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Abstract

This article offers an introduction to the use of interpretative phenomenological analysis (IPA) to conduct research on psychological and social issues in the new genetics. Some key methodological points in the employment of IPA are highlighted. The article examines some of the important issues for health psychologists that arise following advances in new genetic technologies and introduces the articles in this special issue. The article discusses the particular contribution that IPA can make to research in health psychology generally, and to the new genetics in particular.

Keywords

interpretative phenomenological analysis, new genetics, qualitative

THIS SPECIAL ISSUE presents a set of articles employing interpretative phenomenological analysis to explore a range of issues in the 'new genetics'.

The 'new genetics' describes the scientific and clinical advances of the human genome project. This world-wide project is concerned with mapping individual genes to particular locations on chromosomes, understanding the chemical properties of those genes and relating biological functions to particular genetic loci. This research offers the possibility of finding specific genetic loci for particular health conditions, developing diagnostic tests for those conditions and, in the future, enabling therapeutic interventions.

It has been argued that the dilemmas raised by genetic disease are *qualitatively* different from those raised by non-genetic diseases (Murray, 1997; Williamson, 1999). These differences centre on the ability of genetic tests to give information about, not only the individual being tested, but also other members of the same family. Genetic tests can also predict future events in the life of a person who may not yet be experiencing any form of ill health or symptoms. This raises questions about individuals' perceptions of their own bodies, or indeed future bodies, as in the case of prenatal testing. Further issues include questions of confidentiality and fairness in the use and interpretation of medical information (for example: who owns and controls genetic information; who has the right to disclose genetic information and to whom should it be disclosed (Andrews, 1997; Chadwick, 1992)? It is important that social and behavioural scientists engage with the large number of research issues in these areas.

Interpretative phenomenological analysis and health psychology

Interpretative phenomenological analysis (IPA) is a particular qualitative approach that has generated considerable interest among health psychologists. The aim of IPA is to explore how participants make sense of their experiences; IPA engages with the meaning that experiences, events and actions hold for participants. At the same time, IPA recognizes that the researcher's own conceptions are required in order to make sense of the personal world being studied through a process of interpretative activity. IPA has roots in phenomenology (Giorgi, 1995) and symbolic interactionism (Denzin, 1995) but has been developed in the last 10 years as a distinctive approach to conducting empirical research in psychology, offering a theoretical underpinning, a set of methodological procedures and a corpus of studies.

While IPA shares with discourse analysis (e.g. Potter & Wetherell, 1987) a commitment to the importance of language and qualitative analysis, IPA differs from discourse analysis in its perception of the status of cognition. Discourse analysis as conceived in contemporary social psychology is generally sceptical of the possibility of mapping verbal reports onto underlying cognitions and attempts, rather, to elucidate the interactive tasks being performed by verbal statements, how those tasks are accomplished and the linguistic resources drawn on. IPA, by contrast, *is* concerned with understanding what the respondent thinks or believes about the topic under discussion.

It has been suggested that IPA can play a useful role in health psychology (Smith, 1996). Health psychology assumes a chain of connection between physical condition, cognition and verbal response. While IPA may perceive the nature of the links in a particular way, it is also concerned with that chain of connection. While recognizing the gap that can exist between a situation or state and the individual's perception of it, an IPA researcher will be interested in exploring the nature of that gap. Researchers may choose, for example, to focus on how two patients describe in very different ways what is medically diagnosed as the equivalent disease, precisely because this may shed light on the subjective perceptual processes involved. While recognizing that this requires interpretative work, IPA also assumes that the participant's account will provide an entree to that perceptual process. Thus, while there are clearly differences in approach between IPA and the quantitative methods most commonly used in health psychology, we believe a useful dialogue is possible between IPA research and mainstream health psychology because there is a considerable degree of theoretical convergence. A corpus of work using IPA to examine issues in the psychology of health and illness is now emerging. Topics covered include: attitudes

towards sexual behaviour (Flowers, Smith, Sheeran, & Beail, 1998); the experience of chronic back pain (Osborn & Smith, 1998); quality of life (Holmes, Coyle, & Thomson, 1997). These studies are beginning to form a body of knowledge on diverse subjects within the more general field of health psychology, forming a bedrock of research where the priority is to understand, in detail, the client's experience of health and illness.

Doing IPA

IPA studies involve a detailed case-by-case analysis of individual transcripts. The primary aim of such studies is to examine in detail the perceptions and understandings of the specific group studied rather than make more general claims. This is not to say that IPA is opposed to more general claims for larger populations, it is just that it is committed to the prior activity of the painstaking analysis of cases.

IPA researchers usually try and find a fairly homogenous sample. The basic logic is that if one is interviewing, say, 10 participants, it makes little sense to think in terms of random or representative sampling. IPA therefore uses purposive sampling to attempt to find a more closely defined group for whom the research question will be significant. This is analogous to the social anthropologist conducting ethnographic research in one particular community. The anthropologist then reports in detail about that particular culture but does not claim to say something about all cultures. In time, it will be possible for subsequent studies to be conducted with other groups and to gradually make more general claims, with each founded on the detailed examination of a set of case studies. There is no wish to be prescriptive here. How the specificity of a sample is defined will depend on the study; for example, it might in some cases be based on people attending a particular clinic or centre, in other cases it may be according to more standard demographic variables.

IPA researchers wish to analyse in detail how participants are perceiving and making sense of things which are happening to them. It therefore requires a flexible data collection method. While it is possible to obtain data suitable for IPA analysis in a number of ways (e.g. personal accounts, diaries), the best way to collect data for an IPA study, and the way most IPA studies have been conducted, is with the semi-structured interview. This allows the researcher and participant to engage in a dialogue whereby initial questions are modified in the light of participants' responses and the investigator is able to probe interesting and important areas which arise. A semi-structured interview schedule offers maps of possible ways in which the interview may proceed, and is used very flexibly. In practice, the interview may diverge considerably from what was originally envisaged. Interviews are tape-recorded and transcribed verbatim.

The transcripts are subjected to a detailed systematic qualitative analysis, case by case. The first transcript is read and examined a number of times and, with each reading, the researcher annotates the text with initial comments. The next stage involves transforming these comments into themes that capture succinctly the essential features of the initial readings. Subsequently, connections are forged between themes until a coherent and organized thematic account of the case is produced. Connections across cases can be made until a set of superordinate themes for the group of respondents is produced. Each superordinate theme is connected to the underlying themes which in turn, are connected to the original annotations and extracts from the participant. Finally, the table of superordinate themes is translated into a narrative account, where the themes are outlined, exemplified and illustrated with verbatim extracts from the participants. For detailed guidance on conducting research using IPA, see Smith (1995), Smith, Jarman, & Osborn (1999) and Willig (2001).

Using IPA to research the 'new genetics'

We argue that IPA is a particularly useful approach for examining psychological aspects of the new genetics. Many of the issues which arise in this domain are complex, dynamic and dilemmatic and IPA allows the possibility of engaging with such issues. IPA's flexible and detailed methodology is also useful in a domain where the issues are relatively novel and where they raise potentially sensitive and affective responses from participants. A number of studies have already been published using IPA to explore issues in the new genetics, in

particular examining issues around genetic counselling (Michie, Smith, Heaversedge, & Read, 1999; Smith, Michie, Allanson, & Alwy, 2000) and prenatal screening (Baillie, Smith, Hewison, & Mason, 2000).

This special issue is made up of a number of articles presenting findings from studies using IPA to examine a range of issues in the new genetics. Articles discuss the difficulties of deciding whether or not to have a test for a late onset condition (Smith, Michie, Stephenson, & Quarrell), identify some of the important features of genetic counselling (MacLeod, Booth, & Craufurd) and describe the perceptions of people who have undergone genetic testing (Senior, Smith, Michie, & Marteau). Also featured are articles that illustrate how family connections and knowledge are important when making reproductive decisions following testing (Kay & Kingston) and how painful some of the outcomes can be (Robson). The concluding piece describes the quality of life of people living with either an early- or a late-onset genetic condition (Chapman). This highlights some of the difficult reproductive decisions that individuals face and the ethical issues that society faces.

Individuals who know they are at risk of particular genetic conditions need to make a decision about whether to have a genetic test. Particularly difficult dilemmas are raised by late-onset conditions and evidence suggests that people vary in their decisions about whether to take the test (Harper, Lima, & Craufurd, 2000). Knowledge of the future can be difficult to handle, especially if no interventions are possible, but sometimes this knowledge can inform reproductive decisions and so have an impact on future generations. A positive test result can alter the individual's sense of their body, their expectations for the future, their thoughts of the past. The late-onset conditions, where the variant gene has already been passed on to a subsequent generation, can be particularly problematic and feelings of guilt may be intense (Harper & Clarke, 1997). Huntington's disease (HD), an incurable late-onset neurodegenerative condition, is a case in point as outlined in Smith et al. (2002—this issue). Here, a group of women making decisions about taking a test reveal how they conceptualize their risk and the key events that can trigger a decision.

An important issue in the new genetics is the role of the genetic counsellor. Debates focus on the extent to which counselling is seen as neutrally information-giving and emotionally-supporting, or whether it also directs clients into certain courses of action (Clarke, 1994). This debate is extended in the article by MacLeod et al. (2002—this issue), which illustrates how passing on information about genetic risk is not as clear-cut as it is often perceived to be. Clients at the clinic come with their own agenda, their own beliefs and their own representations of illness and inheritance. Sometimes they leave with these altered; sometimes they are much harder to change. The article concentrates on patients' perceptions of what makes their counselling sessions effective.

Predictive genetic testing is increasingly becoming available for conditions where treatment is possible (unlike for HD). Research that aims to understand how people make sense of their risk status after having a test and to assess how they make use of that information is clearly important. The perception of one's illness as being either genetic or environmental may have important behavioural implications (Marteau & Lerman, 2001). Senior et al. (2002—this issue) investigate individuals' perceptions of familial hypercholesterolaemia (FH). Their work shows how participants draw on different causal models and explores the thinking processes participants go through in attempting to make sense of their current situation.

Another important area of research in the new genetics is reproductive decision making and the availability of prenatal tests for particular conditions which may impact on that decision making. Issues which arise here range from consideration of termination of a pregnancy, or deciding not to have children at all, to investigating techniques, such as pre-implantation genetic diagnosis, which use IVF technology (Williamson, 1999). The decision-making process that follows prenatal testing may consider future quality of life of the unborn child and future likely advances in medical technology (Ashcroft, 1999).

Choices carry with them responsibility which may not always be welcome or easy to deal with (Genetic Interest Group, 1999; Juengst, 1999; Levitt, 1999) and the decision-making process may vary in line with personal values

(Evers-Kierbooms, Denayer, Decruyenaere, & van den Berghe, 1993). Kay and Kingston (2002—this issue) examine the responses of women who are known to be carriers of an X-linked condition. In such cases the woman is a healthy carrier of a condition which may be passed to a male child. Kay and Kingston's article focuses on the feelings of guilt and responsibility expressed by women carriers and how these, together with degree of personal experience with the particular condition, affect their reproductive decision making.

As technological advances lead to increasing choice, so the numbers of terminations for foetal abnormality also increase and the consequences for the individuals who make such choices have to be considered. Robson (2002—this issue) shows how the feelings of male partners of females who have undergone a termination of pregnancy are often given little consideration, although significant grief and loss may be experienced. This research not only illustrates the strengths of an interpretative phenomenological analysis in accessing the perspective of participants but also has policy implications in terms of changing procedures in the clinic and for follow-up.

There may be some clear-cut cases where the decision to terminate a pregnancy seems relatively straightforward in accordance with the underlying altruistic assumptions of quality of life of the child to be and his or her family. On the other hand some disabled groups find the advancing tide of genetic testing to be a cause for concern and hearken back to previous practices and eugenic ideas. A key writer in the disability movement proposes greater dialogue between disabled groups and the medical establishment to encourage rapprochement between the generally upbeat confident rhetoric of the genetics establishment and the often gloomy, hostile and suspicious reaction of disabled people and their organizations (Shakespeare, 1999). What is lacking, it is often claimed, is the voice of those directly affected by genetic conditions, and their perspective on quality of life and medical technology (Genetic Interest Group, 1999).

In the final article in this issue, Chapman (2002—this issue) takes up this challenge. It describes the perspective of individuals with either a late-onset incurable condition (Huntington's disease) or an early-onset chronic, and ultimately also fatal, condition (cystic fibrosis). The range of views on quality of life and prenatal testing held by people living with genetic conditions is thus illustrated. The strengths of IPA are highlighted as the views expressed are complex and contradictory.

Conclusion

This article has introduced an approach to qualitative research (IPA) and shown how, in principle, it is well placed to improve our understanding of the issues relevant to a burgeoning area in health psychology. Some of the complicated issues raised by advances in genetic technologies have been examined at different stages of a process, from decision making and genetic counselling to the resulting implications for the individual and family. The complex and deeply personal dilemmas that are raised by advances in new medical technology can usefully be examined using an approach that attempts to gain access to an individual's lived experiential world. The following articles will illustrate how IPA has attempted that task. While the articles focus on several different issues in the new genetics, all have in common the fact that it is the clients' perspective on these dilemmas that is highlighted. We hope the collection of articles will demonstrate how this particular qualitative approach has been able to facilitate a range of research in a fascinating, important and growing area of health psychology.

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