INNOVATIVE HEALTH TECHNOLOGIES PROGRAMME

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Neuroscience Promises And The Challenge Of Brain Imaging To The Conceptions Of Mental And Physical Illness

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RESEARCH FINDINGS

KEY FINDINGS

This research investigated the impact of various advanced methods of brain imaging (specifically fMRI & PET). It focused on how clinical practice is currently conceived, and the ways people thought it would develop in the future. It explored the extent to which the technology is shaping narratives of mental illness amongst researchers, clinicians and the patients themselves. Based on interviews and extensive observation, it examined the variation of opinion among the medical professionals, the neuroscientists and crucially the people being scanned. Overall, the project identified how the technology was already radically changing the ways both medical professionals and patients thought about specific mental conditions.

Amongst the scientists and medics:

- Considerable variation in the interpretation of results coupled with diversity in professional practice and opinion means that stabilization of the field is difficult to secure
- Despite this there is unanimity that imaging will make a unique contribution to understanding both brain function and psycho-pharmaceutical action

Amongst the patients already diagnosed and those being scanned as healthy volunteers:

- Great symbolic value was invested in personal brain images produced by a technology seen to be powerful and redefining of personhood
- The perceived utility or threat of imaging varied by medical condition
- Patients in support groups tended to be more wary of the technology, in contrast with those seeking more individualistic explanations who regarded the images with greater enthusiasm
- Scepticism lay not with the technical aspects, but with a perceived readiness by the medical profession and beyond to adopt a simple, reductionist model of suffering
- For supportive patients, the scan provided new ways to think about their condition, and a radical new way in which mental illness itself could be conceptualised and re-classified beyond that held by the scientists

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By gaining access to some of the most state-of-the-art brain imaging sites in the UK, this research was able to collate data that explores not merely how an innovative technology is applied in practice, but the very ways in which its possible application is creatively explored as the technology itself advances. Close observation and detailed interviews over an extended period allowed the project to generate conclusions from the various medical professionals and scientists involved in the development of the technology, and from healthy volunteers and people with mental illnesses who were scanned.

The Researchers and Medical Professionals

Brain imaging technology is understood by the science and medical researchers to be in its infancy, so much of their language reflects the promise of future developments rather than its current clinical application. Present practice is consequently less certain, and more varied than outsiders might assume. However, present areas of debate and disagreement are not seen to undermine the technology; in fact, they are readily accepted to shape further development towards a unified discipline of neuroscience and psychiatry.

Because both the hardware and software is so complex in both the PET and MRI procedures, no single person can act as the ultimate expert. Correspondingly, there is a surprising degree of variation in actual technique and in the analysis and interpretation of results. For those who see brain imaging as a strictly objective scientific procedure, eventual standardisation is believed to eradicate this.

For others, this flexibility is regarded as an inevitable aspect of such a multifaceted process, and simply is opening up a new domain in which the old arts of medical diagnosis and judgement can be practised. Current scientific practice is therefore diffused with individual convictions and styles of technique; from the initial set-up of the scanner through to the way in which completed projects are reported.

Despite this variation, all the researchers are tentative yet confident that this technology will have a huge impact on psychiatry. They are unanimous that imaging will contribute to a unique understanding of brain function and become increasingly integrated into an understanding of psycho-pharmaceutical action. They therefore express few, if any, doubts that brain imaging technology will have a positive impact on medical practice in the future.

A secondary aspect of the fast-developing technology is an acceptance that every current item of equipment and newly established technique will inevitably be made redundant as innovation increasingly speeds up. This means that few aspects of the medical technology are ever fully stabilised, either within a specific setting or more nationally. Researchers therefore integrate this dimension as a key feature of their work, and agree that if there is to be standardisation within the UK and internationally, it will have to be at a 'meta-level' of principles and delineations of research scope, rather than ever associated with specific practices.

The Patients and Healthy Volunteers

Most research projects involve healthy volunteers, defined as normal, to provide a comparison with the patient cohort. They were largely unaware that data from their scans was actively used to continually update and refine the model of the normal brain that provides the baseline for studies into abnormal structure and function. Their motives were varied, though all were intrigued with the technology, and drew on the language of the gift rather than the seeking of payment to contextualise their participation.

The majority found the relatively lengthy process of scanning to be rewarding, even though some felt highly claustrophobic inside the machine or alarmed by its surprisingly loud operation. Many found the experience 'uncanny', and invested a great deal of symbolic value in the images they were allowed to keep, even though none could identify much beyond the general outline of their brain. The technology tends to generate a great deal of awe, and a sense that medical science is pushing yet another barrier to definitions that concern life and the person.

The project concentrated on two illnesses, schizophrenia and depression, though patients with epilepsy, Alzheimer's and Parkinson's disease were also interviewed. The majority of patients who gave their consent to be scanned hoped from the outset that some definitive feature or aspect would be revealed, even though none thought this would lead to a change in their treatment.

The important differences between a structural scan and one that depicts brain function was rarely understood. This related particularly to issues arising from people with various mental health conditions. The blurring in understanding between what constitutes a structural scan of the brain, and what reveals localised function of parts of the brain under controlled conditions, reflects how for many the promise of the technology is that it can reveal a concrete and physical basis to their suffering.

Thus, the majority of patients had a high expectation of the technology, and saw it serving to provide objective evidence of their condition, even if this was not the intention or finding of the medical researchers themselves. Not only, therefore, did the patients make their own interpretations of the scans without direction from the psychiatrists or neuroscientists, but they frequently utilised the images for a wide range of social purposes beyond the clinical sphere.

Consequently, many had the images framed and put in their homes, or use them as the basis of a wide rage of creative activities. This should be seen not merely as a result of the images' novelty, but as a means by which patients are able to express and display a new way of thinking about their illness. They therefore always talked about these activities in a light-hearted and a meaningful manner.

Media Representations

Few of the scientists and medical professionals paid attention to the rising attention being paid to this technology by the media. Some had specific dealings if they had conducted a study which provoked particular media interest, though even these felt that the scientific and medical basis to their work was invariably undermined.

This caution among the experts contrasted greatly with the views of patients. Most were able to recall reports in the news media and in fiction that suggested brain function was now largely understood. It therefore further legitimated their confidence in the technology, and endorsed a sense of their own 'literacy' in reading and understanding the images. The belief that these representations were unambiguous and essentially photographic gave their own personal scans a further degree of accessibility.

Conflicting Patient Positions

In contrast to those who were highly supportive of the technology, some patients, especially those that tended to be active members of support groups, were more wary of the technology and its application. They saw it as a further encroachment of a strictly biological explanation of their condition that both denies any sociological or cultural perspective, and that deletes or ignores their own experience of suffering. They also rejected the likely links that will arise between imaging technologies and developments in psychophamaceutical treatments. Many therefore refuse to have a scan or to assist with any neuroscience research, and so had to be accessed in the research through alternative routes.

A possible explanation for this division in patient attitudes is that those people in a support group gain a significant identity through their collective involvement. They therefore see a model of illness that individualises their condition as potentially robbing them of an important part of their on-going identity. In contrast, for those patients not well integrated into such a group, the particularistic nature of the imaging, and further, of their own interpretations of the scans, provides an alternative way of living with the condition and gainingmeaning.

The study found a second, and potentially far-reaching, dimension to this dynamic. Some of the patients who willingly accepted the apparently physical demonstration of their condition made new alliances, irrespective of medical condition, with other similarly concurring patients. They tentatively shared a new language with which to describe their condition, ideas about its cause, and its possible future treatment; in short, the scans provided a radically new way in which their illnesses were conceived and classified, that was not necessarily based on the traditional medical categories at all.

About the Project

The project was funded as part of the Innovative Health Technologies research programme, and consisted of two twelve month periods of research and analysis, between March 2001to March 2002, and June 2002 to 2003.

Access to four main London research sites, and some additional UK ones for a wider overview, allowed extensive observation and contact with experts. The project team increasingly became integrated in the daily activities of the research sites, and was eventually given active tasks in the operations of some of the institutions. A total of 57 in-depth interviews were conducted with neuroscientists and medical professionals.

In addition, sites in both the US and Denmark were accessed by the teams collaborators. Here, interviews and observations were collated as part as on-going independent research. Initially, this aspect of the project was intended to provide a clear comparative dimension to the research. What transpired was that current practice has few clear national styles, and that differences tend to follow implicit associations and histories between institutions that frequently cross national boundaries.

Access to volunteers and patients was made via the professional staff initially by telephone or letter, or on site, where initial interviews tended to be conducted. Subsequent interviews were carried out elsewhere, frequently in their own homes. A total of 87 interviews with people who had been scanned were carried out; 41 with healthy volunteers and 46 with people who had previously been diagnosed with a mental condition.

A number of important links were made to user-support groups, two of which actively supported the project and invited the team in to give presentations and catalyse discussion.

Interviews were tape-recorded and transcribed, and all data then entered into a computer package (Nvivo) for on-going sorting, analysis and retrieval. Themes were identified, and sorted according to hierarchies and priorities. On-going analysis was then presented with a sample of the people in the study, both neuroscientists and patients, to provide a further reflexive source of data.