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Research paper

The politics of difference? Providing a cancer genetics service in a culturally and linguistically diverse society

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What is known on this subject

- Women of South Asian origin struggle to gain access to appropriate advice on their genetic susceptibility to cancer.
- Culturally insensitive service provision, in addition to the broader processes associated with institutional racism, is responsible for such shortfalls. However, practitioners experience difficulties in overcoming these shortfalls.
- There does appear to be interest in such advice among women, especially in the case of breast cancer, but little is known about how best to offer support in a way that is acceptable to women.

What this paper adds

- Our findings demonstrate how services can offer care that is sensitive to the needs of women of South Asian origin in a way that facilitates choice.
- The cultural resources available to South Asian respondents when making sense of cancer genetics, although similar to those for the majority of the white community, did demonstrate some differences. Women of South Asian origin, for example, are more likely to associate cancer with death, and are generally less knowledgeable about the origins of, causes of and outcomes associated with a diagnosis of cancer.
- Access to cancer genetics services remains a problem, despite its general appropriateness, from the woman's point of view. Women either had not heard of the service or else had not been referred to the service by their general practitioner.

ABSTRACT

This paper explores how healthcare agencies can better meet the needs of culturally diverse populations, by discussing the policy and practice relevance of a project designed to evaluate a pilot cancer genetics service based in the UK. The purpose of the service was to offer non-directive, trans-cultural genetic counselling as a means of facilitating informed choice among ethnic-minority populations. The evaluation, using qualitative interviews among potential and actual service users from South Asian and majority white populations who had a diagnosis of cancer, explored the accessibility and appropriateness of the newly established pilot service. The findings demonstrated that services can offer care that is sensitive to the needs of diverse populations. However, access remained a problem, and the appropriateness of a service did not necessarily facilitate improved outcomes. Focusing on the dynamics of service delivery is therefore as important as exploring the experiences of those who receive health and social care. In this way we can provide the foundations for more successful interventions.

Keywords: cancer genetics, ethnicity, service delivery, social exclusion

Introduction

The UK, like other advanced industrial countries, struggles to provide accessible and appropriate healthcare to culturally diverse populations (Bhopal, 2007). Despite an apparent willingness on the part of the health agencies to challenge discriminatory practices, problems remain (Ratcliffe, 2004). This paper explores possible ways of engaging with these difficulties, by discussing the policy and practice relevance of a research project designed to evaluate a cancer genetics service whose purpose was to make up for shortfalls in previous provision. This empirical case study is used to introduce a broader theoretical discussion about how healthcare can respond successfully to the needs of an ethnically diverse population. One key aim of the paper, rather than offering a service evaluation *per se*, is to reconcile what can be extremely abstract debates within the specific dynamics of service delivery. We are aware of how accounts of social inequalities can seem complex and sometimes overwhelm more practically orientated debates about how best to organise and deliver service support. At the same time, by ignoring the complexity of such debates, mainstream provision can fall into the trap of 'reinventing the wheel' and not learning from previous insights (Ahmad and Bradby, 2007).

The context of service delivery

Healthcare provision for ethnically diverse populations occurs against a backdrop of socio-economic disadvantage, institutional racism and social exclusion (Parekh, 2006). Despite increasing awareness of the complex nature of culturally sensitive provision, various discriminatory practices, which are revealed in professional assumptions and organisational practices, either ignore or misrepresent the needs of ethnically diverse populations (Karlsen, 2007). Practitioners, for example, still lack confidence when discussing cultural competent practice (Peckover and Chidlaw, 2007), often reverting to simplified generalisations, which they believe enable them to 'manage' ethnic diversity (Atkin and Chattoo, 2007). The pilot service was introduced in response to these concerns. Cancer patients, irrespective of ethnicity, want more information about their condition and its consequences than they generally receive (McPherson *et al*, 2001). South Asian populations and patients from underprivileged backgrounds appear to be particularly disadvantaged and receive poor cancer care compared with the majority population (Velikova *et al*, 2004). Cultural insensitivity on the part of service organisations emerged as particularly relevant, for example, when making sense of the experience of breast cancer (Randhawa and Owens, 2004). However, culturally competent care can be difficult to realise in practice. Accessibility, for example, is becoming increasingly confused with appropriateness, and difference is sometimes emphasised at the expense of potential similarities between different ethnic groups. Current policy and practice can therefore appear to lack an informed and pro-active strategy, and this reflects the broader tensions of providing care within multi-cultural settings.

The number of referrals of people with a family history of cancer to the Regional Genetic Service, where the pilot was introduced, increased from 800 in 1998 to over 2500 in 2006. A growing awareness of the relationship between cancer and genetics helps to account for this increase. However, when these referrals were examined, a bias was found towards individuals from higher socio-economic classes and from the majority ethnic population. In the localities served by the pilot, 5% of referrals were for people of South Asian origin, even though the population classified as 'South Asian' represented 30% of the total population. This could not necessarily be attributed to the younger age profile of the South Asian population or, more generally, to a lack of interest. A previous study demonstrated how women of South Asian origin with breast cancer worried about other family members, and especially their children, developing the condition (Karbani, 2002).

A pilot service, funded by Macmillan Cancer Relief and the Department of Health, was developed to offer non-directive, trans-cultural genetic counselling as a means of facilitating informed choice among previously marginalised populations, through a discussion of risk, screening, testing and risk-reducing strategies in a primary care setting. This service, one of eight pilot services based in primary and secondary care, was part of a broader commitment on the part of policy makers to explore the concerns of people with a family history of cancer, and to provide them with information and support, as a way of developing provision for those whose cancer might have a genetic cause (www.macmillan.org.uk/About_Us/Specialist_healthcare/Cancer_genetics_programme/Cancer_genetics_programme.aspx).

Details of the pilot service can be found elsewhere (Srinivasa *et al*, 2007), and are not the focus of this paper, except in its broadest sense. Of interest to us, however, are the barriers to accessing the service for South Asian communities, and the appropriateness of provision from the perspective of the potential and actual service user, which is used to explore how ethnicity mediates the process of service delivery.

Conducting the research

A qualitative methodology is particularly effective for obtaining an understanding of how people interpreted what was happening to them, within the context of their social relationships (Silverman, 2001). However, it requires a particular form of justification. Our immediate problem in defining a sample was how to capture the experience of a diverse community, of various faiths, cultures, languages and dialects, which has become 'labelled' in the policy literature as 'South Asian.' The practical responses which inform this study tend to classify people according to their ethnic origin and religious identity. There is some theoretical justification for this, as for people of South Asian origin, ethnicity and religious identity often reinforce each other (Modood *et al*, 1997). Beyond this, our sample largely reflected the demographic profile of the locality covered by the pilot, in which Pakistani-Muslims are numerically the largest ethnic-minority group.

Another important consideration, when sampling, is to avoid producing findings that essentialise ethnic differences. When evaluating the pilot, we wished to identify similarities and differences in experience among various ethnic groups, including the majority white population. We therefore included a sample of people from the white community. We accept the problems of defining 'white' in this context, but simply wished to include a sample that would enable us to contextualise the views of our South Asian sample, and in particular to ensure that any differences identified between our samples could be reasonably explained in relation to a person's ethnic origin, while also offering an understanding of the more generic experience of those at risk of developing cancer. We also have to acknowledge that our sample is predominantly female. Finally, we needed to ensure that the comments of those who used the service reflected tangible benefits from the pilot project, rather than benefits that could be gained by more generic (non-genetic) provision. Our sample therefore includes the views of those with a family history of cancer, who had not accessed the pilot cancer service, in addition to the views of a sample of people who had experience of the pilot cancer genetics service.

We gained formal approval from an NHS local ethics committee for our research, which meant that we followed agreed principles of informed consent and anonymity.

Potential respondents were contacted and interviews were arranged. Those who were using the pilot service were identified from practitioners' records. Those who were not using the service but potentially had a family history of cancer were identified from two support groups for women with breast cancer, one largely consisting of South Asian women and the other consisting of white women. Table 1 outlines the details of the sample. Of those who were contacted, no one refused to be interviewed.

All of those who were interviewed had a diagnosis of cancer, and specifically a diagnosis of breast cancer ($n = 52$). Of the five respondents who did not have breast cancer, two had not accessed the pilot service, and had what they described as 'blood' cancer. Of those who had accessed the pilot service, one woman had bowel cancer, of which there was a family history, and two men had Hodgkin's lymphoma.

All of the potential interviewees had access to an information sheet, which was available in English, Urdu, Hindi, Gujarati and Punjabi. In-depth interviews, informed by a topic guide, explored the participants' biographical details as a way of building rapport and contextualising subsequent discussion, perceptions of cancer and cancer genetics, access to services, and

Table 1 Details of the study sample

Ethnicity/religion	Accessing service	Not accessing service	Gender	Total
Pakistani/Muslim	8	14	21 Female/1 male	22
Bangladeshi/Muslim	0	1	Female	1
Indian/Sikh	3	3	Female	6
Indian/Hindu	1	3	Female	4
Indian/Muslim	1	0	Female	1
White/Muslim	1	0	Female	1
White	11	11	21 Female/1 male	22
Total	26	31		57

positive and negative experiences of service delivery. Respondents were able to choose the language in which they were interviewed, and we conducted 11 interviews in languages other than English. These interviews were back-translated, on the basis of conceptual rather than literal meaning. In undertaking the research, we were aware of other ethical issues raised by our work. All of the respondents were aware of their risk of cancer before they were approached by a member of the research team. However, they might still be uneasy and perhaps unclear about this risk. We had the option, after seeking the respondent's permission, of arranging an appointment with a genetic counsellor. Each interview was audio-taped, transcribed and organised into themes. All of the participants' names that appear hereafter have been changed in order to maintain anonymity.

Our approach to analysis was iterative, and it explored concepts, established links between them, and offered explanations for patterns or ranges of responses or observations from different sources (Silverman, 2001). We began by identifying themes relevant to an interview, which were then interrogated in relation to each individual account (as a means of understanding a particular case), compared across cases by highlighting potential similarities and differences, and finally related to respondent characteristics that could be reasonably justified as an explanation which mediated experience. Our aim was to move beyond a semantic and descriptive account of specific interviews towards a level of analysis in which themes were explicated within existing and emerging theory and debate (Riessman, 2002).

Providing a cancer genetics service

Inevitably, the respondents' accounts blend both perceptions of cancer and the cancer journey. However, given the aims of the paper, in which our findings are contextualised within broader debates on provision of healthcare for multi-cultural societies, we did not regard this as a problem.

For those participants who did not access the pilot service, poor communication emerged as an important barrier. Participants' narratives, irrespective of ethnicity, suggest that mainstream (non-genetic) practitioners were not providing easily understood medical information in a way that elicited the patient's collaboration in developing a future strategy of care. Many respondents reflected on how the initial consultation was professional-centred, and was aimed at collecting information, rather than providing an explanation of why such information might be useful. This is often a feature of both primary and secondary care consultations (Robinson, 2001), especially when dealing with more discursive issues, such as screening and risk (Baile *et al*, 2000). These difficulties affect both those who speak English as a first language and those who do not, which highlights the fact that providing consultations in a person's first language does not obviate the need to address broader communication issues.

However, communication difficulties were compounded for those who did not speak English as their first language. The problems of language support have been a constant feature of the literature for at least 20 years (Ahmad and Bradby, 2007). For our respondents, the use of interpreters simply enforced the professional-centred nature of the consultation, and some respondents felt that the interpreters struggled to translate what is often extremely complex information. This introduced uncertainty, which was made worse for those who believed that the interpreters were implicitly making decisions on their behalf and exercising discretion about what information was passed on. Despite this, people who had access to an interpreter expressed more satisfaction with the consultation process than those who had to rely on friends or family members to interpret for them. Gaining access to an interpreter was far from straightforward, and many people felt under pressure to make their own arrangements. In the following extract, Aisha illustrated how such *ad hoc* strategies raise issues of confidentiality:

> 'I think she [nurse] said ''have you got anyone you can bring with you?'' I didn't know who to take. I didn't want anyone to know what was happening to me. I have small children. In the end I took my friend's daughter. They should have given me someone.'

Many respondents felt that they had to balance the need to understand what was happening to them with the need to compromise their desire for confidentiality. Using family members as interpreters could also cause other tensions. Shamim described how her daughter struggled emotionally to translate information that could potentially affect her own well-being (Gaff *et al*, 2007).

Following the initial consultation, irrespective of whether the women had access to the pilot service or not, those with or at risk of breast cancer felt uncomfortable discussing their cancer and family history with male acquaintances, which raises yet another generic issue when making sense of communication and family genetics (Forrest *et al*, 2003; Shaw, 2009). Discussions, especially in the case of breast cancer, were seen to conflict with cultural norms in which women are expected to maintain modesty when speaking to men other than their husbands, although this view was not exclusive to Muslim participants. Many women talked about 'reserve.' Heema, an Indian-Hindu,

remarked that 'It is hard telling anyone because you can't really talk about the illness. It's a bit like feeling shame because it is in a private part.' Annabel, a white woman, similarly commented: 'I mean having to talk about it just makes me embarrassed.'

By employing workers who were multi-lingual and culturally sensitive, the pilot service avoided some of these difficulties. South Asian women were able to discuss their situation with a skilled and knowledgeable worker who often shared their linguistic background. Overcoming language barriers was not the only advantage of employing such workers. Women who were fluent in English commented on the value of having contact with a worker who had cultural insight into the issues that they faced in their daily lives. Several women, for example, expressed confidence that these practitioners understood such issues as the working of broader family relationships, as well as some of the religious sensitivities associated with communicating bad news, while having a more general respect for the important role played by their faith in making sense of health and illness. These women felt that they did not have to justify their cultural difference in a way that is often necessary in consultations with more mainstream practitioners. They also felt that they could speak more freely about their lives, without the risk of being judged. The pilot service also wished to explicitly avoid the professional-centred model of care by focusing on the needs of the women. The experiences of those who had accessed the service, irrespective of ethnic origin, suggest that this objective was achieved. Consequently, the women not only understood more about the genetic risks of cancer, but were also more confident about discussing these risks with other family members. However, those who used the pilot service did not always comprehend the problems of confidentiality that a practitioner might face when disseminating information within families, and interpreted the caution of practitioners as frustrating rather than helpful.

Cancer as metaphor

Capturing the meaning of cancer through metaphor is an important feature of the literature (Sontag, 1978), and reminds us that service practitioners need to engage with lay perceptions which might seem to be at odds with their own constructions about the origins of cancer (Schou and Hewison, 1999). Discussing how people make sense of cancer is especially valuable in developing service support, particularly as it ensures that practitioners can be sensitive to an individual's language and ways of understanding (Dein, 2004). How people create their own understanding of cancer is related to their use of language. This not only enables them to understand what is happening to them, but also allows them to express this understanding to others. However, as Sontag observed, this language can create its own mythology, distorting the 'truth' about illness and isolating the patient from broader cultural understandings which might empower them. This is the practical context in which practitioners have to work, and one that we shall now explore.

White participants were generally better informed about cancer outcomes. Our South Asian sample, however, felt that unless cancer was detected and treated in its early stages, it was an incurable disease (Randhawa and Owens, 2004). Nira, a Pakistani Muslim, expressed the views of many when she said 'That's it. It's the beginning of the end.' South Asian respondents were more likely to associate negative taboos with what they regularly called the 'C-word.' This raises potential barriers when disseminating information about cancer genetics among extended families, particularly when the person has been diagnosed as having cancer. Iqra, a Pakistani-Muslim, commented on how she could not tell her family that she had cancer because they would associate her diagnosis with 'certain death.' Achal, an Indian-Hindu, commented that she would not discuss her cancer with anyone because of the stigma associated with the disease. However, it is difficult to know whether such assumptions reflect ethnic or social class differences, particularly since those from a working-class background express similarly negative views about the outcomes of cancer (Selby, 1996).

Nonetheless, many of the participants, irrespective of ethnic origin, felt that cancer, although a consequence of lifestyle, was something that 'just happened' and was a matter of 'being unlucky', which suggests that fatalism is not solely the preserve of ethnic-minority populations. Furthermore, when the respondents reflected on the possible causes of cancer, they specifically discussed how the available public discourses appeared to be contradictory, and that it was difficult to make sense of them. This is why the respondents had a natural scepticism about attributing any cause to cancer. It was especially rare, irrespective of their ethnic background, for them to associate cancer with a genetic cause. The few who did so had accessed the pilot cancer genetics service, but even then there was some doubt. For example, Amy remarked that 'You can never be 100% certain it is that. So I don't know.' The idea that cancer might run in families particularly troubled several respondents, as it seemed to give cancer a kind of inevitability.

However, the participants were not entirely responsible for their misconceptions. Zareena, like several other women of South Asian origin, remarked that until she was diagnosed with cancer she had believed that cancer only occurred in white women: 'When I

went to the doctor's he reassured me, saying that Asian ladies don't usually get cancer, or there's not much.'

Such misinformation was not confined to women of South Asian origin. Tina's mother died of breast cancer at only 40 years of age, and one of her aunts had also had breast cancer. Yet still her GP did not take her concerns seriously: 'I went to my GP then, that's when I said look, it's in my family, but I always got told it skipped a generation, and that's what you get told every time.'

Ranjit, an Indian Sikh, explained how a well-meaning breast cancer nurse deterred her from further investigation:

> 'Yes but they say it is not true. I said to them check my daughter, they said you should not think like this, just because you have it does not mean that your daughter can have it ... I was worried if I had it, I did not want my children to have it and I wanted them checked.'

The role of a cancer genetics service

As we have seen, the respondents who accessed the cancer genetics service had some understanding about the potential link between cancer and genetics and the potential risk of cancer for their family. Being better informed about cancer was not only important for the individual, but also enhanced their ability to negotiate with other family members, who might have a predisposition to develop cancer. People did not want to introduce the idea that other family members might be at risk of cancer, if they could offer no hope. By challenging long-standing assumptions about cancer, the pilot service was available to encourage more informed choice among those at risk.

However, the interviewees expressed disappointment about the vagueness of the information that they received from the pilot service. To this extent, negotiating expectations emerged as an important aspect of the communication process, particularly when interventions seemed to be counter-intuitive, challenging the respondents' definitions of the nature of medicine, as well as what constitutes family. The respondents expected certainty, which the pilot service could not give them. They wanted to be told whether or not they and their family were at risk, rather than being given an odds ratio, which they found difficult to interpret. However, this perhaps reflects a more generic tension facing modern medicine, with its increasing emphasis on preventive interventions and informed choice, and has little to do with ethnicity or cancer genetics (Bryant *et al*, 2005; Calnan *et al*, 2006).

As further demonstration of their unrealised expectations, the respondents were under the impression that their genetic risk could be determined by a simple blood test. Zareena, a Pakistani Muslim, explained:

> 'Our GP referred us to the service, saying that they would test us for genetics ... but when we got there we had a discussion and she asked us our family history and things. ... It was more of a counselling session ... she said that it wasn't genetic ... but I really thought that I would have a test and definitely know that it wasn't. I was just a bit surprised that just from the history they can determine that ... I don't know it felt like something was missing because they didn't do anything.'

Nor were these responses exclusive to women of South Asian origin. For example, Anne, a white woman, commented that 'I don't see how they can know all that from just talking to you.' These responses reflected a more general confidence in Western medicine and its power to identify and diagnose conditions through scientifically based clinical interventions, while also introducing a sense of uncertainty about the value of taking family histories when assessing a person's risk of cancer. The emphasis on taking a family history particularly confused some people, as it seemed alien to their ideas of scientific medicine. How could diagnosis of such a serious condition depend on the narrative accounts of family members?

The respondents also struggled with the idea that their wider extended family might be at risk of cancer in the same way as their more immediate family, although definitions of who belonged to 'immediate' family depended on a person's own sense of family relationships, based on normative assumptions about obligations, rather than 'biological' definitions. For some, immediate family included aunts and uncles, whereas for others it only extended as far as grandparents. This finding occurred irrespective of ethnicity, and it demonstrates some of the difficulties involved when taking family histories, as definitions of who is family and therefore at risk vary from one individual to another. (For a more general discussion of the implications of this for communicating genetic information, see Armstrong *et al*, 1998 and Shaw, 2009.)

Accessing a cancer genetics service

The appropriateness of the pilot service did not appear to be a problem. However, access was an issue, especially among South Asian respondents, as many who had not been referred to the pilot service were unaware of its existence. Kurshid, a Pakistani Muslim, whose breast cancer was known to have a genetic cause, remarked that 'It is a great thing if I knew about it, but no one has said anything to me.' Once people did find out about the existence of the service, they

expressed disappointment that the practitioner involved in their care had not told them about it. Tina, for example, felt that her GP should have informed her about the service, particularly since there was a history of breast cancer in her family (see above). Fiza, a Pakistani Muslim, and Palvi, an Indian Hindu, both expressed similar concerns. Those who had accessed the pilot service felt that their referral had taken place by chance.

Discussion

Our case study demonstrates how services can offer care that is sensitive to the needs of culturally diverse populations. Those who accessed the pilot service, irrespective of ethnic origin, valued the opportunity to discuss their situations in a way that was relevant to their experiences. This is perhaps not surprising, given that the broader literature indicates that people, irrespective of ethnic origin, value one-to-one, unhurried communication with an informed practitioner (Armstrong *et al*, 1998). Nonetheless, the pilot service not only facilitated a greater sense of informed decision making among respondents, but also led to greater confidence when negotiating with other family members.

Individuals whose families were at high risk of developing cancer also commented on how the service supported them in making decisions about preventive measures, such as mastectomy, which were rarely taken up, and making them more aware of the need for regular health checks. People with families at low risk spoke of how contact with the service helped to alleviate some of the anxiety associated with inherited disease. The South Asian respondents specifically praised the cultural and religious sensitivity, friendliness and flexibility of service provision. Respondents were also turning to genetic counsellors for explanations about treatment options and signposting to other cancer services. This was an unintended consequence of the pilot project, which perhaps highlights some shortfalls in good practice on the part of GPs, cancer consultants and nurses.

However, problems remained and, by exploring these, our findings can contribute to current debates about genetic counselling within families, by exploring similarities and differences among diverse ethnic groups. For example, the participants remained uncertain about the link between cancer and genetics, reflecting generic lay understandings about the potential causes of cancer, irrespective of ethnic origin (Gaff *et al*, 2007). The pilot service struggled to engage successfully with these lay understandings, particularly when information seemed to conflict with the respondents' experience. For example, many of the respondents thought that the taking of family trees was a rather 'quaint' practice, with little relevance to diagnosing cancer. Expectations of the pilot service also exceeded what it could deliver. Respondents expected to be provided with specific information about their risk, and also did not understand practitioners' sensitivities about potential breaches of confidentiality.

The cultural resources available to South Asian respondents when making sense of cancer genetics, although similar to the majority white community, did demonstrate some differences. People of South Asian origin were more likely to associate cancer with stigma and death, which sometimes made them reluctant to raise the issue with other family members. Such views are not entirely absent from the accounts of people from the majority ethnic population, but are less common. More generally, people of South Asian origin were less knowledgeable about cancer than the majority white population, and were certainly less aware of the support available, although in some cases this situation was exacerbated by unhelpful contacts with healthcare professionals. However, social class differences could be as important as ethnicity in explaining this.

Recognising the distinctive quality of these cultural resources is a complex but important task for practitioners, particularly since some of the issues raised in our discussion reflect the more general process of social exclusion. Ethnicity is not always a marker of disadvantage, and although the experience of our respondents demonstrates some differences, it also illustrates similarities to the experience of the general population. Successful healthcare that caters for a diverse population must employ professionals who are culturally literate and able to recognise the impact of cultural resources without falling into the trap of stereotyping their patients. In particular, they need to understand when ethnicity makes a difference and when it does not (Chattoo and Ahmad, 2008).

The pilot service offered ways of practically engaging with difference in a way that is appropriate to a linguistically and culturally diverse population, particularly in working with individuals' own definitions of what is happening to them, rather than by imposing the practitioner's views, sanctioned through professional practice (Dominelli, 2004). However, such reflexivity is not simply about individual reflection on practice, but also requires an engagement with the ways in which institutional practices can sometimes make it difficult for a practitioner to realise reflexive insights. Practitioners associated with the pilot service worked within culturally sensitive organisations, which helped to support and sustain their work (Srinivasa *et al*, 2007). This should not be underestimated, particularly in view of the fact that a common frustration expressed by practitioners concerns the conflict between their own willingness to offer sensitive care and

their organisation's ability, or inability, to support them (Atkin and Chattoo, 2007).

Further tensions have emerged, relating to the difficulties of offering screening in a way that facilitates choice, while not causing unnecessary anxiety (Scott *et al*, 2005). The question arises as to whether information is always a good thing, particularly when there is no treatment for some forms of cancer. Our respondents also expressed concerns about raising the issue of cancer within their families, particularly because they did not want to be responsible for giving other family members potentially distressing information about their relatives (Walter *et al*, 2004; Featherstone *et al*, 2006; Shaw, 2009). Weighing up the advantages and drawbacks of disclosure, particularly when the person to whom information is disclosed might have cancer, or associate it with certain death, is far from straightforward (Cox and McKellin, 1999; Hallowell, 1999).

Such tensions again occur irrespective of ethnic origin, although they probably have a greater impact among social excluded populations. Survival rates for most cancers tend to be worse among ethnic-minority populations. Many of the difficulties are attributed to delays in diagnosis. A more pro-active screening programme might therefore be of benefit, but since the ability of secondary and tertiary services to respond to cultural diversity is in doubt, it is questionable whether this is a viable option. Access without appropriateness is therefore a problem (Sedgwick *et al*, 2003; Fischbacher *et al*, 2009).

In the case of the pilot, the opposite problem occurred, as appropriateness of delivery did not necessarily improve access. This is manifested in two ways, and although it was not exclusive to South Asian respondents, the impact seemed more likely to deny them access to support. First, those who were potential clients of the genetics service, either directly as patients or indirectly as family members, did not know that the service existed, so could not initiate referral. Secondly, there is an overall lack of knowledge among the general population about the relationship between genetics and cancer (Walter *et al*, 2004; Donelle *et al*, 2005).

The problems associated with access raise further and more fundamental issues about how we come to understand equality. The inverse care law appears to be especially relevant when making sense of this (Tudor Hart, 1971). The publicity surrounding the pilot programme did lead to a rise in the number of referrals, and specifically improved the referral rates for people from lower socio-economic groups and from a South Asian background. However, these referrals were disproportionate to the rise in the number of referrals from the white majority community, from higher socio-economic groups (Srinivasa *et al*, 2007). This is probably a generic problem facing those responsible for developing health services, as it is difficult not to perpetuate existing disadvantage, particularly since the middle classes have greater cultural and social resources to take advantage of new forms of service support. However, the role of service practitioners is equally significant in creating the potential for disadvantage. For example, referral to the pilot service tended to be *ad hoc* and dependent on pro-active patients, who are more likely to be from the middle classes, rather than on pro-active healthcare professionals. Ironically, when healthcare professionals were pro-active, they were more likely to be so on behalf of middle-class people from the majority white population.

Our account of access demonstrates, more generally, how the pilot service existed within the context of a healthcare system that struggles with diversity. Healthcare professionals, especially those working in primary care, have an important role in facilitating improved access to service support, by helping people to understand the potential relevance of the service to their lives. This is why focusing on the dynamics of service delivery is as important as exploring the experiences of those who receive health and social care. This requires theoretical reconciliation and practical intent, especially since there is a long-standing and ongoing disparity between our understanding of the issues and our commitment to act (Taylor, 1994). By reconciling this disparity, we can provide the foundations for more successful interventions, in which the emerging evidence can engage with and develop existing examples of innovative practice.

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CONFLICTS OF INTEREST

None.

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