes (Gunaratnam, 2008). Practitioners, for example, look to gain some sense of control during the clinical encounter in a way that enables them to deal more confidently with the difficulties and uncertainties generated by day-to-day practice (Ring et al., 2008). There are many instances in a clinical encounter where practitioners have to offer advice and make decisions, while communicating complex information that does not translate easily into the everyday language of the patient or their family carer. Gender, social class, age, sexuality as well as ethnicity, mediate the process, in addition to more psychological processes, such as the patient's ability to take in potentially distressing information and the practitioners' communication skills (Bury et al., 2005). The complexity this evokes creates a synergy with the cultural competency; encouraging pragmatic responses, easily adaptable to practice and believed to have some connection to 'evidence' (Prez et al., 2008), while simultaneously playing down the extent clinical decision making can become confused with non-clinical decision making, when acting in the 'best interests of the patient'. Professional and clinical judgements, however, cannot help but connect with more discretionary and socially derived forms of practice (Cooper et al., 2003). This is of specific interest to us, particularly since clinical advice within the contexts of cancer and reproduction can easily become associated with moral judgements, obfuscating the boundaries between the private and the public (Plummer, 2003).

DOING THE RESEARCH

The paper focuses on how practitioners accommodated cultural diversity in their day-to-day practice, while negotiating the broader uncertainties associated with their role. It is based on qualitative analysis of a larger dataset collected - after gaining ethical and governance approval - from three English (NHS) Hospital Trusts offering secondary and tertiary care to ethnically diverse populations. The project explored the long term social and emotional impact of cancer on adults (18-40 years of age) who might have been diagnosed in childhood, teens or early adult life, by focusing on the potential impact of treatment on infertility. The dataset, generated by using semi-structured interviews, included a theoretically selected sample of men and women,

from a range of ethnic and cultural groupings, which could be broadly categorised as ‘white’ (including majority and minority) and ‘South Asian’ (Indian, Pakistani and Bangladeshi), who had undergone treatment for (lymphomas, sarcomas, testicular or breast) cancer. To provide context for the young adults’ experience, the dataset included a purposively selected sample of 33 health and social care practitioners representing different disciplines and services involved in caring for people with cancer (see Tables 1 & 2). Seventeen practitioners took part in three focus group discussions and sixteen in individual in-depth interviews; of whom at least six were from a non- white minority ethnic background (including five of South Asian origin and one Iraqi); and five from white minorities (including Ireland, Central and Eastern Europe). Even though participants emphasised that they would never let their personal or religious views affect their judgement, religious views might underpin some of their responses to wider ethical issues.

Table 1: Breakdown of professionals taking part in the three focus groups (n= 17)

Site One	Site Two	Site Three
Social Worker Assisted Conception Unit (ACU) Counsellor; Clinical Nurse Specialist (breast cancer); Clinical Nurse Specialist (lymphoma).	ACU Nurse Specialist (special interest in oncology); ACU Matron; ACU Embryologist; ACU Nurse; ACU Counsellor; ACU Registrar; Clinical Nurse Specialist (Gynaecology/Oncology).	Youth Support Co-ordinator (ages 18-25 years old); Activities Co-ordinator (ages 13 to 18 years old); Clinical Nurse Specialist (lymphoma); Clinical Nurse Specialist (lymphoma and myeloma); Consultant Oncologist (breast cancer); ACU Embryologist.

Table 2: Breakdown of professionals taking part in interviews (n=16)

Site one	Site two	Site three
Clinical Nurse Specialist (Young Oncology); Clinical Nurse Specialist, Liaison (Late effects, Young Oncology) Social Worker; Assisted Conception Unit (ACU) Counsellor; ACU Andrologist; ACU Embryologist.	Third sector organisation, (equality and diversity officer); Consultant Haematologist; ACU Consultant Reproductive Medicine; ACU Sister.	Oncology Registrar (paediatrics and young adults); Clinical Nurse Specialist (germ cell/brain); Clinical Nurse Specialist, Late Effects (paediatrics, teenage , young adults); PCT cancer lead; Clinical Psychologist; ACU, Reproductive Medicine Consultant.

Focus group discussions and interviews specifically explored the ethical and moral dilemmas faced by practitioners when providing long-term care; and in particular asked how they discussed (in)fertility with their patients. As a consequence of our original sampling frame, practitioners would have needed to engage with patients from a range of different cultural backgrounds. This enabled the research team to engage in a meaningful discussion with practitioners about the influence of culture (and ethnicity) on patient perceptions and preferences. We did not, however, ask about cultural competence per se or whether they felt competent in addressing diversity. We felt this would put practitioners on the defensive. Instead we asked them about their experiences of providing care to patients from diverse ethnic backgrounds and whether they felt that there were any specific issues they wished to share relevant to religion, culture or language within particular ethnic groups. This was felt to better reflect how practitioners operated. When practitioners talked about issues of gender, age, culture or religion, we asked them to provide examples so that it was easy to analyse similarities and differences as they applied across ethnic groups. Focus group discussions gave us a feel for broad professional values and normative assumptions informing a particular service, while facilitating a debate among practitioners from different disciplinary backgrounds (see Kitinger, 1994). Individual interviews allowed us to explore day-to-day practice of individual practitioners in more detail and the specific challenges individual practitioners faced in providing culturally competent care.

The need to use the complexity generated by our patients' accounts, as a way of focusing our engagement with practitioners, presented us with a particular ethical dilemma. We had to be careful in keeping what patients told us, separate from our discussions with practitioners involved in their care. To ensure this, we developed composite examples, subtly changing details to further protect patients' identity, while in others examples, we removed key contextual information. The research team were equally aware of how the circumstances of practitioners, patients and localities included in the research tended towards the unique. Consequently, when presenting our findings, certain information has been removed, to ensure individuals and fieldwork sites cannot be identified.

The transcripts were analysed thematically looking for similarities and differences in accounts within and across disciplines (Silverman, 2009). Our overall aim was to move beyond a

descriptive account by linking general themes common to professional practice with existent and emergent theory as suggested by the focus of our research question (see Riessman, 2008). Our interest in cultural competent care reflected an a priori theme and was used as a device to frame our analysis, which in turn connected more broadly with the dilemmas faced by practitioners, as they attempt to manage risk and justify their claims to expert knowledge, while using their discretion to offer sensitive care, consistent with their professional values. This forms the basis of our broader engagement with policy and practice and our argument for a more reflexive understanding of the challenges of providing culturally competent care within an increasingly diverse society.

PRESENTING THE FINDINGS

Negotiating ethical dilemmas

Our empirical account begins by focusing on the dilemmas faced by practitioners when offering reproductive advice to those whose fertility might be affected by cancer treatments. These dilemmas represented practitioners' usual starting point when reflecting on appropriate care and support. While age, type of cancer, prognosis and various biographical features can mediate an individual's emotional response to the possibility of losing one's fertility, gender – at least in the first instance - was seen by practitioners to make a greater difference than ethnicity. For example, while most men we spoke to had been offered and/or taken up the option of sperm preservation prior to starting treatment, only three women had been offered the choice of freezing their eggs or embryos. This largely reflected technological differences in the complexity of preservation techniques and the time involved, although at times professional codes further mediated this. Oncologists, for example, tended to focus on starting treatment as soon as possible, so as to increase the patient's chance of survival. This might, at times, override a concern for, or an open discussion about fertility and preservation, especially for women, where harvesting eggs can take six to seven weeks. By contrast, practitioners within reproductive medicine were more likely to focus on how best to maximise the options for preserving fertility before starting treatment.

However, a focus on fertility 'preservation', as outlined in policy documents (NICE, 2005), goes beyond technical details of a treatment protocol and practitioner' calculations reflect

broader cultural values and norms. Infertility, for example, was seen to strike at the heart of womanhood and as a potential threat to masculinity. In managing this, practitioners mentioned how they struggled to reconcile a person's normative right to reproduce and have a family against the possibility of remission and perhaps premature death, before a child had achieved independence. One of the senior adult oncologists (a woman of East European origin), expressed personal unease about someone embarking on a pregnancy when they were unlikely to live to raise the child, yet she remained sensitive to the needs of her patients and their families. Like most other practitioners, she would not actively intervene unless the decision compromised clinical care or threatened a patient's life:

It may be a bit selfish in a way to want to leave somebody behind, but I don't think that's my decision as a doctor to not allow them the opportunity.

In contrast, a consultant (a woman of Indian-origin) in reproductive medicine considered it ethically wrong to support a woman's decision to have a child unless she was in remission:

So if they haven't had an appropriate remission and it's (tumour) positive it'll be inappropriate to let them, you know...people can jump off the cliff but you don't have to walk with them to the top of the cliff.

This example reminds us about the potential dangers of a woman undergoing a pregnancy, who might need further treatment, thereby jeopardising her own health and that of the baby. It also reflects the cultural importance of the mother's role in nurturing her new-born. In responding to a question whether the possibility of a father's premature death would be any different, the same consultant in reproductive medicine felt the ethical dilemmas in relation to a man who had stored a sperm sample before treatment was different and while her response acknowledged the legal status of fatherhood, wider cultural assumptions about parenthood also surfaced:

It's a totally different scenario ... and the law says that the child has a right to have a father or a father figure, and there've been a few times when we have treated people in those circumstances when they're terminally ill but they want to have a child. We would assess how the child's needs would be met and ask our counsellors to see them, along with the potential father figure. And usually it is a step-family with children... the brothers of the girl [mother] or... step in and say, 'We'll be the father figure, godfather for the child'...we'll look after them and help them support our friend/relative.

Discretion is, therefore, an important aspect of clinical responses; juxtaposing what could be seen as straightforward clinical judgement (such as continuing with a pregnancy or allowing the use of stored sperm), with more socially embedded ethical, social and legal discourses. This not only explained why practitioners from the same disciplines did not always share the same views, but also demonstrated their attempts to contextualise the experiences of the patients they encountered. This is how ideas about culturally competent practice could begin to find a receptive professional audience, as practitioners attempted to provide individualised care. Dealing with these factors in practice, however, created some unease and uncertainty. In negotiating discretion, some practitioners feared ‘getting it wrong’, especially when the patient was younger or of a different ethnicity or gender from them. This, however, had to be balanced against their need to act.

Negotiating context and responding to diversity

Most practitioners, irrespective of disciplinary background, acknowledged that along with gender, age or life course can be more significant in how individuals experience threats to fertility posed by treatment than ethnicity, culture or religion. While such an observation reflected the realities of their practice, in certain situations it could mask their anxieties at dealing with cultural diversity and in unpicking gender/life course effects from those associated with ethnicity or religion. This simultaneously illustrated the complexities practitioners faced when attempting to facilitate individualised care, while vindicating their use of cultural generalisations, which were seen as necessary in making their work manageable. Interestingly and despite the diverse range of Asian backgrounds included in the study (such as people from Indian, Pakistani and Bangladeshi backgrounds, revealing a range of regional diversity, including various faiths, such as Islam, Hinduism and Sikhism), practitioners felt at ease working with the generic idea of ‘South Asian’ or ‘Asian’, while using the experience of those whom they regarded as ‘white’ patients, as a point of comparison. It should perhaps be added that there was ‘silence’ about how the experience of white minorities (such as those of Irish, East European or Turkish origin) might be different from the white majority.

Consequently, practitioners’ attempts at being culturally sensitive - which they recognised as important - were offset by their application of cultural generalisations, derived from broader

societal norms, which might have little relationship to the actual experiences of their patients. This was brought into sharp relief by their accounts of why patients of ‘Asian’ background faced particular issues within the context of cancer and infertility. This is how their assumptions about the gendered consequences of infertility, assume meaning in relation to ethnic origin. To illustrate this, we introduce an example where the issues facing women, who need to negotiate broader societal pro-natalist assumptions, alongside a possible risk to their fertility, following treatment, assume additional connotations because of practitioners’ generalisations about the patriarchal gender relations within an ‘Asian’ family. Women – irrespective of their ethnicity - were generally thought to face a greater emotional burden when dealing with potential threats to fertility than men, a theme well covered in wider literature. A (white) clinical nurse specialist remarked:

The whole issue of, this is who I am, this is, this is my, what make me a woman, this is sort of, and this inability to conceive, being robbed of that, you know, causing huge problems in their life.

However, several practitioners – irrespective of disciplinary background - suggested that the impact was far worse for women of ‘South Asian’ origin, who were thought to be subject to more rigid gender roles, privileging their child-bearing abilities. A (white) nurse specialist remarked on a particular issue she faced with South Asian women:

It’s difficult when young people are saying that their fertility... is almost more important than their actual being or actual life.

There were further speculations that strong pro-natalist values within ‘Asian’ communities, led fathers to prevent young, unmarried women from having treatment at the cost of risking their lives, since treatment was believed to jeopardise their chances of an arranged marriage (also see below). Such stories of Asian’ young women refusing (or being prevented from having) treatment seemed, however, to have a mythical status since when probed the examples cited were often based on hearsay or reflected a more complex set of circumstances. For example, at one of the sites, a young woman (whose example was often used to prove the case) had already undergone chemotherapy that could have threatened her fertility but had later, refused to undergo a hysterectomy when she had a recurrence of her cancer.

Practitioners accepted most couples – irrespective of ethnicity -wanted children and this was broadly supported by our interviews with patients. The association of womanhood with motherhood cut across cultural backgrounds; whereas many men – irrespective of ethnic background - found the prospect of infertility threatening to their manhood. It was only when talking about South Asian patients, however, that professionals identified pro-natalism as a defined, collective problem, which could undermine their attempts to maintain good practice. Any strain or breakdown of conjugal relationships, due to infertility among South Asian patients, for example, was attributed to their ‘pro-natalist’ culture. On the other hand, examples of white partners breaking off relationships in a similar situation were attributed to inter-personal strain and choice. One of the practitioners mentioned the case of a white man whose fertility was affected by cancer treatments. The man broke off a long term relationship with his partner who was keen on having a child using donor insemination. Neither her desire to have a child nor his inability to ‘get his head round’ donor insemination were attributed to ‘culture’ or a wider set of shared values; but a personal preference. In facilitating cultural diversity, practitioners drew on familiar codes when codifying and regulating patient behaviour and making it the basis of routine care. Their specific response to diversity relied on broader discursive practice associated with the ‘other’. Consequently, similar behaviours could assume a different meaning, depending on the ethnic origin of the individual.

A culture of silence?

For some practitioners, generalisations about ‘Asians’ extended to a lack of empathy in conjugal relationships and the widely held belief that ‘they’ followed the community tradition of ‘arranged marriage’, which excluded individual choice and romantic love. This tradition, for example, seemed to make relationship breakdown more likely, when fertility became an issue. One (white) oncology nurse explained:

I do feel that sometimes, because it might not have been shared about their past problems, in the Asian area as it might have been in other cultures, that perhaps they’re not as sympathetic, the men that they marry, as such. I’ve seen equal, equally as many marriages fall apart, I’m sure, in that. But I do wonder if the, the empathy isn’t there because they haven’t, they haven’t known. A lot of our [white] girls that marry, that

maybe their relationship would have fallen apart anyway, but their boyfriends might have been someone who was in class with them and knew about their past diagnosis.

Further, some practitioners identified South Asian patients' requests for fertility analysis as being triggered by proposed marriage negotiations. An oncology nurse specialist explained:

[It is] usually at the arranged marriage stage because they don't want the new family to be aware that there might be an infertility problem. So we've certainly had that before, that this is a taboo subject, we are not to talk about it because it might scupper their chances of a good match.

Some practitioners had also 'heard of' South Asian parents, attempting to veto fertility being discussed with their child and either encouraging or discouraging fertility testing. Interestingly, none of the patients in our sample described such a scenario. The only man who was upset about not having had a chance to discuss fertility before starting treatment (when he was diagnosed in his teens), believing that it was his father who had precluded the discussion from taking place, happened to be White. Some of our South Asian participants specifically remarked that having children was not that important to them. Picking up on this, one practitioner – an adult oncologist of East European origin – used her experience to develop a more nuanced approach to ethnic differences by citing an example of a young Bangladeshi woman, who - although she knew she was unable to have children - went on to be happily married. Good practice is, therefore, possible, although this tended to be the exception rather than the rule.

South Asian patients were identified by practitioners as being particularly vulnerable to family and community influences and our fieldwork discussions identified a whole range of assumptions about how 'Asian' parents of younger patients tended to be over protective and insist on sitting in on consultations, which practitioners felt could be awkward, especially if discussions focused on fertility, sexuality and issues of body image. When probed, however, many practitioners recalled similar examples of white parents wanting to continue to sit in on consultations once their children became teenagers or young adults. This led them to reconsider whether such actions reflected changes in parent-child relationships associated with the shared cancer experience rather than culture. Nonetheless, while recognising parents' desires to accompany their adult children to consultations, the involvement of South Asian parents and especially fathers was, at times, seen as controlling, intrusive and driven by concerns about

‘arranged marriages’; whereas that of ‘white’ parents was more often seen as reflecting their struggle to detach from the intensity of the shared cancer experience over a period of time.

The over-bearing and suffocating nature of ‘Asian’ family life found particular expression in professional’ views about a prevailing ‘culture of silence’. Oncology and reproductive medicine practitioners held beliefs that fertility was valued especially highly within South Asian communities: an expression of tradition which meant marriage was more universally practised than in ‘white’ communities, accompanied with higher expectations that children should follow. This explained the ‘culture of silence’, believed to be prevalent among South Asian communities, when fertility matters were raised. A specialist (white) oncology nurse remarked:

I’ve certainly had a number who don’t want their families to know anything about them if they’re going for fertility assessment. So that was something that they’d decided they wanted to do, but it was very much their decision rather than their family’s decision. Whereas with the British girls, you know, tended to find that, or, or, and males, that they didn’t mind the families being involved...So that’s certainly been something that’s different, they seem to want more confidentiality when it comes to involving the, the families.

Some fertility specialists spoke of South Asian men in particular asking for letters to do with sperm banking to be marked ‘confidential’ or sent to an alternative address. Whether such perceptions actually reflect the realities of professional practice is a moot point; although we would not deny that for some patients of South Asian origin, the relationship between self, close/extended family and wider community might operate differently. However our interviews with white patients suggest that they shared similar concerns and shared information selectively, according to notions of emotional proximity and privacy. Practitioners’ accounts acknowledged this; interpretation, however, remained the problem. Sharing information about fertility treatment selectively with family and friends, much respected as a matter of privacy and choice in a white family, was construed by practitioners as secrecy in relation to South Asian families.

Tradition could also be strongly connected with the absolutism of religious belief, which in turn became associated with fatalism. This is an increasing theme in the literature on cultural diversity and it is difficult to make sense of this, particularly since fatalism, alongside active

engagement remains a common feature in how people – irrespective of ethnic origin - make sense of chronic or life threatening conditions (see Bury et al., 2005). Patients we interviewed – irrespective of their ethnic origin - expressed such views. One of them took recourse to his Muslim faith to help him deal with his potential infertility, although his belief in ‘what will be, will be’ (fate) did not preclude him from preserving a sperm sample before starting treatment. Fatalism was more of a resource than a constraint, enabling individual reconciliation with the condition. This was a moral duty (huquq al ibad) and one encouraging active engagement rather than passivity, which was further supported by the empowering belief that Allah burdens only on those that He has enabled to carry such burdens. An oncologist of East European origin was able to use such knowledge to support one of her patients. A young Muslim man attributed his illness and poor prognosis to Allah’s will. He declined treatment, feeling he had to accept his fate. The oncologist, troubled by her duty of care to him, arranged a meeting with a local Imam to learn more about the issue. She also encouraged the young man to talk to the Imam, after which he concluded that refusing treatment was contrary to the teachings of Islam; being Allah’s property, meant he had a duty to preserve life. The point here is not whether the young man was ‘wrong’ in his interpretation of Islam or that another Imam might have offered a different account, but that the oncologist respected her patient’s religious views and went out of her way to seek advice.

In contrast, reified notions of religion, more specifically Islam, were perceived by many practitioners as determining men’s inability to ‘produce a sperm sample’. Muslim men were perceived as having particular issues with sperm banking due to their ‘lack of experience’ and/or assumed proscription against masturbation within Islam. Not only does this perception disregard the therapeutic context within which sperm banking is located, it also naively assumes that religious/cultural guidelines are somehow magically transformed into codes of practice in minority ethnic groups governed again by ‘tradition’. From an Islamic point of view, the act was defined by the therapeutic context of illness and treatment, and since the stored sperm was intended to be used by the individual only within the context of a conjugal relationship, most regarded it as appropriate. Moreover, preservation of a sperm sample, although relatively simple and non-technical, raised more general social difficulties for our sample of patients, irrespective

of ethnicity. Men found the process socially embarrassing and emotionally difficult, especially within the context of having been diagnosed with cancer and feeling seriously ill.

This is an example illustrating how patient experience contrasted starkly with the assumptions, reflected in professional practice. Ethnicity as expressed through culture, did mediate experience, but in a nuanced and subtle way. It did not predefine experience. Questioning how context defines a person's experience is as important as understanding how it can support successful outcomes. To illustrate this, we end our empirical account by reflecting on similarities in two men's experience, despite their different cultural and ethnic backgrounds. Rahul, of Indian origin from a Sikh family in his mid-thirties, broke up with his (Punjabi) girlfriend as a consequence of different expectations about their relationship:

I met up with somebody and we were going...to get married and then I was completely honest with her about my low sperm count. So she had second thoughts and she wanted to meet the doctor and have a discussion.

His partner, however, wanted him to undergo a fertility test. He was upset by this pre-condition and broke up with her. Rahul, although wanting children, did not want to marry someone just to father children. Adam, a 'white' man in his early thirties, was diagnosed with non-Hodgkin's Lymphoma, while living with his girlfriend. He had banked a sample, naming her on the consent form as someone entitled to use the sample posthumously in case of his death. Though Adam was keen on banking a sample and had clearly contemplated having children, he was not ready for fatherhood. His girlfriend, however, was more anxious about the future and keen to have a child soon after he completed his cancer treatment. His girlfriend's anxiety about his probable death and desire to have a child, brought Adam face to face with his own mortality and resulted in an eventual break-up.

DISCUSSION

Practitioners in the field of oncology and reproductive medicine encountered various generic, ethical issues, which have considerable influence in defining their relationship with patients. How practitioners managed and negotiated such moral and emotional uncertainties represents a fundamental starting point in understanding their role; and is a reminder of how culturally competent care is not a disembodied, disconnected strategy but part of a broader philosophy of

care. Part of these difficulties could be explained by their need to make their work manageable and meaningful in accordance with a broad range of normative values, which come to define professional practice (see also Lipsky, 1980). This requires various calculations as practitioners negotiate treatment and care with a patient, who may have different values, assumptions and interpretations of what is happening to him or her (Gooldin, 2011).

To this extent, practitioners acknowledged there was a potential social distance between themselves and the patient, which required the negotiation of cultural differences (see also Betancourt et al, 2002). Successfully negotiating this was seen as the basis of more individualised care and is where culturally competent care assumed meaning for practitioners. Practitioners, however, struggled to understand individual agency, within the context of more collective values and assumptions associated with culture. Perhaps ironically, their approach in facilitating individualised care tended to rely on static, idealised views of culture, creating an illusion of a solution to a complex situation (see Lo and Stacey, 2008), particularly when it is used alongside idiosyncratic and poorly contextualised ideas of cultural practices, derived from broader social discursive practices, which often emphasise the ‘other’.

This connects with long standing discursive practices associated with ethnicity and health. For example, South Asian communities were treated by practitioners as conglomerates of well-defined cultures, living in patriarchal and extended family structures (see Chattoo and Atkin, 2012). Common assumptions evident in practitioners’ accounts, for example, included the overbearing and suffocating nature of ‘South Asian’ family life; and the absolutism of tradition, culture and religious belief. This contrasted with their views of white British families, whose behaviour - while subject to similar stereotypes - was explained by individual preference and choice. Essentialism - in which the experiences of ethnic minority population becomes understood in relation to their collective ethno-cultural background, rather than the broader social context in which their experience is realised – remained fundamental in explaining this. There is, however, a vast, long standing literature which discredits essentialism and rather than continuing to explore how it is expressed, a more pertinent series of policy question is why does it persist? And how can it best be challenged?

The perceived value of programmatic and formulaic evidence based responses, while providing the imagined reassurance of helping practitioners respond to complex situations, which carry the risk of exposing their vulnerability and claims to expert knowledge, partly explains the continued use of essentialised notions (see Padela and Pozo, 2011). Such models are believed ‘helpful’, facilitating attempts to make the unfamiliar, familiar or at least manageable within the context of the clinical encounter. Some degree of generalisation is inevitable as it enables practitioners to make abstract knowledge more amenable to everyday practice; offering them security by excluding ‘complex and messy existential questions’ (Gunaratnam, 2008, p273). Further, codifying individual patient behaviour, in a way that sustains supportive relationships, while reflecting the complexities of care, appeals to the broader moral sentiments of liberal professionals (Lupton, 2003).

Culture can be facilitative, when making sense of patients’ experience, but this is often misunderstood by practitioners, whose response is often informed by equating culture with ethnicity or culture as reducible to a list of values and beliefs. ‘Cultural’ explanations of ethnic differences in health can, for example, seem to emphasise the idiosyncrasies of particular ethnic groups and has arguably led to a narrow focus on aspects such as dietary requirements, religious and spiritual practices (see accounts of ‘ethnicity and culture’ in most English NHS National Service Frameworks). Ethnicity, however, is more than simply ‘being of’ or ‘belonging to’ a particular group but is an expression of a person’s negotiation of multiple identities within different social and historical contexts. Seen in this way, ethnic identity as it applies to health is complex and shifting, reflecting an on-going and creative dialogue between culture, ancestry, histories of migration, language, faith and religion, nationality and a shared heritage (see Chattoo and Atkin, 2012).

Consequently, the problem could in some ways be regarded as ‘thin description’ (Lo and Stacey, 2008) as patients become little more than a product of cultural traits. Practitioners’ preference for the word ‘community’ and frequent use of broad terms such as ‘Asian’ offered further evidence of this, as did their concern with fatalism. The problem facing practitioners was how to effectively engage with the subtle nuances associated with culture in a way able to combine individual and collective perspectives, while also being helpful to practice. This created

practical as well as more general, pedagogic tensions: and ones which further refined models are unlikely to resolve. To some extent, the power imbalance between cultural interpretations is one of the reasons disparities exist in the first place, and culturally competent care cannot help but reproduce these. As we have seen, there are several alternative and less helpful cultural generalisations, common in the broader society, which practitioners can draw on, when making decisions (see also Kymlicka, 2001). Conflating ethnicity, language, culture and religion into one manageable variable simply confused the situation, especially when patients acted in ways practitioners did not expect them to. Patients' own accounts suggest cultural identity has sufficient creative flexibility to offer a framework for action without ever becoming prescriptive and predictable and this offers the basis of a more productive engagement with cultural differences.

The problem is not with culture per se but more with how it assumes meaning in the context of the medical encounter (see Ballard, 1989). Culture tends to be stripped of context and simplified, so as to make it useable. Consequently, cultural understanding becomes uncontested; another technical act, removed from broader social and political realities and the various historical values and assumptions, associated with how ethnic diversity is imagined. Bureaucratic norms underpinning welfare further and reassuringly confirm this approach, as they reflect the cultural values of a majority (see Chattoo and Atkin, 2012).

Those of Pakistani origin living in Britain can find them described as Pakistani, South Asian or Muslim, contingent on context. The person themselves may at times, wish to emphasise their religious identity; in other situations their sense of national heritage might be important. Young people of South Asian origin, for example, are increasingly using religious affiliations, such as Muslim or Hindu or Sikh, in addition to ethnic origin, when describing their identity. The popularity of terms such as British-Muslim illustrates this, although this sense of Britishness is open to further negotiation. Young people of Pakistani origin, for example, might see themselves as 'British' but not 'British, British' (see Chattoo and Atkin, 2012). The idea of South Asian might also have little meaning to the lives of the people it describes. It represents a heterogeneous category that denotes four countries of origin within the Indian subcontinent (with Sri Lanka often excluded), where regional, linguistic and religious affiliations as well as different

histories of migration and settlement predominate. This is why comparisons between the experiences of broad groups such as ‘white’ and ‘South Asian’, evident in our practitioner accounts, had limited analytical value. In explaining similarities and differences across and among ethnic groups we need to destabilise the dualism between majority and minority, immigrant and host, and traditional and Western cultures, while reiterating the view of culture as a dynamic process marked by social divisions of gender, generation and socio-economic position.

Debates about identity appreciate that it is always multiple: who we are and where we belong has many aspects (Jenkins, 2004). To some extent, practitioner accounts reflected this - albeit in rather generalised way - as they juxtaposed a gendered identity, a broad ethnic identity, a religious identity with an identity they associated with an adult with possible infertility, following cancer treatment. Gender as we have seen, assumed a particular significance and was an important starting point, when practitioners discussed the various ethical dilemmas they faced (see also Hudson, 2012). Their assumptions about ethnic diversity become mediated through this and explain why practitioners thought the impact of infertility was greater for South Asian women than white women.

This leaves us with an important question: how do we create an understanding of illness experience without essentialising and over-generalising difference? There is no doubt a lack of evidence could be part of the problem. Disseminating and understanding good practice, for example, is rarely mentioned in the broader literature. We would argue, however, that such evidence requires more of a general reconciliation within a broader theoretical context, in which the discursive practices, informing professional behaviour becomes transparent. Ethnicity in effect, frequently becomes understood as a potential ‘risk factor’ - an assumption supported by policy and research - and requiring a response, even in some cases, when one is not always necessary. Patient responses to infertility, demonstrated considerable similarities reflecting a generic experience, occurring irrespective of ethnicity. This is not to deny differences that might be informed by culture or religion; or that some people from minority ethnic communities suffer disadvantage and discrimination, which deny them access to appropriate services. Religion, for example, provides moral boundaries for choices related to infertility treatments and an

explanation for why a particular choice may be considered just or unjust (see also Author, 2008). Nonetheless, religion as a collective body of beliefs and practices does not predefine individual negotiations of moral choices; nor is it the preserve of ethnic minority population (see Remennick, 2006).

Perpetuating deterministic frameworks, so as to make practice manageable, reproduces individual subjects as passive victims of their social positioning by virtue of their ethnic background. Encouraging assumptions about how culture might play out in any particular encounter is, therefore, problematic. Perhaps not surprisingly, practitioners became increasingly confused by policy guidance requiring them to respond to individual differences, while simultaneously encouraging them to use generalisations as a way of managing complex encounters (Peckover and Chidlaw, 2007). To this extent, attempts to colonise the unfamiliar and simplify the complex, can erode the responsibility for more reflexive forms of thinking. The consequent sequestration of experience reflects a more general, potentially disenchanting struggle to engage with context and agency (Giddens, 1991). In effect, a more robust understanding of culture is needed; and one that does not reduce culture to a formula or a set of quantifiable resources.

Our findings suggest a concern to standardise is ultimately counterproductive and can render practice insensitive; in complete contradiction of its intention. It is of course, unrealistic to expect practitioners to know how to manage cultural diversity in all contexts, but more general critical thinking and appraisal, which questions not only what is known, but how it is known would seem beneficial. Consequently, culturally competent care needs to encourage a more subtle theoretical reconciliation of collective cultural values and norms, which leaves room for individual interpretation, while simultaneously, challenging beliefs about the 'other', which mistakenly become (mis)associated with knowledge. Critically engaging with how policy defines and 'imagines' cultural competence would seem a helpful starting point. Some practitioners we spoke to easily adapt such approaches, showing great sensitivity, suggesting it is not incompatible with clinical practice. This is why we argue for a more pluralistic response to facilitating cultural competent care. We need reflexive practitioners, able to apply critical insight in responding to an individual's circumstances, while also retaining a degree of scepticism, when thinking about cultural generalisations. This involves understanding how illness experience is

socially negotiated, defined by the social space in which it takes place, while adapting a less instrumental and more contextualised and nuanced approach to culture.

To succeed, culturally competent models have to avoid cultural determinism, when presenting collective responses, while simultaneously circumventing idiosyncratic, sophistic and subjective guidance that make any efforts at generalisation impossible (see Bhui et al., 2007). This is the challenge facing policy and practice, particularly since practitioners need to be encouraged to consider what is ‘familiar in the unique and unique in the familiar’. Greater sensitivity to the subtleties with which individuals use cultural values and norms to give meaning to their experience is called for (see Fanshawe and Sriskaandarajah, 2010). In support of this, understanding and engaging with ethnic diversity should be seen as integral to the general training of health and social care practitioners, rather than as an ad hoc ‘competence’ to be achieved through brief training sessions. Such training should also help practitioners understand how their own judgements, values and assumptions impact on the patient.

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REFERENCES

Chattoo, S. and Atkin, K. (2012) ‘Race, ethnicity and social policy: theoretical concepts and the limitations of current approaches to welfare’ in Craig, G., Atkin, K., Chattoo, S. and Flynn, R (eds) *Understanding Race and Ethnicity*, Bristol: Policy Press, pp 19-40.

Ballard, R. (1989) ‘Social Work with Black People: What's the Difference?’ in Rojek, C., Peacock, G. and Collins, S. (eds) *The Haunt of Misery*, London: Tavistock, 123 – 47.

Beck, U (1992) *Risk society: towards a new modernity*, London: Sage.

Betancourt, J. R., Green, A. R., and Carrillo, J. E. (2002) 'Cultural competence in health care: Emerging frameworks and practical approaches', New York: The Commonwealth Fund.

Bhui, K., Warfal, N., Edonyal, P., McKenzie, K., and Bhugra D (2007) 'Cultural competence in mental health care', *BMC Health Services Research*, 7, 15.

Bury, M., Newbould, J. and Taylor, D (2005) *A rapid review of the current state of knowledge regarding lay led self-management of chronic illness*, London: National Institute of Clinical Excellence.

Cooper, L.A., Roter, D.L. and Johnson, R.L. (2003) 'Patient-centered communication, ratings of care and concordance of patient and physician care' *Medical care research and review*, 57(1), 181-217.

Crawshaw M and Sloper P (2010) 'Swimming against the tide' - the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer', *European Journal of Cancer Care*, 19, 610-620

Culley, L., Hudson, N., Rappoer, F., Katbamna, S. and Johnson, M. (2006) 'British South Asian communities and infertility services', *Human Fertility*, 9(1), 37-45.

Department of Health (2007) *Cancer Reform Strategy*, London: Department of Health

Drew, S. (2003) 'Self-reconstruction and biographical revisioning: survival following cancer in childhood or adolescence', *Health*, 7(2), 181- 199.

Fanshawe, S., and Sriskaandarajah, D. (2010) 'You can't put me in a box': super-diversity and the end of identity politics in Britain, London: Institute for Public Policy Research.

Giddens, A. (1991) *Modernity and self-identity: self and society in late modern age*, Oxford: Polity Press.

Gooldin, S (2011) Cultural competence and ethnical incompetence: notes from a study of the new reproductive technologies in Israel, *Diversity in Health and Care*, 8(1), 34-54.

Gunaratnam, Y. (2008) 'From competence of vulnerability: care, ethics and elders from racialized minorities', *Mortality*, 13(1), 24-41.

Hudson, N (2012) 'Researching infertility in British South Asian Communities reflecting on intersections of ethnicity, age, gender and reproductive identity' *Diversity and Equality in Health and Care*, 9(3), 191-200.

Inhorn, M.C. and van Balen, F. (2002) (eds.) *Infertility around the globe: new thinking on childlessness, gender and reproductive technologies*. Berkely: University of California press

Jenkins, R (2004) *Social Identity*, London: Routledge

Karslen, S., Becares, L., and Roth, M. (2012) 'Understanding the influence of ethnicity on health' in Craig, G., Atkin, K., Chattoo, S and Flynn, R., (eds) *Understanding 'Race' and Ethnicity*, Bristol: Policy Press.

Kitzinger, J. (1994) 'The methodology of focus groups: the importance of interactions between research participants'. *Sociology of Health & Illness*, 16: 103-121.

Kymlicka, W. (2001) *Politics in the vernacular: nationalism, multiculturalism and citizenship*, Oxford: Oxford University Press.

Lipsky, M. (1980) *Street Level Bureaucracy*, New York: Rusell Sage

Lo, M. M. and Stacey, C. L. (2008) 'Beyond cultural competence: Bourdieu, patients and clinical encounters', *Sociology of Health and Illness*, 30 (5), 741-55.

Lupton, D (2003) *Medicine as culture*, London: Sage

Mirza, H (2009) *Race, gender and educational desire: Why Black women succeed and fail*, London: Routledge.

National Institute for Health and Clinical Excellence (NICE) (2005) *Improving outcomes in children and young people with cancer*, London, National Institute for Health and Clinical Excellence

Padela, A.I. and Rodriguez del Pozo, R (2011) 'Muslim patients and cross gender implications in medicine: an Islamic bioethical perspective', *Journal of Medical Ethics*, 37, 40-44.

Peckover, S. and Chidlaw, R. (2007) 'The (un)-certainties of district nurses in the context of cultural diversity', *Journal of Advanced Nursing*, 58 (4) 377-385.

Plummer, K (2003) *Intimate citizenship: private decisions and public dialogues*, Seattle, University of Washington Press.

Prez, K.A., Allen, J.K., Carson, K.A., Cooper, L.A (2008) 'Provider and clinic culturally competent in a primary care setting', *Social Science and Medicine*, 66, 1204-1226.

Remennick, L. (2006) 'The quest for the perfect baby: why do Israeli women seek prenatal genetic testing?' *Sociology of Health and Illness*, 28(1), 21-53.

Riessman, C.K. (2008) *Narrative methods for the human sciences*, Thousand Oaks: Sage.

Ring, J.M., Nyquist J.G and Mitchel, S. (2008) *Curriculum For Culturally Responsive Health Care*, Oxford, Radcliffe.

Silverman D. (2009) *Doing Qualitative Research: A Practical Handbook*. Sage, London.

Simpson, R. (2004) 'Localising a brave new world: new reproductive technologies and the politics of fertility in contemporary Sri Lanka', in Maya Unithan-Kumar (ed) *Reproductive Agency, Medicine and the state*, Oxford: Berghahn Books

Teal, C.R. and Street, R. (2009) 'Critical elements of culturally competent communication in the medical encounter: a review and a model', *Social Science and Medicine*, 68, 553-543.

Throsby, K. (2004) *When IVF Fails: feminism, infertility and the negotiation of normality*, Basingstoke: Palgrave Macmillan.