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- Anonymity for respondents/participants is assumed to be an integral feature of ethical research
- The legal requirements of the Data Protection Act assume anonymity should be maintained wherever possible
- Most researchers go to considerable lengths to protect respondents' identities
- Respondents may, however, feel that they 'lose their ownership' of the data when anonymised
- The allocation of pseudonyms to protect identity can cause unanticipated distress
- The practicalities of mixing real names and pseudonyms in publication can be complex

The Anonymity of Research Participants: Assumptions, Ethics and Practicalities

Anne Grinyer

When researchers consider the issue of the anonymity of research participants, concern may be most likely to focus on how it can be maintained, particularly when under pressure from authorities to divulge identities (Grinyer 2001). However, what I consider here is the apparently underestimated likelihood of research participants wishing to be acknowledged in published research thus enabling them to retain ownership of their stories.

The consideration of mechanisms to protect the identity of research respondents appears to have become central to the design and practice of ethical research. Consequent assumptions about the desirability of anonymity are embedded in various codes of ethical conduct. For example The British Psychological Society's code says the following:

Participants in psychological research have a right to expect that information they provide will be treated confidentially and, if published, will not be identifiable as theirs.

(Robson 1995:43)

The British Sociological Association Code of Ethical Practice adopts a similar stance:

Research participants should understand how far they will be afforded anonymity and confidentiality and should be able to reject the use of data gathering devices such as tape-recorders and video cameras.

(BSA:704)

The same code of ethical conduct continues by emphasising the importance of respecting the anonymity and privacy of research participants. A range of authors in a variety

of methodological texts address anonymity, and the norm is to emphasise the importance of maintaining it (for example: Heath and Luff 1995:308, Newell 1995:110, Procter 1995:258). Thus the usual 'rule of thumb' according to Barnes (1979:39) is that data should be presented in such a way that respondents should be able to recognise themselves, while the reader should not be able to identify them.

Since the introduction of the Data Protection Act (1998) which came into effect on 1 March 2000, the consideration of anonymity and privacy is no longer simply a matter of ethics; it can also have legal implications. The fundamental principle of the Act is the protection of the rights of individuals in respect of personal data held about them by data controllers – including academic researchers. Concerns relating to the misuse of personal data have stemmed from the vast amount of data that new technologies have enabled to be amassed on individuals, though the Act also applies to both electronic data and manual data (paper, card indices, files etc.).

The Act addresses a number of issues relating to anonymity and says that anonymisation should be carried out as far as possible to increase the security of data processing. Once data have been completely anonymised and can never be reconstructed to identify the individual, they no longer constitute personal data and so are exempt from the Act. However, the commissioner ac-

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knowledges that in practice true anonymity may be difficult to achieve and recommends that all unnecessary, identifying detail should be stripped from research data prior to publication. In instances where the identity of an individual may be difficult to conceal because of details of personal circumstances, explicit consent must be obtained before publication can proceed.

Such mechanisms for the protection of individuals do of course have a central place in the design and conduct of ethical research and there are many instances in which the guarantee of anonymity to research participants is of paramount importance. Yet these concerns may have led to a culturally embedded assumption that anonymity is an ethical prerequisite, particularly in areas of investigation that may be of a sensitive nature.

All the guidelines discussed thus far are based on the premise that individuals not only deserve the protection of anonymity, but that they actively desire it. However, the experience of a recent research project with the parents of young adults with cancer suggests that the issue of identity/anonymity is more complex and less predictable than it might at first appear and may problematise some of the ethical and legal requirements for good practice.

A challenge to the orthodox assumptions

The research sought to understand the effects on families when young adults between the ages of 18–25 are diagnosed with cancer. A call for narratives was made and disseminated through a number of cancer charities and other relevant organisations. The reasoning behind this methodological approach was that respondents would be able to decide without pressure if they wished to contribute an account, they would be able to choose when and how they responded and would be able to present the account in their own terms. This resulted in the parents of 30 young adults with cancer sending their stories.

The call for narratives, in accordance with accepted ethical practice (Grbich 1999), assured potential respondents that their identities would not be disclosed in any result-

ing publication. Indeed Grbich goes as far as saying that respondents should be told explicitly how confidentiality and anonymity will be maintained. It was therefore not questioned by anyone involved in the research project when, during the transcription phase, pseudonyms were allocated to all the characters within the narratives. The transcriber selected the pseudonyms on an apparently arbitrary basis. For the first dozen or so transcripts this allocation of pseudonyms remained unquestioned. However, as the data continued to be submitted, my fellow researcher and I began to query the process. At first we simply doubted the appropriateness of the renaming. For example, a respondent called Gabrielle was renamed 'Joan', although somehow this did not appear to be an 'equivalent' name. But as the research progressed we also began to question whether some respondents might prefer to be referred to in publications by their own names. The parents who had been brave enough to send the narratives had shared with us some of the most intensely painful and intimate details of their family's lives. How would they feel if they had been allocated a random pseudonym and what would be the effect of seeing their lost son or daughter referred to by another's name?

As a result of our unease at the allocation of pseudonyms, all participants were written to and asked if they would prefer to be called by their own names or to be allocated a pseudonym in any publication using extracts from their narratives. To our surprise only seven of the respondents said that they would like pseudonyms to be allocated. Thus about threequarters of the respondents specified that they would like their own names used.

Despite the disquiet that caused us to question the use of pseudonyms, the overwhelming desire for the use of real names challenged our assumptions about the accepted norm that respondents prefer anonymity. But in spite of our attempts to satisfy the wishes of respondents, after the publication of a journal article based on the research (Grinyer and Thomas 2001) it became apparent that at least one respondent had made a mistake in her request for the use of pseudonyms. After the publication of the article,

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all respondents were sent a copy. Many replied thanking us for raising important issues and helping other families facing similar problems. However, one parent with whom we had had frequent correspondence prior to the article's publication, did not reply to us. It was not until some months later, before the publication of a book based on the narratives (Grinyer 2002), that we again contacted her in relationship to the use of photographs she had sent. She replied apologising for her earlier lack of response and said that despite her request that we use pseudonyms, when she had seen her words attributed to another's name, and reference to her dead son also allocated a pseudonym, she realised she had made a grave error. In her own words:

I was very moved by the whole article and the experiences of other parents. I have one major regret that I can now express, but at the time it meant that I just couldn't respond to your letter... Looking back I was very disappointed not to see Stephen's and my name in print. Even though my words were there, I felt as though I had somehow lost ownership of them and had betrayed Stephen's memory. That was entirely my own fault. I know that you followed my original wishes but this was a great mistake on my part. I was also upset because my family and friends found it odd as well. They expected and wanted... our names too. **Please if you use any of my writing or photographs in the future can you be sure to use all our real names.**... I had been looking forward to the transcript of your article in order to share other's experiences, but without our real names I didn't feel part of it. I didn't show it to anyone because I knew they would not have recognised Steve.

Gabrielle (real name, emphasis in original)

Fortunately, this change of heart became known before the manuscript of the book had been submitted and so the names could be changed in time for publication.

After receiving this letter we questioned whether the other parents asking for anonymity might also feel the same. Interestingly, when going through the list of those asking for pseudonyms we found that most of them came from the parents of a son or daughter who had survived the cancer (only seven of the young people in the study had

survived). Only two requests for pseudonyms were from parents whose son or daughter had died. We had no means of knowing if the decisions on names relating to the seven surviving young adults had been taken in consultation with them, but our assumption was that it had been a joint decision and in these cases we made the judgement to allow the pseudonym to remain unquestioned. While there are ethical issues about who should take the decision relating to the allocation of names – these were after all young people legally entitled to make their own medical decisions – it was not felt appropriate to pursue the matter and verify the process of consultation that might have taken place within the family. However, again making a judgement based on what we knew of the circumstances, one of the two respondents whose son had died and who had requested pseudonyms was contacted and asked if she would like to reconsider her original decision and instead to have the real names of herself, her son and wider family used in the book about to be published. This parent telephoned the same day the letter arrived and said that she and her family had decided they would change their minds and would like their real names to be used.

In contrast, we contacted one respondent who had opted for her real name to be used to suggest that she might like to reconsider. This was because she had provided some personal details of family members that we feared she might find embarrassing if published. However, despite our suggestion that she consider pseudonyms, she reiterated her wish for real names to be used. Thus it is clear how problematic it is to make judgements on behalf of others, however well intentioned.

Practicalities

In addition to the issues discussed thus far, there are practical problems associated with the use and allocation of pseudonyms, the mixing of real names and pseudonyms and the changing of names after they have been embedded within a text.

The first practical problem that was faced during the writing of the book was that there was a mixture of real names and pseudonyms, and that some of those allocated pseu-

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donyms wanted them to be changed to their real names, while some of those whose real names had been used wanted pseudonyms. The reallocation of names to accord with respondents' wishes proved a time consuming and complex matter. To have anticipated at the outset of the research process that such issues might arise would have saved hours of complex editing.

The second problem was whether those who wished to have pseudonyms should be able to select their own name. In using real names there was already some duplication that necessitated the use of initials to distinguish them. To have risked yet more respondents wishing to be known by names already used seemed problematic. Yet there is always the danger that allocating names to respondents will result in them being called by a name that has bad associations or that they simply cannot relate to. Who makes the choice, the researcher, the transcriber or the respondent? This may be of some importance as all are likely to make different choices that will have an impact on the outcome for the respondent. In this case the resulting text has a mix of real names and pseudonyms. While these could have been differentiated by the use of italics, a decision was made not to show which were which as the reader does not need this information.

Conclusions

The research amongst the parents of young adults with cancer raised a number of unexpected practical and ethical issues, none of which appear to be covered in orthodox guidelines or texts on the practice of research.

While it is essential that the interests of research participants should be protected, there does appear to be a risk that accepted practice embedded into ethical guidelines and legal requirements may not always be experienced by respondents in the ways anticipated by the researcher. The balance of protecting respondents from harm by hiding their identity while at the same time preventing 'loss of ownership' is an issue that needs to be addressed by each researcher on an individual basis with each respondent. Even then, it is still possible that respondents will make the 'wrong' choice, as did

Gabrielle in this research. Therefore, where possible, to show respondents their words in print at a draft stage so that they can make a more informed judgment may be the only way in which to maximise the chance that their wishes are fulfilled. Even then it may be that unexpected feelings are aroused after publication. However, if researchers are aware of the issues and consult with respondents as fully as possible throughout the research and publication process there will be less chance of research participants feeling that they have lost ownership of their stories. There is after all an ethical dimension to a researcher deciding on behalf of respondents that their identity should be concealed without verifying the respondents' wishes.

Finally, it must be acknowledged that the research project in question has a number of features that distinguish it. It deals with a very emotional and personal issue, the responses were entirely 'voluntary', there was continuing contact between the research team and the respondents and no institution that might wish to maintain secrecy was involved. There may also have been stronger motivation for respondents in such an area to have their experiences recognised and acknowledged. Nevertheless, it still challenges assumptions about the identification of respondents in sensitive research.

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