



Current arrangements for disclosure in nursing and health research protocols

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Research ethics

Achieving a balance

Many ethical issues have to be considered when identifying personal health status whilst undertaking nursing and health research. **Consent**, the **dignity** and **privacy** of the research subjects, **voluntary** participation and protection from harm - are commonly addressed through good practice in data management, informed consent and the application of basic ethical principles.

Additional features can make **qualitative research** more challenging. Holloway & Wheeler (1995) note an increased vulnerability and likely researcher-nurse duality.

Benefits



Risks

Basic principles

Beauchamp & Childress (2001)

- Respect for autonomy
- Nonmaleficence
- Beneficence
- Justice
- Professional duty
 - Veracity
 - Privacy
 - Confidentiality
 - Fidelity
 - Dual role



Planning how to deal with disclosure

Predictable disclosure

..what you might reasonably expect

Disclosure of clinically relevant information, generates specific ethical problems because of the potential conflicts between clinical and research roles, privacy and protection, individual vs common goods (Bevan et al, 2012).

Methods

Participant observation

To identify current practice, a 12-month cohort of research ethics applications (N=96) were reviewed using a **documentary analysis** approach, noting cases where any arrangements had been put in place to accommodate the management of individual findings where the researchers were able to predict disclosure of potentially relevant information.

Findings 1

Low risk study of non-vulnerable people

Descriptive studies of health status in otherwise healthy populations where no special disclosure arrangements were found. This category included studies that *purposely avoid* collecting personal details, thus making any disclosure impossible.

The study will not involve naming specific client cases in relation to sexual health promotion. The focus of the interviews is to explore nurses' experiences and decision making process of delivering sexual health promotion to migrants

Anonymity is sometimes confused with confidentiality: both have limits.

Findings 2

Low-risk studies where disclosure is likely

Observational studies of ex-patients, clients of informal care, nurses and other carers of people with health concerns. Disclosure of previously unreported aspects of the illness or patient care can be predicted, where the research topic coincides with the disclosure topic: in these cases planned to provide support and advice to participants. Researchers also enlist supervisors:

...before the data collection starts each participant will be made aware in the PIS and verbally that confidentiality may not be conserved if information is revealed that indicates a risk to him or herself or others. If this does arise the principle researcher will report this to her academic supervisor in the first instance... The PIS includes guidance on sources of help and support.

Findings 3

Interventional studies with risk of harm or inconvenience

Less populated category of study, involving investigations at higher levels of risk with vulnerable populations. This category included cases where specific clinical partners were available to address disclosure through direct referral.

If a cause of concern is disclosed by a participant in the interview, for example, intention to harm oneself, the researcher will inform the participant of these concerns and emphasise the importance of reporting this to appropriate professionals... The issue will also be raised by the researcher with the chief investigator (supervisor) in confidence to ensure that the correct procedure was followed and to make the chief investigator aware of this. The participants GP should also be contacted immediately in this case.

Example

What level is this?

If at any time during the interview the parent participant discloses issues that cause concern e.g. severe depression, wanting to harm child / self, then the interviewer will at the end of the interview inform the parent participant of these concerns and the need to report them to the appropriate personnel.

- If the concern is primarily concerning the safety of the child then the duty social worker would be contacted, according to the Children's Order 1995 and Child Protection Policies.
- If the primary concern is about the parent participant then the organisation from which the parent participant was recruited will be informed and the GP contact details obtained.
- The GP and the duty social worker would be contacted immediately.
- The interviewer would not leave the parent participant until the duty social worker has said it is safe to do so.

Conclusion

Other findings, discussion

The approach to duty of care in disclosure did not seem to relate to other ethical principles. The level of participant anonymity and confidentiality varied across the approaches, independently of disclosure or risk.

Ethical consideration is crucial in planning research: arrangements for disclosure of clinically relevant details to researchers has been reported (Olsen et al, 2003). Further work is needed to understand the implications of privacy and anonymity.

Thank you

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