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The ethics of participating in research

Simple statements of risks and benefits may not reveal the complexity of human responses to research participation

IN THIS ISSUE OF THE JOURNAL, Scott and colleagues (page 507) report on a retrospective study of family members' experience of participation in a previous study following their child's diagnosis with Ewing's sarcoma.¹ The research is important because it casts empirical light on an ethical issue often debated in human research ethics committee meetings: how does research affect those who participate in it? Ethics committees can be very cautious about granting approval for research into sensitive areas because of concern about the impact on research participants.

People participate in research for many reasons. They may feel an obligation to their doctor, they may not think they have a choice in the matter, they may hope or believe they will benefit from the research, or they may just wish to help others.²⁻⁴ Regardless of the reasons research participants may have for participating, the National Health and Medical Research Council (NHMRC) guidelines⁵ make clear that the primary duty of members of ethics committees is to attend to the "dignity and wellbeing" of research participants. Ethics committees focus, above all, on the risk of harm or discomfort to participants and on the requirement that participants make a free and informed choice to participate in research. Committees need to bear in mind that

In clinical research... the risks of participation must be balanced by the possibility of intended benefits to the participants. In other research involving humans... the absence of intended benefits to a participant should justly be balanced by the absence of all but minimal risk.²

However, the data from Scott et al suggest that balancing risks and benefits is not necessarily a straightforward matter. How research participants experience risks and benefits can be rather complex.

First — at least for research into sensitive areas such as serious and life-threatening illness — participants may find it painful and distressing to recall past events or articulate complex emotions. However, doing so in a supportive environment may actually be beneficial. Scott et al indicate that the benefits gained by participants in their study came *despite* the pain of talking about distressing events. I would argue that the evidence in their article suggests that some benefits seemed to accrue to participants *because* they could talk about painful experiences. Ethics committees may be able to separate out the risks and benefits conceptually, but in people's experience of taking part in research, as in other areas of our lives, things are seldom so tidy.

Furthermore, the qualitative data reported imply that an additional benefit to participants was the opportunity to learn more about Ewing's sarcoma. Research participants often ask questions — about their illness and its treatment, about the researcher's opinion of the medical care they are receiving, or about other treatment alternatives that may be available. Participating in research can provide extra contact

with "experts", which may be of benefit to participants. The question arises, "Is it ethical to inform prospective research participants of such benefits?". Members of ethics committees may not be comfortable with answering "yes" to this question, because they are likely to be worried about the coercive effect of such information. They may also be concerned about other factors that come into play when the researchers' role is extended to include answering participants' questions. They may be apprehensive about the possible effects on the scientific integrity of the research itself; they may believe that research staff are not the best people to answer questions about the participant's condition; or they may be concerned about role confusion for researchers when they also provide advice.⁶ In addition to considering *how* researchers should respond to requests for information, it is important to consider *why* researchers are being placed in this position at all. It is an indictment of our healthcare system that patients may think they need to take part in research in order to have their needs for information and reassurance met.

The study by Scott et al also raises the tricky question of the role of altruism in research participation. Nearly all of the study participants felt that their involvement would benefit others. Researchers may encourage such beliefs, often in the context of explaining that they can not guarantee that the research will benefit the participants themselves. The possibility of benefit to others is sometimes all that can be held out as an incentive for potential participants. Even here, however, things are not that simple. Feeling that others are helped by our involvement in research can be of benefit to us, as concern for our own interests and concern for others' interests are actually closely intertwined.^{7,8} Sometimes we act altruistically because we enjoy the feeling of being an altruistic person and the positive response it engenders in others. In a sense, our self-interested choices can be re-interpreted as altruistic, and *vice versa*. In Scott and colleagues' study, feeling that others might benefit from their involvement perhaps offered the participants a way to make sense of difficult and otherwise inexplicable events.

Finally, the whole issue of risks, benefits and altruism is further complicated by questions about whose notions of risks, benefits and altruism are to count. Ethics committee members, research participants and researchers are all likely to offer different interpretations of these concepts in specific situations. For example, should ethics committees intervene if research participants choose to believe their involvement will help other people like them if, in fact, there is little evidence that this will occur? Can committee members or researchers accurately judge the risks and benefits of research for a participant, or should the emphasis be principally on facilitating choice? Human emotions and ethics are complicated, and simple statements of risks,

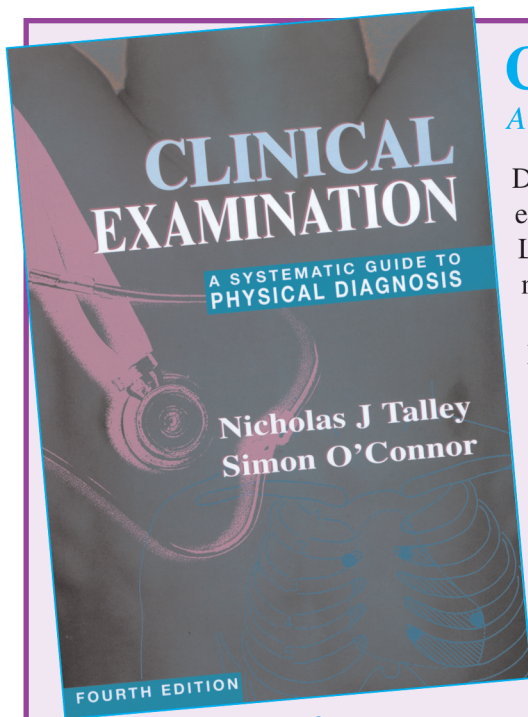
benefits and altruistic intent are unlikely to reveal the complexity of the situation.

What are ethics committees, researchers and participants (potential and actual) to make of all this? They should, at least, recognise that guidelines are only that, and can never substitute for careful and nuanced consideration of the meanings of terms such as “risk” and “benefit”. The NHMRC’s *Commentary on the national statement on ethical conduct in research involving humans*, released this year, provides something of a roadmap in this area.⁹ But committees will still need skills, knowledge, time and resources to consider these issues thoughtfully. While skills and knowledge may not be in doubt, we know that many committees lack the time and resources needed to do justice to these thorny issues.¹⁰

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