Contents

Pictures of Young Caring

Background

Children with care responsibilities

Recent estimates of the numbers of young carers (children and young people who provide informal care for relatives, usually parents, in the home) suggest there are approximately 175,000 in the UK (Barnardo's, 2006).
Since the early 1990s, increasing government and public attention has focused on the needs of young carers, and research studies have highlighted both the nature and extent of children's caring duties when parents have chronic health problems or disabilities (Aldridge and Becker, 1993, 1994; Bilsborrow, 1992; Frank, et al, 1999; Aldridge and Becker, 2003). Until more recently, however, little was known about children's caring experiences in specific contexts, such as where parents have severe and enduring mental health problems. *Children Caring for Parents with Mental Illness* (Aldridge and Becker, 2003) was the first study to address this issue and looked at children's co-residency and caring experiences from the perspective of the children themselves, their mentally ill parents and the key professionals involved in the delivery of services.

Children's participation in research

A critical problem identified in the 2003 study was that qualitative research methods, which employed interview techniques, were neither adequate nor appropriate in every case to capture the views of particularly vulnerable children who felt unable or unwilling to participate in interviews. It became clear that even qualitative research studies could potentially be missing the voices of those most in need of recognition, help and support.

Fear among children (and their families) of professional interventions in their lives, as well as the often difficult and painful circumstances in which they live means young carers are often hard to identify and include in practice interventions, but more significantly, from an empirical perspective, can be difficult to engage with. This difficulty is also reflected in research with other vulnerable groups who do not have the verbal capacities to participate in interviews, for example those with learning disabilities. Failure to address this problem will only serve to alienate these groups further unless more appropriate, participative methods are identified and used (see Aldridge, 2007).

This tension is further amplified when considering recent government initiatives and policies that emphasise children's inclusion and participation. The formulation and implementation of Every Child Matters (2003), the new

Children Act 2004 and the appointment of a Children's Commissioner for England and Wales are all underpinned by an intention to encourage and increase children's participation as active social agents.

Objectives

The aim of the study was to identify 20 children who were helping to provide care for parents with serious mental health problems. These children would be given disposable cameras in order to create photographic diaries of their caring, and other meaningful experiences (for a full discussion, see *methods*). Two key objectives underpinned the broader scope of the investigation, based on the principles of children's welfare and competency (young carers as children with distinct needs and as active participants in research):

- to further our understanding about children's experiences of living with, and caring for, parents with serious mental health problems (including children's health and social care needs);
- to test the efficacy of photographic participation and elicitation methods among this group of vulnerable children (young carers).

The first intention relates to the social welfare of young carers and the policy and practice contexts in which their needs are addressed. In the longer term and in respect of outputs from the research study it was hoped that the study would help to inform health and social care policy and practice about young caring in the context of parental mental illness, using children's own visual data.

It was also hoped that the study might extend our understanding about children's competency in these contexts and, directly and valuably linked to this, enable children and young people themselves to demonstrate their ability more as (participative) co-researchers than research subjects. Underlying this research study, then, was the epistemological intention to engage with what has been termed the 'new sociology of childhood' (Wyness, 2006) which, 'takes it as read that children can be understood as competent social actors [and] as fully constituted social subjects' (Wyness, 2006, p 263).

In terms of the visual methodological approach specifically, it was important to understand whether using photographic participation techniques among children (who used cameras to visually represent their experiences) and elicitation methods, where their images were used as a basis for conversation-like discussions, would give us greater insight into children's inner worlds.

Meeting objectives

The objectives in respect of the two key aims of the study were met absolutely and, indeed, exceeded initial expectations, particularly in terms of children's participation in the study (and their enjoyment of using the photographic method) as is demonstrated in the results and discussion below.

In terms of furthering understanding about young caring in the context of parental mental illness, greater insight emerged from the visual data both in regard to the nature of children's responsibilities and their relationships (and the importance of what we refer to as 'two-tier' friendships) and their coping and resilience skills.

With regard to the efficacy and usefulness of the photographic method, the research study also fulfilled its objectives and, again, exceeded expectations. Not only did the children and young people enjoy their participation in the study, using the cameras to visually demonstrate their experiences, but they also revealed a high level of competency in understanding, directing and collecting the visual data.

Access and confidentiality - protection versus participation

The study required implementation of ethical and consent procedures in accordance the British Psychological Society's guidelines (BPS, 2001), 'working with vulnerable children and young people'. Children and parents were asked to give written permission and consent to take part in the study (with the understanding that they could withdraw at any time) and consent for their photographs and narratives to be used in any outputs. This also included gaining consent from those who children and young people photographed in the course of the visual data collection phase. Access to children and families was gained via young carers projects whose staff were asked to identify potential children and families who fulfilled the research criteria.

Some staff had real and genuine concerns about the confidentiality issues raised by the research and some decided these were too great even to approach families they had in mind who might fulfil the criteria. Thus, an emphasis (or over emphasis) on protection among some staff could have become preventive or exclusive had it not been for a general willingness to overcome some of these issues by working in partnership with the research team. From an ethical point of view, then, the study involved achieving an appropriate balance between protection and participation: allowing children who wanted to tell their stories to tell them in appropriate and sensitive ways, but with due regard to confidentiality and informed consent procedures, and working closely with project staff.

Data protection and schools

A further problem not anticipated from the outset of the study was the issue of data protection in schools, particularly in relation to taking photographs on school premises. Many schools have a policy whereby pupils are not allowed to take cameras onto school premises, nor are pupils allowed to take photographs in school or of other children in particular (without permission or consent from parents). However, in seeking permission to use their cameras on school premises, the participants in the study would inevitably identify themselves as young carers – something a number of the children and young people were keen to avoid. The needs and wishes of the participants were

prioritised in this case, with due recognition also given to data protection issues. Thus, even though some children took photographs in school without permission, these images are not used in this report nor will they be included in any future outputs.

Methods

Participatory visual research

In respect of children and young people, there are a range of techniques increasingly used in the social sciences which shift the balance away from the written or spoken word to approaches that focuse on visual or multi-sensory methods (Clark et al, 2003). Increasingly, these new approaches have incorporated the use of different media, for example giving cameras to young people to record their own perspectives (Clark et al, 2003; Gadd et al, 2000; Rasmussen, 1999).

Photographic participation and elicitation

For this research study we used photographic participation and elicitation techniques. The children and young people in the study *participated* directly in the research process by using cameras to demonstrate visually their caring experiences when parents had serious mental health problems. Over the space of two weeks the children and young people created a visual diary, which constructed a narrative of their caring lives. The direction they received was to take photographs that they felt were important in demonstrating what it was like to live with, and help to care for, a mentally ill parent, and other meaningful aspects of their lives. A content analysis of the photographs was undertaken to generate themes and categories. The *elicitation* stage involved using the visual images to stimulate discussion with the participants about their caring and other meaningful experiences (see Sharpe, 2003). The narratives created during this stage were thematically analysed.

The aim was to identify and gain access to 10 children in the Midlands region who were caring for parents who had had severe and enduring mental health problems, and who were receiving treatment via the Care Programme Approach. Twenty young carers were identified by project workers in Leicestershire, Derbyshire and Lincolnshire. These young carers were contacted by the researcher and agreed to take part in the study (although four later withdrew). In all, 16 children and young people participated in the research.

Results

Table 1. represents a profile of the young carers in the study and the contexts in which they care.

Gender	Age	Position in family	No. of Siblings	Other adults in household	Other adults who helped	Care for whom	Care recipient condition
							Table 1: Profile of young carers, their families and caring contexts
Male	17	Eldest	3	None	None	Mother/ siblings	Chronic Depression
Female	15	Eldest	3	None	Maternal Grandparents	Mother	Depression and substance misuse
Female	15	Middle Upper	6	Father	Father	Mother/ siblings	Depression/ Diabetic Neuropathy & Reactive Attachment Disorder
Male	15	Middle Upper	3	None	None	Mother/ siblings	Chronic Depression
Female	14	Middle Upper	2	Mother's boyfriend	None	Mother	Depression and anxiety
Female	14	Youngest	1	Mother's boyfriend	None	Mother	Schizophrenia
Female	14	Middle Lower	6	Father	Father	Mother/ siblings	Depression/ Diabetic Neuropathy & Reactive Attachment Disorder
Male	13	Middle Lower	6	Father	Father	Mother/ sibling	Depression/ Diabetic Neuropathy & Reactive Attachment Disorder
Female	13	Youngest	1	Step-father	Sister	Mother	Depression and Cardiomyopathy /Fibromyalagia
Female	12	Middle Lower	3	None	None	Mother	Chronic Depression
Female	12	Middle Upper	3	None	Maternal Grandparents	Mother	Depression and substance misuse
Female	10	Youngest	3	None	None	Mother	Depression
Male	9	Eldest	1	None	Brother's father/family friend	Mother	Manic depression
Male	9	Middle Upper	2	Mother's boyfriend	None	Mother/ siblings	Depression / Learning disability
Female	9	Youngest	3	Lodger	None	Mother	Personality disorder and anxiety
Female	9	Middle Lower	3	None	Maternal Grandparents	Mother	Depression and substance misuse

In all, 287 'posed' and 'candid' photographs (see Greek, 2005) were taken by participants and these were examined in turn for their content, alongside the narrative accounts of all participants. The narrative appraisal and content analysis were separate exercises in the research framework but not mutually exclusive phases in the research process. The content analysis (Krippendorf, 1990; Weber, 1990, Holsti, 1996), involved a systematic analysis of all forms of content and was broken down into distinct categories relating to the central aims of the study (exploring children's caring experiences and relationships in the context of parental mental ill health and gauging the efficacy of the method). Each variable forming the content analysis was crossed referenced against the location in which the photograph is set (so altogether 574 counts were made).

From the outset, it was important to consider the geographic context in which participants took their photographs because previous research shows that

physical space and travel are more likely to be restricted for children with care responsibilities than for their peers (see Dearden and Becker, 2000), and this was demonstrated in the findings. Thus, participants' childhood and caring experiences were located in and around the home (195 images) at play or recreation (50 images), which included locations within walking distance from home, and at school (42 images).

The categories and themes that form part of the following discussion are based on the results of the content analysis and are also guided by what the children showed us, and told us, were important and significant aspects of their caring lives and experiences. Thus, the analysis is broken down into two phases that focus on the 'internal' and the 'external' narratives derived from the photographs. Banks (2001) defines the internal narrative as 'the story, if you will, that the image communicates' and the external narrative as 'the social context that produced the image, and the social relations within which the image is embedded at any moment of viewing' (p 11).

A total of 287 photographs were analysed for content (see table 2) and location (see tables 2 and 3).

	Location			
Table 2: Thematic and content analysis of photographs taken by young carers				
	Home	School	Play/Recreation space	Total
Content of photo				
Play and leisure				69
Imaginative	9	-	6	15
Television (Guide)& DVD	12	-	-	12
Craft work	11	-	-	11
Soft Toys	2	-	9	11
Reading, creative writing, & Diaries	5	-	-	5
I.T. Equipment	4	-	-	4
Balls	2	-	-	2
Music	2	-	-	2
Personal care	2	-	-	2
Mobile phone	2	-	-	2
Holiday Caravan			2	2
Calendars	1	-	-	1
Social networks				64
(Friends) Outer circle	-	32	2	34
(Friends) Inner circle	5	9	9	23
Family Friend	6	-	-	6
Teacher	-	1	-	1
Family				61
Sibling	20	-	10	30
Parent	16	-	1	17
Cousin	5	-	6	11
Parent's partner	3	-	-	3
Responsibilities				42
Washing-up	15	-	-	15
Caring (sibling or parent)	8	-	1	9
Gardening	5	-	-	5
Drinks (kettle)	4	-	-	4
Cooking	4	-	-	4
Vacuuming	4	-	-	4
Cleaning	1	-	-	1
Animals				28
Dog	11	-	2	13
Rabbit	8	-	-	8
Cat	7	-	-	7
Symbols				23
Bedroom	11	-	2	13
Homework	5	-	-	5
Medication	3	-	-	3
Keys	1	-	-	1
Crucifix	1	-	-	1
Total	195	42	50	**287**

Table 3: Frequency of content and location of photographs			
Content	Total	Location	Total
Play and Leisure	69	Home (in and around)	195
Social networks	64	School	42
Family	61	Play/recreation	50
Responsibilities	42		
Animals	28		
Symbols	23		

Photographic participation and elicitation

Below are examples of the photographic and narrative data derived from both the participation and elicitation phases of the research study (nb: names have been changed). It is important to emphasise that this is a selection only. The research generated rich visual data and not all of the photographs can be included in this report. However, the data will be represented more fully and in greater detail in additional outputs – as photographic albums on the YCRG website and in live and online exhibitions.

Table 2 provides descriptions of all thematic categories included in the analyses and the most frequently occurring categories relating to each theme are set out below as representative examples of the visual and oral data:

Play and leisure
Imagination

> *I've got a very good imagination. These are two Star Wars pictures/photos, whatever. These mean quite a lot to me because they are my favourite things and what I do is take ideas out of it and like muck around with them. I've done stories were I've changed the idea around and stuff like that. It just helps me to relax.*
>
> *(Debbie, 13)*

> *It's a picture of me. In my mind I was pretending that I was a superhero. Superman.*
>
> *(Kwame, 9)*

Social networks
Friends

That's my friend Kate. The only time we get to go out is when we are like studying together, and that's outside the library. She's not a carer but her mum has also got diabetes, but not as worse as my mum. She's seen me help my mum. She used to be around here every time I had to wash the pots actually. I did them for a few weeks non-stop. She helped sometimes as well. If my mum asks for anything and I got up to do it, she would try and take part herself and try and help herself.

(Rachel, 15)

Family
Parents

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, really, really, bad day I will be doing absolutely nearly everything. Dressing her, doing washing, vacuuming, cleaning, and loads of things. These two weeks why I did not show anything in these photos is because these two weeks were perfect, they've been very good. What dad does is try and get money so he comes up with some weird and wonderful things, and he's trying to get on the market. He's always trying to do something new. He's trying to just get some money in. (Debbie, 13)

Responsibilities
Washing up

I clean up a lot for my mum. I cleaned up this morning because her leg was in pain. I wash-up for her sometimes; I make her drinks and that - cups of teas.

(Qelita, 9)

Caring

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. They showed me how to do it….to relief my mum's pain. I have to help my mum with her medication and injections. That's me helping the girls get ready for school in the morning. We take it in turn washing the pots from Sunday dinner. We take it in turn during the week, me and Ben as well. We all take it in turns. (Kate, 14)

Animals
Cat and dog

This is a picture of my cat Rizzo. He's a beautiful cat. He's one year old (human years). I care for him. Sometimes I buy the cat food and feed him. I enjoy playing with him. This is a picture of my best friend's dog. I love cats and I like other animals. (Sarah, 15)

Symbols
Keys and medication

When my mum is ill I have to lock all the doors and we are not allowed to answer the phone because she thinks somebody is going to hurt us and stuff. It used to make me feel unhappy but not anymore. I'm supporting mum. Sometimes I do get a bit annoyed. The next one 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. It says it all on the medication. When I follow her to the doctors I wait in the waiting room. I take her but then she has to go in by herself because she goes in and talks and does not want to upset me. I check her medication when she's got home or when she's feeling ill and times like that I have to go and get them personally and make sure she takes them and watch her.
(Eva, 14)

Discussion

The needs of young carers

The study has provided greater understanding about children's resilience and coping strategies when they help to provide care for mentally ill parents. It has also helped promote children's participation and agency through use of the photographic method itself. However, analysis of the visual data also highlights aspects of young carers' needs that would be important for health and social care practitioners (and policy makers) to consider when making needs assessments. Thus, the nature and extent of young carers' responsibilities, including administering medication to parents with serious mental illness (see the example of Eva, above), would be important considerations for practitioners when considering intervention strategies (i.e. how to help prevent children from becoming, effectively, their parents' nurses). Children's administration of medication is an issue that, while highlighted to some extent in early research studies as an example of children's caring responsibilities (see Aldridge and Becker, 1993, 1994), has not been fully addressed in practice.

The visual data and narrative accounts point also to the need for greater recognition of young caring in the context of parental mental illness, and about the role and importance of other relationships in young carers' lives aside from their caring relationships with parents. While the young carers in the study did not present themselves simply as carers (despite the fact that the intention was to encourage them to visualise their caring experiences), 15% of the images related to their responsibilities as carers, including the tasks they carried out with and for their parents, as well as the household duties they undertook. Interestingly, it was mainly in the category of 'caring' that

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participants objectified themselves by posing for the camera while someone else took the photographs. Children's need for recognition for what they do as carers is highlighted in this study (see also Aldridge and Wates, 2005) through the photographic participation approach that enabled participants to present themselves visually as carers. The fact that a number of the children and young people specifically asked if their photographs could be used in outputs so they could show publicly what it is they do is also evidence of their need for recognition.

Resilience

Newman (2003) has argued that more insight is needed into young carers' resilience, 'whose circumstances may render them vulnerable to pessimistic cognitive styles of thinking' and that there is a dearth of child welfare interventions…that 'utilise experimental methodologies' (p 113). This study has addressed both of these shortcomings through the visual representation of young carers' resilience in the context of parental mental illness; and their competency is also demonstrated through engagement with the visual method itself.

The ways in which the young carers in this study demonstrated their resilience in the face of difficult and often painful circumstances are both divertive and reductive. Divertive strategies can be passive, i.e. using visual and audio media and imagination (30 images; see also Kwame above), as well as active divertive approaches through art and craft work, gardening, recreation etc (40 images). Both active and passive divertive strategies can have reductive outcomes in terms of alleviating physical and emotional stress as well as relief from boredom in often restrictive environments. Care of, and affection for, family pets (10% of images) was also a factor in young carers' coping tactics (see examples above).

The resilience of young carers was also demonstrated in their active negotiation of (two-tier) relationships with friends. The purposeful formation of 'inner circle' friendships (23 images) – those who knew participants were carers – and 'outer circle' friends (34 images), who did not know about their caring roles, is reflected, in part, in previous studies. In the photographic study, however, young carers were clear in both their visual representations and narrative accounts that it was they who controlled the 'knowing' in each case. We know that young carers (and their families) are fearful of professional interventions that might lead to family separations (see Aldridge and Becker, 2003; Barnardo's, 2006; Meredith, 1991), but what is clear from this study is that young carers carefully negotiate their friendships and other relationships based on their perceptions of trustworthiness. For example, as one young carer said (photograph not included due to confidentiality issues):

> *This is a picture of my best friend and my friends Levi, Becky, and Kristy. Only two of the four girlfriends know that I'm a carer. It's because of the length of time I have known the two friends why they know I'm a carer. I can trust them. I need to have trust in people before they can know I'm a carer, because some*

people are not trustworthy. The whole school would know, and it's my own personal business. This is a picture of Harry inside class at school. He makes me laugh. He's not my boyfriend, just a friend. He doesn't normally pose. He does not know that I'm a carer. We've been friends for about four years now. I trust him but it depends with what information. I trust girls more than I do guys. None of my mates at school are carers. I have one friend who lives at the top of the street who is a carer.

(Sarah,15)

Competency

One of the aims of the study was to test the efficacy of the photographic participative method among this group of vulnerable children and young people. The research was successful in two ways in this respect: participants showed themselves to be capable social and empirical agents through the effective deployment of the method; and the young carers in the study enjoyed the participative use of the camera work to demonstrate their caring (and other) experiences. Both of these outcomes underline the importance of, and potential for children's and young people's active participation in future research studies.

Part of the elicitation phase of the study included asking participants about the usefulness of the method itself in demonstrating visually their caring (and other) experiences. The following examples illustrate the effectiveness of the photographic method for participants:

'I think it was positive, because it helped in a way to realise what you are doing' (Tim, 15).

'*It was pretty easy taking lots of photos…fun…I have taken some photos before, but not a lot'* (Kwame, 9).

'It was easy because I just did what I normally do so, just get somebody to take pictures of me doing it' (Ben, 13).

'You know what you are going to talk about before you asked [the] questions because you have the pictures and you kind of get to chose kind of what you talk about' (Eva, 14).

'I've actually found it quite funny and also quite quick and easy for me. Because instead of just remembering it or putting on a piece of paper [written diary], you quickly get the camera and quickly shoot it' (Debbie, 13).

'I think it's been good actually... this is a lot better because I can remember my experience I've gone through and tell you about them' (Rachel, 15).

'I though it was quite easy and enjoyable as well because I had something to do and concentrate on' (Kate,14).

It is possible to draw comparisons here with research studies in other areas that have served to promote vulnerable respondents as active participants in research processes. I refer here to the 'normalisation' studies of people with learning difficulties (see, for example, Walmsley, 2001), and recent moves to work with people with learning difficulties as active research participants outside the boundaries of disability research. In my work with vulnerable groups, including those with learning difficulties, I have argued, 'If the participants in research cannot tell us, but are able to show us, their experiences through photographic participation methods (as in this case) then this only emphasizes the positive, inclusive advantages of using such a technique and particularly for the participants themselves' (Aldridge, 2007, p 12).

Conclusion

It was not the intention of this photographic study to present the findings in outputs that relied only on textual and discursive analysis of the data, but to allow the children and young people who took part in the study to demonstrate visually their experiences of living with and caring for parents with serious mental health problems in appropriate outputs. This report serves, then, as an overview of the findings and focuses mainly on the thematic analysis of the visual data as well as the participants' narrative accounts that help to explain and explore further the meaning therein.

In participative research of this nature it is important that the interpretation of the data does not rely on the voice of the researcher but on the voices of the children and young people themselves (see Aldridge, 2007). In this photographic study, the voices of the children and young people (through their narrative accounts) serve to reinforce the eloquence and importance of the photographs themselves. The children and young people who participated in the study did not ask to show their work in an academic type report, although they were happy to accept that this would be one of a number of necessary and important outputs resulting from the research. Those children and young people who took part wanted to show visually, more than they wanted to tell verbally, their day to day experiences of living with and caring for parents with mental health problems.

In this sense, then, this report should be seen as an introductory and companion document alongside further, planned, visual documentary evidence on young caring in the context of parental mental illness. It is our intention to produce both live and online exhibitions and photographic albums of the visual data collected during the course of this study (the latter will be available on the YCRG website over the coming months).

However, while it is important that the young carers who took part in the research project have opportunities to exhibit their photographs that delineate their caring and other meaningful experiences, it is equally necessary to consider the messages from this research in terms of policy and practice. For

both policy makers and practitioners who work with young carers and their families the messages from this research are clear. What is required is a deeper understanding of, and recognition for, the contributions children make to caring when parents have serious mental health problems. Reference to the recommendations in Aldridge and Becker's (2003) study on the experiences of children who care for parents with mental illness are relevant here. Thus, monitoring and mapping children's experiences and needs alongside the needs of their mentally ill parents, remain important stages in providing help and support for the whole family (see ibid, chapter 5).

However, from what the children and young people have shown us in this photographic study, it is clear that professionals also need to understand the role of significant others in young carers' lives (including teachers, other adult relatives, friends, even family pets) and the contributions they can make in terms of helping children and young people cope with their often difficult and painful circumstances. It is also important that the issue of children administering medication to parents is addressed as a matter of some urgency. While other research studies have pointed to children's medical responsibilities in this respect (see Aldridge and Becker, 2003; Dearden and Becker, 1998; 2004), this is an aspect of young caring that has never been fully addressed or remedied by appropriate health or social care interventions. There are clearly serious implications for both children and parents when children take responsibility for administering medication to parents who have serious mental health problems. Previous research has shown that young carers often have little understanding about diagnostic and prognostic indicators relating to their parents' mental or physical health problems (see Aldridge and Becker, 2003); that children should be administering medication about which they know little, and for mental health problems about which they are also equally uncertain, is clearly something that should be addressed as a matter of some urgency.

The broader methodological implications of this study point clearly to the need for greater recognition of children's contributions as competent social agents in research strategies. The recent emergence of the participation agenda has called for children and young people to be included in theory, policy, political processes and in research (see Davis and Edwards, 2004). Hill et al (2004) have also recognised that, 'most research about children has been carried out on them rather than with them' (p 86). This research study has endeavoured to fulfil both participative and inclusive objectives and, through the use of photographic participation techniques, has also ensured that the research conducted here has not only been *with* children but also *by* them.

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