

Pictures of young caring

Jo Aldridge explains visual methods in social research.

There is a growing interest in social research in exploring and understanding the needs of vulnerable children from their own perspectives and in promoting a genuine participation agenda. However, until recently research on children and young people tended to regard them as objects of study rather than active social agents with important contributions to make to public and political discourses. But without children's genuine participation in such discourses then it is likely that their needs will not be fully understood or realised.

Participative methodologies

Research on young carers in the UK has shown the importance of adopting methods that are based on the views of children and young people themselves, so that their voices can be heard both publicly and politically. Young carers are defined as children and young people under the age of 18 who provide care for their ill or disabled parents (or other relatives) in the home and there are estimated to be around 200,000 children providing such care in the UK.

The types of caring responsibilities these children undertake range from practical domestic duties such as cleaning, cooking, and managing household budgets to emotional care provision and intimate nursing type duties such as toileting and bathing parents. A number of research studies have highlighted the impact of caring on children when such care responsibility becomes long term or disproportionate to their age and level of maturity. The effects of caring on children can include poor educational achievement, low self esteem, poor transitions to adulthood and vulnerability to criminality, especially where families experience poverty.

Most research studies have focused on children's experiences and needs when they care for parents with a range of mainly physical health problems. More recently, however, studies have focused on children who care for parents with specific illnesses, in particular those with serious mental health problems (see Aldridge and Becker, 2003).

While child-parent relationships can be strengthened by children taking on caring responsibilities, parental mental illness can also exacerbate children's vulnerability. Parents with serious mental health conditions often experience a range of other problems, including chronic physical illness and/or alcohol or substance misuse as well as problems related to the impacts of social exclusion such as low incomes, poor housing etc. As a consequence children may experience discrimination, stigma by association, isolation from their peers, and vulnerability to criminality (see Princess Royal Trust for Carers (PRTC), 2009).

These children also prove particularly hard to reach and difficult to include in research studies because they often do not wish to disclose their caring roles to outsiders for fear of child protection or safeguarding decisions that may lead to family separations. Furthermore, it is clear from working with these children that some do not wish to take part in research studies that rely on conventional interview methods because either they do not want or feel unable to talk about their experiences, which may be too painful or distressing for them.

In which case, it becomes necessary to consider other research methods that do not rely on children's verbal input or capacity but that still promote their participation. A number of

pioneering research studies have used photographic participation methods with vulnerable respondents in a range of contexts and these have generated compelling visual data. In Radley and Taylor's (2003) photographic study with post operative hospital patients, for example, the authors concluded that the photographic method provides the potential to 'tell in different voices and see through different eyes from beyond' (see also Sempik et al., 2005).

Images of caring

The *Pictures of Young Caring* study (Aldridge and Sharpe, 2007) included 20 children whose ages ranged from nine to 17 all of whom helped to care long term for parents with serious mental health problems ranging from chronic depression to schizophrenia and personality disorder. The aim of the study was two-fold: to gain further insight into the needs and coping strategies of children who care for parents with serious mental illness; and to test the efficacy of the method itself.

Disposable cameras were given to the young people and, over a two week period, they were asked to take pictures of meaningful aspects of their lives relating to their caring experiences. Following this initial phase the children were invited to talk about the photographs they had taken if they wished. Some children wanted to explain the background to their pictures while others simply wanted the images to 'speak for themselves'.

A basic content analysis of the 297 images generated from the study was conducted in order to identify any patterns in the subject matter of the photographs. The content analysis was broken down into two phases that focused on the internal and external narratives derived from the photographs.

Visual analysis

The visual data revealed the ways in which the children coped with the demands and strains of caring and of living with the uncertainty of parental mental illness. These were categorised as either passive or active divertive strategies, the

former being represented through the use of visual and audio media and imagination (30 images; see Figure 1), and the latter through art and craft work, gardening and recreation (as represented in the 40 images collated). Both active and passive divertive strategies had reductive outcomes in terms of alleviating physical and emotional stress for the children as well as the relief from boredom in often confined or restricted home environments.

Many of the photographs revealed the bonds the children shared with parents, with their friends and even with family pets. A number of the participants also produced images that related to their caring responsibilities, either photographs of themselves caring (in which case they asked other family members to take photographs of them performing domestic tasks) or of the person for whom they were providing care (see Figure 2 and 3).

Visual evidence relating to the more pressing needs of children who care for parents with serious mental health problems was clear from the images and accompanying narratives that revealed children's nursing type responsibilities and in particular the management and administration of medication to parents (Figure 4). In such cases, children are in effect acting as their parent's nurse and taking on inappropriate responsibilities that can and do have serious risk implications. The UK has already witnessed the tragic death of a young carer who overdosed on her mother's medication. The visual evidence generated in this study shows clearly that this aspect of young carers' lives is something that requires urgent attention.

Ethical considerations

Using visual methods in social research, especially with vulnerable participants, raises some important ethical issues. Confidentiality and consent procedures are particularly pertinent. An inevitable objective of any visual study of this kind is to make the private public which, in this case, involved exposing aspects of vulnerable children's lives to the 'public gaze'. In such cases, it is

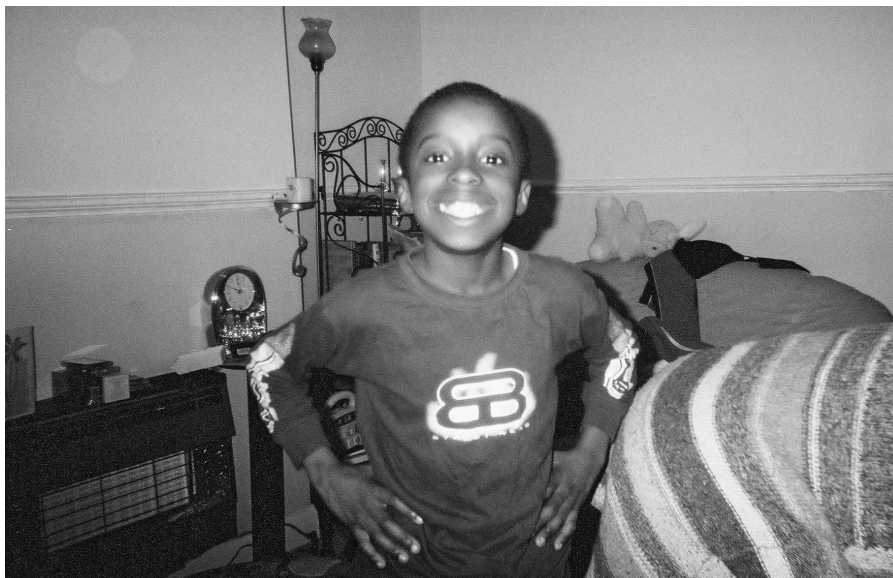


Figure 1: 'It's a picture of me. In my mind I was pretending that I was a superhero. Superman' (Chisomo, 9, cares for mum who has depression and learning disability)

essential that ethical guidance and procedures are strictly adhered to throughout. As well as institutional and professional ethical approval, all the children and parents involved in the study were asked to provide written permission and consent to participate (with the understanding that they could withdraw at any time) and consent was obtained from all parties for the photographic data and narratives to be used in any public outputs. This also included gaining consent from all of the subjects

who featured in the photographs themselves.

An important ethical issue that emerged during the course of the study was that many of the young carers took photographs while they were in school. Most schools these days have policies that prevent pupils from taking photographs on school premises and from taking pictures of staff or other pupils without obtaining permission and following informed consent procedures. However, in seeking to gain

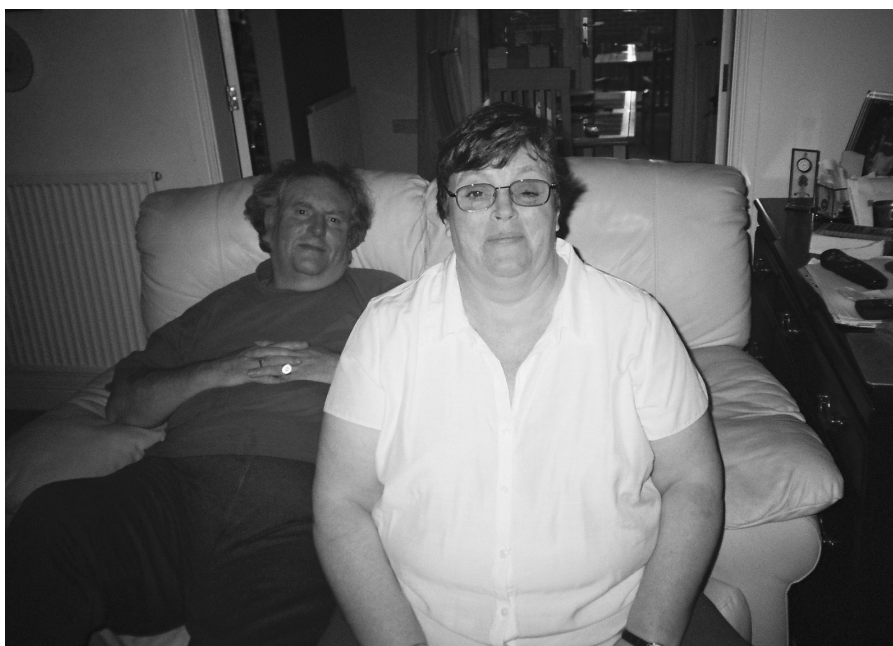


Figure 2: 'That's a picture of my mum and dad; you just want to hug them. I'm a carer for my mum. On a really bad day I will be doing absolutely everything. Dressing her, doing washing, vacuuming, cleaning and loads of things' (Fiona, 13, cares for mum who has depression)



Figure 3: 'Some of the things I do are look after my younger sisters and I have to rub my mum's feet because you have to push the circulation through. I have to help my mum with her medication and injections. That's me helping the girls get ready for school in the morning' (Lucy, 14, who cares for mum who has depression)

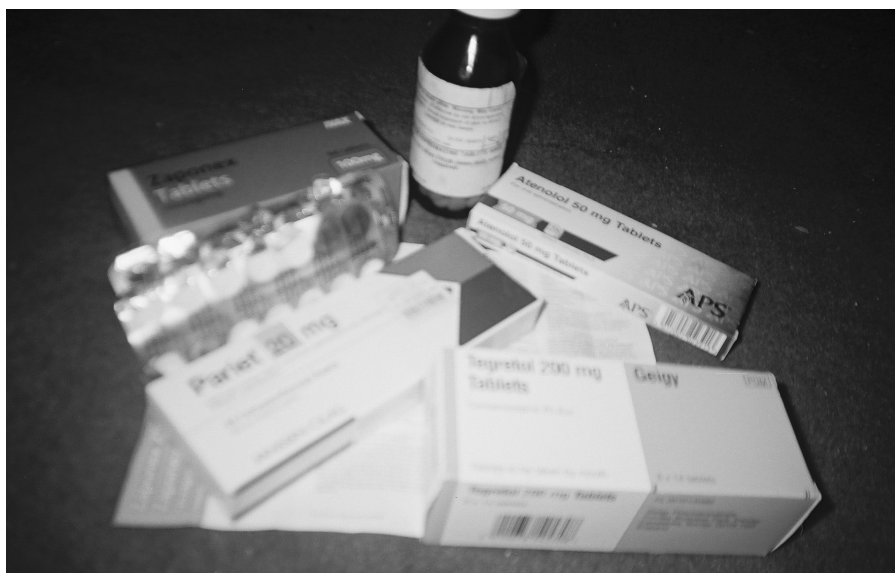


Figure 4: 'This is a prescription I go down and get for my mother. I know what the medication does but I'm not sure which one does which... I check her medication... and make sure she takes them and watch her' (Emma, 14, cares for mum who has schizophrenia)

permission to take and use photographs in school, the participants would inevitably have had to identify themselves as young carers – something a number of the participants were keen to avoid. The needs and wishes of the participants were prioritised in this case. Thus, even though some children took photographs in school without

permission, these images have not and will not be used in any outputs.

Although many of these confidentiality and consent issues seem challenging, they should not be seen as insurmountable obstacles in undertaking or using visual methods in research or in practice. A key principle is to take account of these ethical considerations and

procedures during the planning stages of any visual study that includes vulnerable participants.

Policy implications

The images generated from this study lent a powerful visual dimension to our understanding of children's experiences when they live with and care for parents with serious mental illness. The messages for policy and practice are equally clear – children develop their own ways of coping with the anxieties associated with caring but they need practical help and support and they need interventions that prevent them from taking on inappropriate caring responsibilities. The issue is not how to prevent children from caring because often they want to care in some way, but how to prevent the impacts of caring from increasing their vulnerability to a range of negative life experiences, including isolation, social exclusion, and offending behaviour. ■

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