

Original paper

Beyond the immediate players: do researchers have moral obligations to others?

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This paper highlights the need for researchers and research ethics committees to look at the implications of a research study beyond the immediate research question, and the dignity, safety and wellbeing of research subjects, going on to consider whether the results of the study could be detrimental, for example, to more vulnerable groups in society. Although the case studies described come from workplace-based psychosocial research, it is suggested that the lessons drawn from these could be applied more generally.

Keywords: researcher, moral obligations, workplace, psychosocial research, methodology, consequences.

Introduction

Harris [1] has argued that there is a strong moral duty to perform good research, as long as the research subjects are adequately protected. In addition Brabin et al [3] have commented that ‘research should have social value and be sufficiently important to justify exposing individuals to risks’ and that it should also follow the rigorous methodology described in their paper. Researchers will therefore have to balance conflicting moral duties ‘to secure scientific results on the one hand and to protect the rights and interests of their subject(s) on the other’ [3].

The question this paper seeks to address is whether researchers also have a moral duty to consider the wider implications of their research beyond the study participants, for example, where there might be a negative impact on disadvantaged groups in society.

Case study 1

A study by Kawakami [4] sought to identify genetic predisposition to stress in a group of workers by seeking a relationship between the results of a genetic test and the responses to questionnaires assessing stress and job performance. In this particular study, the relationship was in fact not established. However, such research seeking to establish genetic predisposition to mental health vulnerabilities is by no means isolated [5].

Genetic information and employment

There may be valid reasons advanced why genetic research may help in psychological diseases, for example, in the development of new treatments. However, there may also be concerns about such research, for example the possible use of the informa-

tion by insurance companies. Laurie and Mason [6] have quoted a MORI report on public attitudes to human genetic information, and the result was that: ‘the use of genetic information to set insurance premiums was thought to be the least appropriate of the possible uses of that information’. For their part, the ABI (Association of British Insurers) do want to reassure the public that the insurance companies will deal with genetic information in a sensible and responsible manner, and they have a moratorium, in agreement with the government, which was extended in 2006 for a further five years to 2011 [7]. In this, insurers have agreed that: ‘customers will not be asked to, nor be put under any pressure to, undergo a predictive genetic test in order to obtain insurance’. In addition, customers will not be required to disclose a blood relative’s test, nor any predictive genetic test result taken after they have taken a policy, nor any genetic test result which arises out of clinical research.

However, in this paper, the focus will be on the implications of genetic research in the employment context.

In the study described above, the researchers suggested that had some workers been identified as being more vulnerable to stress then support mechanisms, such as an offer of stress management training, could have been put in place to reduce this risk. This may be a positive approach, and could work where employers are benevolent. However, many employers may take the alternative view that it would be cheaper to get rid of such workers, especially during times of recession or other financial pressures. Indeed, they may argue that if these workers are more at risk of

developing stress (that is, carry a 'stress gene'), then they are more likely to under-perform at work during difficult times, such as during organizational change. To exclude them at an earlier stage would arguably make the company more 'competitive'.

There are, nonetheless, many reasons why there are concerns about the use of genetic information in this way. Those who would argue against disclosure of genetic information to third parties could invoke the right to privacy. This right can be justified ethically in different ways, for example, using consequentialist arguments (that individuals would refuse to be tested if the consequences were detrimental), or arguments based on the respect for autonomy [8]. The UNESCO Universal Declaration on the Human Genome and Human Rights states that: '...no one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity' [9]. On the other hand, Holm has argued that 'there is nothing intrinsically special about genetic information compared to other kinds of health related information. For every allegedly special feature or special combination of features of genetic information it is possible to find non-genetic health related information which shares these features' [10].

In the United Kingdom, the Faculty of Occupational Medicine (FOM) maintains that 'the nature of genetic information means that there are particular dangers of unfair discrimination' [11]. They point out that the precise meaning of genetic tests is still often poorly understood, and predict that 'in the future, the concept of unfair genetic discrimination will be used to regulate the use of pre-existing genetic information in employment'. The current edition of the FOM guidance [12] cites there being only one instance of pre-employment genetic testing in the UK, namely in the exclusion of those with the sickle cell trait from being jet pilots, as the risk of low blood oxygen leading to a 'sickle cell crisis' is high. In such instances where the dangers to the individual, and to others, would be very high, and the working environment could not be made sufficiently safe, we may accept this genetic screening as being morally justified.

On the other hand, Rawbone [13] has suggested that the moral issue underlying genetic screening for employment purposes might seem to be one of autonomy versus paternalism: should people be permitted to assume risks to their health?

In the United States, a genetic test has been piloted as a pre-employment screen for beryllium workers [14], as there is a genetic variation which could indicate a greater vulnerability to developing chronic beryllium disease, if exposed to beryllium. Thus, if this were to be implemented as a standard pre-employment test in that industry, those who tested

positive for this genetic screen would not be recruited as beryllium workers. It could appear, at first sight, to be helpful to exclude such individuals, to prevent their developing occupational disease, but this is contrary to the accepted occupational health principles of reducing workplace exposure to protect, not just the most resilient workers, but also the more vulnerable ones. This is reflected in the way that workplace exposure limits are derived. It is a fundamental approach of occupational health practice to protect the health of all workers at work, and this is supported by health and safety legislation. By reducing the levels of harmful dusts and fumes in the workplace, more workers would be able to work in that environment, and making work accessible to more individuals must be good for society as a whole. In addition, one could argue that there is something morally reprehensible about an employer who does little to reduce the levels of harmful substances in his workplace, relying instead on a number of individuals whose genetic make-up would render them less affected by that substance.

Therefore the question we should perhaps consider is whether we should endorse such research at all, if we are uncomfortable with the consequences?

The 'subjects', that is, those workers who participate in such studies (case study 1, or the beryllium studies) probably do have some protection against discrimination. One would expect, for example, that the research protocols would require informed consent, and that the data be anonymized as far as is possible, so the subjects may not be directly affected. The moral obligations of the researchers in that regard would probably be satisfied. But do the researchers' responsibilities end there? Should they bear any responsibility for the use of such information to discriminate against those in the wider working population, who have this vulnerability exposed by their research investigations?

Before these questions are further explored another case study will be described, and the issues that arise from both case studies presented will then be discussed to help answer the questions posed.

Case study 2

An MSc student presented a study proposal to a university research ethics committee (REC). The study would involve retrospective collection of sickness absence data in an organization, and compare those who had declared mental health conditions at the pre-employment assessment (PEA) stage, with those who had not. The hypothesis to be tested was that those who had (and had declared) mental health problems would also need more time off work subsequently, mainly through relapses of their medical condition, but also because they would be more vulnerable to pressures arising out of work.

Issues from case study 2

The REC did not have concerns about the methodology proposed. The student had obtained the agreement of worker representatives, and as the information was anonymized, individual cases could not be identified, so there was no confidentiality issue.

However, the REC was concerned about the possible outcome of the study, if it did in fact confirm that workers who declared mental health problems at PEA had more sickness absence. The employer could then try to reject such applicants (although there are anti-discrimination laws in the UK, there is anecdotal evidence that these can be circumvented), to the detriment of that population.

On the other hand, the student did convince the REC that this employer was in fact very supportive of socially-disadvantaged groups, and the REC was convinced by his arguments and the evidence he presented. He showed for example, that this organization already had much support in place for those who were more vulnerable.

Although the study has gone ahead with this understanding, the REC also stressed that when he did eventually publish his results, he should be mindful of other employers who might not be as supportive of those with a history of mental health problems, and would simply use the results as an excuse to exclude them from the workplace. He believed that he could present his findings in an objective and balanced way, and the REC accepted this.

Discussion

Both the case studies presented illustrate the problems that can arise out of psychosocial work-based research, in that the results of such research could place those who suffer, or have suffered, or have an increased vulnerability to, mental health problems, at a further disadvantage in the labour market. It is already very difficult for those stigmatized in this way to find work: 79% of those with significant mental health problems are unemployed [15]. Sometimes, there may be very valid reasons why an employer may need to discriminate on the basis of some serious and specific psychiatric disorders, such as for those who would work with vulnerable groups (children, for example). The potential harm that the vulnerable group could face (in a very limited number of cases) would make this the morally correct choice. Even then however, one must treat this approach with caution, as most individuals who have a past history of mental illness, such as anxiety or depression, would be no risk at all to vulnerable groups, and each should be individually assessed by a competent professional.

As previously discussed, when one considers the potential consequences of such research, one may ask whether it should have been pursued. Godfrey [16] has explored the question of whether it is 'ethical to

conduct an investigation at all', in the context of all research, and has suggested that studies can be graded from their research question as 'ethically offensive', 'ethically acceptable' or 'ethically imperative'. He further proposed that by also considering whether the study could be conducted ethically, that is by evaluating the study design ('unacceptable', 'improvable' or 'unexceptionable'), a 3 x 3 matrix could be constructed. He described how this matrix could help an REC in its decision to accept, reject or recommend modifications to, a research proposal. This appears to be a generally useful approach; but would it identify the concerns that are presently being raised in this paper?

Clearly, in case study 2, the REC had identified concerns beyond the immediate study and its subjects, and had discussed these concerns with the researcher. However, the fact that this was raised as an ethical issue at all may have been dependent on the expertise of the REC membership [17], including those who had specialist knowledge of the subject area [18]. In case study 1, this concern was presumably not identified by either the researchers or the REC. Indeed, had the Godfrey matrix been applied to both studies, it may not have picked up these concerns. After all, the study designs were methodologically sound, and the research questions in themselves would not have been classed as 'ethically offensive'. Therefore, more likely than not, they would both have been considered 'ethically acceptable', using the method he describes. Moreover, as Hunter [19] points out, the NHS Governance arrangements describe the aims of RECs as primarily 'to protect the dignity, rights, safety and well-being' of the research participants. Not much thought seems to have been given to issues beyond the immediate players.

What of the researcher's responsibilities? The Clinical Trials Regulations 2004 [20] state that: 'The rights, safety and well-being of the trial subjects are the most important considerations and shall prevail over the interests of science and society' [21]. The focus on the researchers' responsibilities to their subjects is such that the researcher-subject relationship has been a matter of much debate. Some have argued that this relationship is essentially a fiduciary one [22], whereas others have vehemently opposed this view [23]. The reason why this debate is highlighted here is to emphasize that much of the attention so far has been on the subjects, and maybe rightly so. However, arguably, if we only focused on the subjects, and overlooked the overall impact that the research could possibly have, then more harm than good could result from some of this research.

The ultimate aim of carrying out psychosocial research must be to improve the mental health and wellbeing for all in society. If, as Harris suggests, there is a strong moral duty to carry out good research, then there must be a strong moral duty to ensure that

the outcome of the research is beneficial. If the outcome could or would actually further disadvantage the more disadvantaged groups in society, that cannot be seen as a morally good outcome. Despite the best efforts of many, there is still a stigma attached to mental health conditions. Those who suffer, or are seen to be at greater risk of suffering, from such conditions, already find it much harder to find employment. Surely putting more barriers in their way cannot be good for them, or for society? And yet, research such as described in the case studies can eventually put such barriers in their way. The studies were surely done with the best of intentions, and the researchers themselves could foresee benefits that could be derived from their activities, but probably overlooked possible negative consequences.

Should we, then, propose that no workplace psychosocial research at all should be carried out, because the results could be detrimental to some disadvantaged groups? There are many examples of such research being of benefit to all. For example, research which has focused on causes of workplace stress has contributed to the development of strategies for prevention, and research that has evaluated the benefits of intervention measures for those suffering from workplace stress, has contributed to the evidence base, thereby hopefully improving outcomes for sufferers, through more appropriate interventions. Nor should we propose that studies which compare the disadvantaged, or potentially disadvantaged, groups with other groups of workers should never be carried out. Such studies could potentially help in the prevention of relapses of mental illness, or planning better support or early interventions, and possibly the more vulnerable workers or potential workers would benefit the most. This appears to have been the intention of the researchers in both case studies described. The problem, it seems, lies not in the results of such studies, but in the way that those results are then interpreted by employers. Some altruistic employers may use this information positively to help and support the more vulnerable of their workers, whereas employers who are less so would use the same information to exclude applicants or disadvantage existing workers. The responsibility, it could be argued, lies more with a society that does not value its disadvantaged members sufficiently to exert pressure on employers to act with more compassion, than with the researchers, who simply provide the information.

However, maybe researchers should not be let off so lightly: They are aware that they do not present research findings into a vacuum, and they ought to be aware of the realities of the society they live in. They need to be aware that this information could be misused, and take steps to reduce the likelihood of misuse. This may mean, on some occasions, not carrying out the study at all.

The potential for misuse will vary greatly between studies, and this potential could, and should, be assessed at the early stages of a study being developed, along with the research questions and the study design.

In case study 1, that is, research that could lead to the identification of a 'stress gene', would be too easily abused by many employers, and maybe should not be pursued. Others may take a different view, but at the very least, the pros and cons of such research should be debated at an early stage. For case study 2, on the other hand, as long as the researcher is sensitive to the potential for misuse of his results, it would probably still be safe to proceed. If the results are presented in a way that emphasizes that there is a high prevalence of mental ill-health anyway, so that trying to better support those with such a history is a more practical and better option for employers, then this study could be helpful, rather than detrimental, to this group.

Conclusion

How far should the moral obligations of researchers extend? In addition to ensuring that their research aims are valid, their research question(s) ethically acceptable, the study design unexceptionable, and having due regard to the subjects' dignity, safety and wellbeing, should we expect them also to bear some responsibility for the possible consequences of their research findings?

Although studies drawn from workplace-based psychosocial research have been used here to explore this question, it is likely that the same conclusions could apply to most areas of scientific research.

The researchers who initially explored atomic structures could not have foreseen the devastating use that knowledge would lead to, and we would not impute any moral responsibility for such applications on these earlier researchers. Clearly, not all outcomes are easily predictable from new knowledge, and maybe that is why some view research and researchers with suspicion. Indeed, what knowledge is derived from scientific research [24] is itself not entirely predictable, as it relies on inferential reasoning from the data obtained, and this topic is also a matter of philosophical debate.

On the other hand, researchers, through increasing the frontiers of knowledge, do aim to improve the lot of mankind, and to do what is morally good. If the eventual outcome of some research studies could be detrimental to some groups in society, especially the more vulnerable, then this cannot be a morally good outcome. It would seem reasonable to suggest that those who plan and carry out such studies should also feel morally responsible for the effects or outcomes that may ensue from these.

However, if researchers give careful thought to the wider implications of their study, and RECs conduct-

ing the study review scrutinize the protocol beyond the narrow study aims, then there will be a much greater chance that the results of research will benefit all in society, including the most vulnerable.

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