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- Black people's health: ethnic status and research issues
- Penelope Scott

Defining the focus of the research

The Health of the Nation (HON) brought into public and policy focus the specific health issues of minority ethnic groups. The HON policy stressed that 'research is essential to any strategy to improve health'. This has given health policy research a new lease on life although not a 'carte blanche' as the policy clearly defines the research agenda. Much of the research informing the HON and stemming out of it has been clinical and epidemiological in nature. This type of research, however, does not always engage with the issues of power and socioeconomic circumstance that are integral in structuring the health experience of minority groups, including minority ethnic groups.

Giddens defines power as 'the ability of individuals or groups to make their own concerns or interests count, even where others resist'. He further elaborates by noting that power and inequality are closely associated. Certainly by this definition minority ethnic groups in the UK can generally be considered both powerless and disadvantaged. Studies of the socioeconomic experience of minority ethnic groups have shown that members of these groups experience high unemployment rates, have low paid occupations and poor working conditions and suffer poverty and poorer housing tenure. Their under-representation in the political process not only reflects their lack of political power but also serves to reinforce it.

These characteristics of minority ethnic groups in general are the basis for prevailing social definitions and perceptions of Caribbean people as a minority group in the UK. However, this construction is further defined by views of them as 'deviant' with reference to their over-representation in

school exclusion rates,⁵ the incidence of mental illnesses and involvement in crime.⁶ Doctors and health professionals also collude in the labelling of Caribbeans as deviant by pronouncing them as 'non-compliant'.⁷ These perceptions coalesce into an establishment view of Caribbean people as a dysfunctional social group failing to fit the norms and expectations of mainstream society.

In this chapter I shall be raising some issues inherent in researching minority ethnic health status by discussing current research, including my own on diabetes in the Caribbean community. This disease has a high prevalence rate among Caribbean people, and is associated with poorer health outcomes and higher mortality for members of this group compared to their white counterparts. Through examples taken from research I will firstly make the more general points that the 'power' of the researcher is constantly challenged and that the research process itself is not a fixed, controlled activity governed solely by the 'how to' rules of standard methodological texts. Secondly, I will demonstrate that data collected are products not only of the methods used but also of the various contexts and actors that together constitute the process. In considering these two points I will argue that research is both 'experiential' and 'reflective' practice: in the 'research economy' all processes, activities and experiences need to be considered for their potential value in the analysis and interpretation of data.

Research traditions

Epidemiological and clinical studies with their largely positivist/empiricist methods constitute the majority of research done on Caribbeans with diabetes. The strength of such studies is that they provide useful information for health planners and health professionals treating the clinical aspects of the disease. On a more general level also, the quantitative research methods used by such studies have proved invaluable in revealing the extent and systematic patterning of social inequalities in health and illness. However, the major weakness of these studies is that the information they offer is rigidly biased towards the physiological. The biological determinism of the medical sciences fails to acknowledge the complexity of the challenges faced by the person with diabetes, who, as a social and cultural being, must undergo radical dietary and lifestyle changes. Consequently, the data yielded by these disciplines present only a partial picture of the disease's impact on the individual and cannot offer a complementary in-depth understanding of the social and cultural factors affecting diabetes management.

By contrast qualitative research, which is often grounded in a more critical epistemology, brings into sharp focus the real life issues and contexts structuring the experience of individuals with the disease. However, very little research attention has been directed towards an examination of the health experience and beliefs articulated by minority ethnic groups themselves and to date no sociological studies have looked in depth at the experience of Caribbeans with diabetes. Among the limited number of studies that have examined general health beliefs and knowledge, most have been conducted among Asian populations, 11 while a few others have presented findings on beliefs among West Indians. 12

Goals of research

The study of diabetes among Caribbean people lies at the intersection of interests between the medical/scientific community, social research, health planners and Caribbean people themselves. However, as most of the research conducted to date has been epidemiological, it serves primarily the needs of health managers planning the provision of services and other scientific researchers who are interested in the distribution of the disease and in generating hypotheses about its possible causes. This is not to deny that all this has relevance to Caribbean people with diabetes. However, it does little to effect real change in the health status of this ethnic group. It is also likely that from their perspective this type of knowledge would be considered remote and as not engaging in issues that are relevant to them and that have an impact on their ability to manage the disease. Only qualitative research methods can more faithfully articulate these concerns and bring into public policy focus the issues which Caribbeans view as important.

The examples and discussions presented in this section are the product of two research projects on diabetes that I have undertaken here at the Social Science Research Unit. The first of these was an exploratory qualitative study (1994–5) funded by the Economic and Social Research Council (ESRC) which examined the lay health beliefs and service use experience of both White Britons and Caribbeans with diabetes. The second project (1996–7) was funded by a medical charity, the British Diabetic Association (BDA), and followed up on the findings of the exploratory study. The second project used both quantitative and qualitative research methods to study the issues being addressed. The decision to use a quantitative method was in part influenced by a recognition of the need to use a research method which proved familiar and acceptable to the clinical gatekeepers at the BDA.

The first and most obvious way in which the powers of the social researcher's concepts and methods are challenged is on that tortured journey to secure research funds. I initially tried to find funding for the first diabetes project from the BDA. This project, costing £21,691, aimed to conduct in-depth interviews with a sample of 24 Caribbean and White British patients with diabetes and key informant interviews with a range of health professionals selected from GP and outpatients clinics in Cambridge and London. This application to the BDA's Research Grants committee

was unsuccessful; the unattributed comments by the sole referee quoted below are a salutary reminder of the chasm that exists between the goals and methodological outlooks of medical and social scientists:

It is hard to see that the present protocol demands 10 months support: I would anticipate that a maximum of half this period of time would be required both to perform the necessary interviews and provide the appropriate documentation . . . The plan of investigation proposed will not yield any decisive results, nor is it apparently intended to . . . I would like to see a more probing and definitive study planned: although more expensive, it would have the potential of providing a definitive answer and in the long run would be more cost-effective.

The definition of research here, that it provides 'definitive' answers, is grounded in a positivist understanding that the reality being investigated and the data so produced are observable facts that can be explained in terms of general laws governing their relationship to each other. Research, as the term is used in this extract, is therefore conceived of as the very linear activity of providing solutions to problems, a definition which has its epistemological roots in positivism/empiricism. The expressed concern about the cost-effectiveness of the study is an instructive reminder of the economic imperative, which features significantly in decisions regarding research funding. In a sense this 'commodifies' research; defines it as a product but unlike the general marketplace of goods and services, which is subject to fairly established and predictable laws, what counts as 'cost-effective' by funders is often subjective and not transparent.

The referee's comments that the time allocated to do the research is excessive is also significant as it betrays a more general ignorance about qualitative research endemic in the medical scientist/scientific community. A recent article in the *British Medical Journal* on qualitative research methods is an encouraging breakthrough in trying to advance the merits of these methods in health research.¹³ However, there is still a tremendous amount to be done to educate the medical scientific community on the contribution these methods can make.

The poor understanding among medics about what qualitative researchers do is manifest in several ways. At a most basic and crude level this lack of understanding is rooted in the different starting points of enquiry between the medical scientist and the social researcher. Although both are concerned with how to improve health, the former sees the individual's illness or disease as the main focus of concern whereas the latter sees the individual within the context of his/her cultural and socioeconomic environment as the necessary beginning of any serious investigation leading to improved health status. Added to this are the different epistemology and methods of enquiry, which further separate the worlds of the medical and social scientist. These differences inevitably raise the question: how does the qualitative

researcher 'situate' her/himself and respond to the dominant methodological paradigm in health research?

My own experiences of interacting with health professionals, particularly doctors, and attempting to explain what I am researching and how, has been instructive in revealing the pervasiveness of the scientific worldview and the ways in which it is self-perpetuating. Explanations of the research, in my best lay 'sociologese', usually elicited professionals' response that I was looking at 'how people's culture affected the management of their disease'. What is striking about their interpretation is the way in which they uncritically constructed culture as a variable. To do so logically fits the positivist framework of biomedical sciences. This is potentially dangerous however, as the inherent reductionism of positivism, reflected in such an interpretation, reinvents culture as a static, homogenous factor that can somehow be influenced or changed wherever it is perceived as dysfunctional in diabetes management. What was also apparent from health professionals' discourse on their Caribbean patients was that they used culture as a term denoting 'otherness': it was a term that was applicable to other people. Subsumed under the 'culture' terminology was a hodge-podge of different food habits and lifestyle behaviours; in effect anything that in their perception was different or unfamiliar. The inherent ethnocentrism of this use of culture is also, as Smaje argues, one face of racism in the health service.14 It has the potential to create stereotypical and victim blaming views of the role of culture in chronic disease management. On a more general level, the emphasis on culture deflects attention away from the more fundamental issues of inequality in access to material and other societal resources, as well as from socioeconomic and gender differences in health experience.

The existing gulf between the medical and social scientist and the slippage in communication that inevitably arises is quite amusingly exemplified in the following telephone conversation I had with a general practice doctor in Cambridge. I had written to him asking whether I could recruit a subsample of diabetic patients from his clinic. As time passed and I did not receive a reply to my letter I rang him. The following is a paraphrase of the conversation.

PS: I'm ringing up in connection with a letter I wrote to you about a research project I'm doing entitled 'Ethnicity, lay beliefs and the management of disease among diabetics'.

Dr: Could you repeat the title again for me please.

PS: 'Ethnicity, lay beliefs and the management of disease among diabetics'.

Dr: Oh, yes...hmm...ethnicity...what's that?

PS: Well, ethnicity . . . it's from the word ethnic . . . it refers to the shared background, traditions and culture which identify one group of people as distinct from another.

Dr: So is ethnicity a word then . . . is it in the OED [Oxford English Dictionary ??

PS: Well, yes, when I last checked it was.

Dr: Okay, and lay beliefs, that means patient expectations, doesn't it. Right, I'm with you now.

This extract also introduces a question which is perhaps at the heart of any discussion of minority ethnic health. What exactly is meant by 'ethnicity' and how reliable is it as a category or variable in research? Ethnicity is now to a large extent used instead of race to study and understand human differences. Race has been discredited as an acceptable and meaningful category in health research for a number of reasons, including the argument that no race possesses a discrete package of genetic characteristics; genetic diseases are not restricted to certain racial groups although risk varies by origin; there is more intra- than interracial genetic variation; and the genes responsible for features such as skin colour are few and atypical and not responsible for disease.15

As a concept, ethnicity is not easily defined. Generally social scientists use ethnicity to embrace all the ways in which people seek to differentiate themselves from others. These markers include language, religion and historical or territorial identity,16 as well as what Wallman terms 'symbolic identification',17 which includes dress, diet and kinship systems. In many instances also, another important marker of ethnicity is physical appearance; in particular skin colour. As a result, defining ethnicity is closely associated with the ideological construction of race.

An increasing number of researchers have drawn attention to the problematic way in which ethnicity has been constructed and applied as a category in research studies. 18 One example of this is a study that concluded that all members of minority ethnic groups are more likely to develop psychosis and that determinants of this increased risk are the personal and social pressures of belonging to a minority ethnic group in Britain. 19 Comparisons were made between a white group and all those who placed themselves in the Asian or black groups as defined by the Office of Population Censuses and Surveys (OPCS). However, 22 of the 39 people with psychotic disorders in the white group were also from ethnic minority groups, including Irish, Turks, Cypriots and Greek Cypriots, or were from other European countries. The study therefore did not examine what it set out to do. In order to test whether being a member of an ethnic group is implicated in the onset of psychosis the researchers should have made comparisons between all the minority ethnic groups and the white British sub-group.

One criticism of ethnic health research centres on the point that much of it focuses solely on ethnicity, thereby inferring that it is ethnicity itself that causes poor health. This 'victim blaming' is pervasive in studies on ethnic populations,²⁰ By contrast, critics argue that people's health experience is structured by factors associated with their ethnic background as opposed to ethnicity itself.

A further issue that current usage of the term ethnicity often fails to address is the heterogeneity of the ethnic populations studied. The terms Asian, Chinese and Afro-Caribbean for example, disguise important differences in diet, religion and language that are relevant to health and disease management. These categories also ignore the important differences that may exist according to social class, gender, age and generation. Research studies must acknowledge these factors and use methods that can deal with these intra-group differences, otherwise the data produced will be flawed. Another problematic way in which ethnicity has been operationalized has been in the way that it has been used to develop categories that people impose on others. The 1991 census for example, has been criticized for using categories that conflate race, ethnicity and nationality. Some observers argue that the difficulties with external categorization are that it is falsely non-political and that the people so categorized may not necessarily identify with these groupings.²¹

Certainly my own experience of doing research among Caribbean people has highlighted problems inherent in the ways people belonging to a distinctive group are labelled or defined. Caribbean people, for example, are often grouped together with Africans; this grouping is apparently organized on skin colour. This 'racializes' the groups and by so doing ignores the cultural heterogeneity between and among them. By default this implies that all black people are the same. The ambiguous categories 'African Caribbean' and 'Afro-Caribbean' are the popular constructs emerging from this misinformed view of black people among the ethnic majority. These terms are not widely accepted among Caribbean people. As one of my interviewees said quite sarcastically: 'What is Afro-Caribbean supposed to mean? Afro . . . Afro is a hair-do from the 1970s!'

The ambiguity of these terms creates practical problems for the researcher relying on the classification of ethnicity used for example, on hospital records. This confusion over the meaning of terms also leads to a suspicion of the integrity of the data produced and of statistics compiled by administrative bodies relying on these categorizations in the monitoring of health service use and provision.

Of course, taking issue with the current categories introduces the more complex conceptual question of what constitutes 'Caribbean' ethnic identity in the UK. This undoubtedly would be different to Caribbean identity in the Caribbean, if it does, in fact, exist, which some observers dispute.²² An answer to this question is complicated and highly politicized. It raises further questions, such as who decides? And whose interests are represented in the construction of this identity? What mechanisms and forums exist at local and national level to facilitate a debate on this? If indeed a

UK Caribbean ethnic identity has been forged, how can it challenge and replace the dominant view of Caribbean people by the majority group? Does the political infrastructure exist to do so?

The research process

The nature and content of the data collection process and the factors influencing this are important but neglected issues in researching minority ethnic health. The qualitative interview is a socially constructed encounter, and the data produced are as much a product of the social relations characterizing the process as the research method used. Unfortunately many studies on ethnic minority health, particularly where interviewers have been members of the ethnic majority, have failed to adequately take this on board. Among the previously cited studies looking at the experiences of Caribbean people, Donovan is the only author who engaged with this issue.²³ She concludes that her racial identity as a white woman researching black people's health did have an impact on the process, although she does not elaborate on how. On the other hand, Thorogood's work very appropriately locates her research subjects in the context of power inequalities but she does not address the probability of inequalities that her membership from the ethnic majority may bring to bear on the research process.²⁴

From my own experience in researching White British and Caribbean people with diabetes, I would certainly argue that there is evidence suggesting that my own Caribbean background was a distinct advantage in facilitating the interview process with the Caribbean interviewees. Rapport with the Caribbeans developed fairly spontaneously. Although I had decided beforehand to start by inviting interviewees to ask any question they had about the research or myself, it seldom proved necessary to issue this invitation to the Caribbean sample. We traded stories about how we ended up in England, what part of Jamaica or the Caribbean we are from and generally how we coped with the cold weather and lack of sunshine. The interviews developed out of these conversations and the ensuing discussions were punctuated with heartrending stories of loneliness and isolation as well as details of the trials of family demands and interpersonal conflicts, encounters with racism and love triangles. One woman shared quite explicit details of her husband's extra-marital affair, describing how she discovered them 'in flagrante' on the living room sofa. From her account it was clear she had come to accept this relationship. When she realized that I was having trouble locating Caribbeans with diabetes in the area because, for one reason, the hospital did not record ethnicity, she insisted on giving me this woman's phone number, and urged me to contact her because she had diabetes too. In another instance a male respondent admitted during the course of the interview that before coming to England

he had been a 'gunman' and had served a custodial sentence for shooting a man.

These accounts may not have dealt directly with the issues being examined but they are significant in two ways. Firstly, they are an important signal of the trust and rapport characterizing the interview process and secondly, they facilitate an understanding and interpretation of the issues of the research as the data are contextualized by rich personal histories. In retrospect, most of these interviews, particularly those with women, more closely resembled social encounters as part of an ongoing relationship. Hospitality and invitations to return were extended, other members of the family were introduced and in situations where the interviewee lived alone family photographs and even decades-old wedding albums were brought out and displayed. In one instance, at the end of the interview, an old Jamaican lady asked me to accompany her upstairs to her bedroom and continue talking to her as she got ready for a chiropody appointment. As I sat on the edge of her bed watching her comb her hair, she resumed talking about some of the issues of the interview, digressing at times to talk about a daughter who was going to move back home because she had separated from her husband. This particular incident perhaps best represents the character and tone of interviews with the Caribbean sub-sample.

The interviews with the White British sub-sample differed significantly. Initial conversations were polite and were confined to matters relating to the interview and the invitation to ask the researcher questions was not taken up. Generally, there was no sharing of personal details and the interviewees did not elaborate on the issues of the research in the way that the Caribbean sample had. This meant that the interviews were shorter. There was however, one outstanding exception. A 54-year-old woman I spoke with was suffering from depression. Although she addressed the issues of the research, often in an oblique way, she spoke at length about her depression and her domestic and financial difficulties. She stressed repeatedly that her family did not give her any moral support at all and expected her to 'get on with things' at home. Her life was evidently extremely difficult and her physical appearance and surroundings spoke of neglect and deprivation. This woman clearly had a desperate need to be heard and her extreme distress acknowledged. As the interview progressed she appeared to get some therapeutic benefit from being allowed to speak. This experience served as a salutary reminder that a researcher must be ready and prepared to deal with a variety of scenarios, issues and other agendas while collecting data in this way. Apart from this interview there were two instances where men spoke about the very personal matter of impotence - a complication of diabetes. In one of these instances, the 55-year-old interviewee commented, 'You're the first person that's known about it because I feel at ease with you'. It is difficult to know with any certainty why this interviewee felt at ease to disclose this information.

Whatever the reason(s), the comment provides an insight into the complexity of factors affecting the interviewing process and the quality of data collected.

These comparisons bring several points into focus. The first concerns the argument that my own ethnic identity probably worked to my advantage while interviewing the Caribbean sample. This is not to suggest that researching black people's health should be the preserve of black researchers or that the research data on black people produced by white researchers are automatically biased. Certainly, there would be a case for inverting the argument and suggesting that my own intuitive understanding and knowledge of Caribbean culture could lead me to unwittingly over-interpret data or overlook data that an outside observer would probably view as significant. However, the potential tensions this introduces are not dissimilar to the usual tensions qualitative researchers face in deciding, for example, to place weight on an event because it took place or using their judgement to ascribe significance to some infrequent quotations or occurrences. What I am suggesting is that, consistent with the philosophical positions of relativism, which propose that there is no single, unbiased truth, the accounts of black interviewees elicited by both white and black researchers may differ in content and focus but are equally valid. However, it is incumbent on the researcher to expose to the wider research audience all characteristics of the interview process that may have influenced the responses given.

A further point that these comparisons underscore is the flexibility of qualitative research in accounting for differences between groups. The standard way of collecting data by interview is that the same questions are asked to different people or groups, a method that to some extent implies a homogeneity in the way people respond. However, the examples presented demonstrate that different ethnic groups respond differently to the experience of being interviewed by the same interviewer. The fact that one group of interviewees consistently replied and elaborated spontaneously on the topics raised whereas many of the other group required some measure of prompting to elicit information raises issues on how to interpret the data. In this particular study, however, the differences in beliefs, practices and experiences of the health service were so profoundly different that this modified the difficulties in interpreting the data. A virtue of using qualitative research methods to study health beliefs across ethnic groups is that it is able to deal with these differences.

The fieldwork experiences previously outlined also serve to expose possible ethnocentric biases in existing models of qualitative research. Cornwell's distinction between 'public' and 'private' accounts in qualitative research interviews for example, does not appear to be appropriate in describing the interviewees' responses.²⁵ One component of Cornwell's argument in support of this model is that private accounts that more faithfully reflected respondents' views and opinions were more likely to be elicited over time

when they had developed trust in the researcher. This viewpoint does not, however, easily 'fit' with the profile of my interviews with the Caribbeans. These interviews were generally characterized by open discussion about the research topics as well as intimate details about their lives. This does not necessarily mean that the Caribbean sample did not have their own ways of what Cornwell terms 'managing their appearance' in the interview. It is yet to be proven though whether this dichotomous model of the public and private is elastic enough to cope with the idiosyncratic or culturally specific ways that people from minority ethnic groups respond to the experience of being interviewed.

Feminist models of research, which argue that a non-hierarchical relationship in the qualitative interview is ethically desirable, do address the question of unequal power relations in research. However, how appropriate is this model to address and describe situations where the researcher and researched are bonded at some level by an assumed shared experience of exclusion and racism and as a result could arguably be considered as equally 'powerless' in that sense? The relative ease with which Caribbean interviewees engaged with me apparently on the basis of our shared ethnicity seemed to diminish or at least mask any need on my part to redress any power imbalances that could be viewed to exist based on our differing class or educational backgrounds.26

In fact the 'power relations' characterizing the interviews were fluid and constantly shifting. Quite often I was asked fairly personal questions, particularly by some of the male respondents who saw the interview as a 'man-woman' encounter at some level and so sexualized the experience. In these instances I sometimes became aware of my own vulnerability and 'powerlessness' as a woman. Where the general personal probing by interviewees left me feeling exposed, the 'power' inherent in the relative anonymity of the traditional interviewer role was stripped away. This reversal of the 'researcher' and the 'researched' roles clearly altered the dynamic of the interview and disrupted the research agenda in several ways. It was only in situations where I felt to some degree uncomfortable or threatened by unwanted male attention that this disruption convinced me to alter or abort the interview or research plans. No research data are worth risking one's personal safety for. On a more general level these experiences argue for the development of a code of practice for researchers that would offer guidelines for dealing with potentially threatening situations.

Doing research among any social group raises the difficult question of how far the researcher has a responsibility to feed back the results of the research. The further question of whether or not study participants actually want to know the research outcomes must also be considered. None of the Caribbean people interviewed in the studies referred to here requested information on the research results. This could well be rooted in a view of research as remote and 'powerless' to effect change in their lives. It is

ethically important though for the social researcher to attempt to alter this perception. This can be partly achieved by explaining to prospective participants how the research, particularly if it is health-related, can make a difference to their daily lives and enable their voice to be heard in forums where change can be effected. There are also channels at local levels community newspapers, radio stations and organizations - that can be used to disseminate findings that may facilitate, for example, the management of chronic diseases such as diabetes.

Conclusion

Most current research on minority ethnic health is 'scientific' and therefore primarily serves the interests of health planners or the scientific community itself. There is a gap in the available research, which is critical or social constructionist in its methods and interpretations. When studying health conditions such as diabetes, which ascribe a responsible role to the individual in its management, only these approaches can generate the types of knowledge that facilitate a greater understanding of the disease's impact and that are ultimately of direct relevance to the Caribbean community.

This chapter has chronicled my attempts to secure funding and my experiences in researching Caribbean people's health. These experiences are instructive in illustrating the ways in which the researcher's power and agenda are constantly renegotiated within the various contexts of the process and in relation to the various actors who participate in it. The various compromises, trade-offs and experiences in any project constitute important information, which should both inform and frame the analysis of the data. A failure to do so can result in data that appear 'sanitized' or 'vacuum packed', as the important dimensions of 'power' and 'process' do not feature in the analysis.

Notes

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- 3 A. Giddens (1993) Sociology, 2nd edn. Cambridge: Polity Press, p. 54.
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