



ETHICAL RESEARCH INVOLVING CHILDREN

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HARMS AND BENEFITS

Working with socially excluded and multiply vulnerable children in research: Using participatory methods with young carers

Background context:

Since the early 1990s, evidence from research studies on young caring has helped to inform and shape health and social care policy and practice in the UK, and has meant that children who provide informal care for their sick or disabled parents (or other relatives) in the home have access to dedicated young carers' services. However, when services are not provided and when caring becomes long term or disproportionate to children's age and level of maturity, adverse consequences for children such as poor psycho-social development, low educational attainment and poor transitions into adulthood, can occur. In the *Pictures of Young Caring* study conducted by members of the Young Carers Research Group at Loughborough University, UK (see: www.ycrg.org.uk), the objective was to understand the needs of children who cared for parents with serious mental health problems.

The ethical challenge:

In UK health and social care policy and practice, young carers are identified as vulnerable when assessed as children in need or when they present to services. Attempting to identify and recruit these children for social research studies can thus be challenging, especially when it is perceived that research processes themselves may enhance or contribute further to children's vulnerability. Research on young caring has also shown that some children – particularly socially excluded children or multiply vulnerable young people – often do not want, or feel unable, to participate in research studies that rely on their verbal contributions, for example, through the use of interviews or focus group methods. When children present as unwilling or difficult to recruit in these ways for research purposes it is more likely they will be left out of research studies altogether if different, more inclusive methods are not utilised.

Choices made:

For multiply vulnerable young carers and other marginalised groups of children, participatory methods are necessary in order to offer more flexible and even creative strategies for engaging with them in research processes that aim to be transformative – that is, that intend to change lives. In the *Pictures of Young Caring* study participatory visual methods were used. Photographic participation and elicitation methods enabled the children and young people to collaborate in the research process, as co-researchers and co-analysts. The visual approach also meant that the children were able to show – rather than being asked to verbalise – their experiences of living with and caring for parents who had long-term mental health problems. The children created photographic diaries of their caring experiences and the photographic data were also used as visual

prompts in follow-up discussions with the children about their needs as carers. The visual evidence highlighted specific aspects of caring and mental health issues that would not have been identified in studies using more conventional methods. Importantly, the children themselves engaged well with the photographic method and these approaches have since been used elsewhere in both research and practice contexts. For example, a number of young carers' projects and services in the UK have introduced photographic workshops to enable children to demonstrate visually their caring experiences and activities and to talk more openly about these.

Reflexive considerations:

- Researchers should consider engaging collaboratively with vulnerable children congruent with global agendas on children's rights, including their right to participation.
- Some children, particularly those defined as vulnerable or multiply vulnerable, may require research methods that are more flexible and inclusive and that consider children as, for example, collaborators in research design and implementation – as co-researchers, co-analysts etc.
- Children engage well with methods that do not rely on their verbal contributions alone.
- Using participatory methods, such as photographic participation and/or elicitation techniques can help foster closer relationships between researchers and vulnerable participants.
- Visual methods and other participatory or inclusive approaches present a number of ethical challenges and it is important that researchers adhere to strict confidentiality and consent procedures when using these methods.
- Confidentiality issues can be challenging when visual methods are used but these are not insurmountable; researchers should ensure that all photographed subjects provide written consent to be included in any public outputs from the research, and that processes for anonymizing images are used where necessary.

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