

University of Edinburgh

Under Pressure.

A Study of Mental Health Needs of Young Carers

For Edinburgh Young Carers Project

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Introduction

This report describes the findings from a study of mental health needs of young carers. The aim of the study was to explore whether young carers who attend the Edinburgh Young Carers Project (EYCP) identify problems and worries in relation to their well-being,¹ and what support they feel they have to meet those needs.

The study was conducted with the full cooperation of EYCP workers, who commissioned the research, met with the researcher to discuss methodology, administered the survey, and made all practical arrangements (including telephoning and arranging transport) for those who wished to be interviewed.

Children, young people and mental health

It is impossible to be certain about the prevalence of mental health problems in children and young people. Current estimates suggest that as many as 1 in 5 young people in the UK has a mental health problem (Holmstrom 2002). But there is always a continuum between mental well-being and mental disorder or mental illness, and it is difficult to define the cut-off between what is normal and what is not (Dogra et al 2002: 18). While the majority of young people are mentally healthy, it is known that as they move into their teens the incidence of a range of mental health problems increases dramatically: emotional disorders (including anxiety and depression), eating disorders, alcohol and drug use, serious anti-social behaviour and deliberate self-harm and suicide all increase in adolescence (Aggleton et al 2000: 3). Lothian Health produced a report in 2000 which indicated the following areas of concern:

- There has been a 3 to 4-fold rise in diagnosis of attention deficit hyperactivity disorder (ADHD).
- There has been a 20 per cent increase in incidence of suicide and parasuicide among young people.

¹ The form of words 'problems and worries in relation to well-being' was used in preference to 'mental health' because it was recognised that this may be an unfamiliar term to some children, and carry negative connotations for others.

- Numbers of 13-16 year-olds who self-harm have been rising year on year, with even more marked rises in 17-18 year-olds, particularly for recurrent episodes of self-harm (Lothian Health 2000).

Studies suggest that young carers may be particularly at risk of developing mental health problems. While helping parents and other family members is an important part of growing up and may encourage maturity, self-esteem, responsibility and independence (Bowis 1995), research also indicates that being a young carer may bring social isolation, stress, tiredness and depression (Dearden and Becker 2000). The focus of this study was to find out what young carers in Edinburgh have to say themselves about their worries and problems in relation to their well-being.

Research methodology

The study was conducted in two parts. Firstly, young carers were invited to fill in a self-completion questionnaire which asked them a series of questions about themselves and what they see as their problems and worries, and invited them to give their names if they wished to take part in an interview. Following this, interviews were set up with those children who had nominated themselves, after their parents had been sent a letter explaining the purpose of the interview and seeking their agreement to interview their child. The focus of the research was therefore on the children's perspectives, following the practice of recent research carried out with children (for example, Alderson 1995).

The questionnaire asked both closed and open questions (See Appendix 1). It thus provided both a general overview and specific information about children and young people's perspectives on their caring responsibilities and their problems and worries. In addition, the tape-recorded interviews allowed some areas to be explored in more depth and gave children the opportunity to contribute their own experiences directly.

The study did not ask young carers specifically about the caring tasks they perform, the amount of time they spend in caring, or the general impact of caring on their lives. These areas were not seen as the primary focus of this study and they have been

extensively covered in other research studies on young carers (including Aldridge and Becker 1993, Dearden and Becker 1995, Mahon and Higgins 1995).

Given the limited timescale and funding for carrying out the research, it was not possible to do a comparative study with young people in Edinburgh who are not identified as young carers. Nevertheless, the results of the research provide a useful case-study example of young carers' views of their well-being, and can be placed in the context of what is known from wider literature on adolescents' mental health (for example, Aggleton et al 2000, Dogra et al 2002).

Questionnaires were analysed with the help of a statistical computer package, SPSS; interviews were analysed using traditional 'cut-and-paste' methods, aided by the computer analysis package, NUDIST.

Research sample

61 children and young people took part in the study overall. All 61 filled in research questionnaires in April 2002, and 11 went on to be interviewed during May 2002.

Of the 61 children and young people who took part in the survey, 34 were girls and 25 were boys. Their ages ranged from 5-9 years through to over 16 years, although the greatest number were in the 10-15 years age-group (75 per cent were in this group). 50 of those who completed the survey described themselves as white; 9 said that they were black, Asian or other (2 children characterised themselves as 'in the middle of black and white' and 'half Asian'); and 2 did not give their ethnicity. (See Appendix 2.) Interviews were conducted with 11 children and young people, 6 of whom were girls and 5 boys. Their ages ranged from 9-17 years and all were white.

The survey sample should be set in the wider context of children and young people using EYCP. 145 children and young people are currently attending the project, 73 of whom are boys and 72 girls. Although their ages range from 5 to over 16 years, most are in the 10-15 group (77 per cent are in this age-group). 85 per cent of young carers are recorded as white; 15 per cent as Asian or other. These figures indicate that 42 per cent of the children and young people who are active members of the EYCP took part

in the survey. A higher percentage of girls took part, but there was a reasonable representation of both genders. The age and ethnic mix of survey informants almost exactly parallels that of project users.

There are two interesting issues here. Although the project workers defined a similar percentage of young people as white, they categorised minority ethnic children differently to the ways that children in the sample defined themselves. This suggests that definitions of ethnicity are extremely problematic, for project staff and young people. It is also noteworthy that 15 per cent of young people using the project are from minority ethnic backgrounds, suggesting that EYCP is reaching a much higher number of this group than might be expected given the overall population of minority ethnic children living in the Lothians.² The project is also reaching a greater number of boys than might be anticipated. A national study of young carers shows that 61 per cent of young carers are female and 39 per cent are male (Dearden and Becker 1995).

Household composition and caring responsibilities

51 per cent of young carers who took part in the survey live in a lone parent family, compared with 39 per cent who live with two parents, and another 8 per cent who live with others. Significantly, 67 per cent of all children have siblings.

41 per cent of young carers reported that they care for one parent; 13 per cent care for a sibling, and the rest care for a mix of parents, siblings and others. One child noted that he does not care for anyone.

Stated reasons for caring include physical disability, mental health and behavioural reasons (often described further by young people as alcohol abuse), and learning disability (including autism, dyslexia and 'having a sister who is 11 but functions like a 6 year-old). Many young carers (almost 15 per cent of the total group) identified more than one reason for caring. When the figures are aggregated, almost 40 per cent

² In 1999, 1.6 per cent of the Scottish population were from an ethnic minority (Labour Force Survey 1999). More recent census figures (from the 1991 Census) suggest that 2.6 per cent of children aged 5 to 17 years in the Lothians are 'black, Asian or other'. The real figure today is expected to be higher, given the significantly younger age profile of the minority ethnic population in Scotland, and the related fact that they are having more children.

of young carers reported that they look after someone with a physical disability; 15 per cent said they care for someone with problematic behaviour; 13 per cent have a family member with a learning difficulty and almost 10 per cent care for someone with a mental health problem. These statistics are broadly in line with national figures which indicate that the largest single group of care recipients (up to 60 per cent) experience physical ill-health or disability (Blyth and Milner 1997).

But there is another issue here. Significantly, nearly 40 per cent of all children who filled in the questionnaires chose not to answer this question. This raises three possibilities:

- they do not know why they attend EYCP.
- they did not understand the question.
- they did not wish to answer the question.

It is possible that some younger children genuinely do not know why they attend EYCP. Studies indicate that understanding illness (one's own and those of others) is something which comes with age and maturity. Children have to learn about health and illness, just as they learn about all other areas of life, and this is a complex interpretative process involved in defining bodily experiences as either 'normal' and acceptable or as 'worrisome' and constituting signs of illness (Christensen 1999). Some children, moreover, may not have understood the question. There may have been some confusion for younger children, or those who have recently started to attend EYCP, about use of the word 'care': does it refer to 'care' as in 'love' or 'care' as in 'look after someone'? Unable to work this out, some children may have left the question blank. There may also have been some children and young people who chose not to answer the question. It seems reasonable to suggest that some young people have been told not to talk about problems at home; others may experience feelings of stigma in relation to reasons for caring and so prefer not to talk (or indeed write) about this. Children who are carers often report feelings of stigma and keep their caring a secret from others (Mahon and Higgins 1995). 9-year old Lucy said in interview for this study that she did not tell her school-friends about her mother's disability because 'I don't want to spread it or anything in case I get bullied or something like that'.

Given the high non-response rate, it is likely that any suggestion that physical disability is the main reason for caring in this study is unreliable. It may simply be easier to tell others about a parent's physical disability than about their mental health or behavioural problems. Caution will also have to be exercised in drawing inferences in relation to reasons for caring and problems and worries identified by the young carers in this study.

Young carers were asked to give an indication of how long they have been caring. They were not asked to give exact numbers of years given research evidence which suggests that children gauge time in different ways to adults (Christensen and James 2000). Only 7 per cent of carers (n = 4) reported that they had 'just recently' begun caring. 53 per cent stated they had been caring for 'quite a long time'; 34 per cent had been caring for 'as long as I can remember'.³ Taken together, this suggests that 87 per cent of young carers have been caring for a substantial amount of time, and likely to be much of their lives.

Findings

The study demonstrates that children and young people attending EYCP identify a range of problems and worries, many of which are likely to have a serious effect on their overall well-being. Whilst most young carers are able to talk to a number of different people about their concerns (both family members and professional staff), a significant minority (over 1 in 10) have only one person or no-one that they talk to.

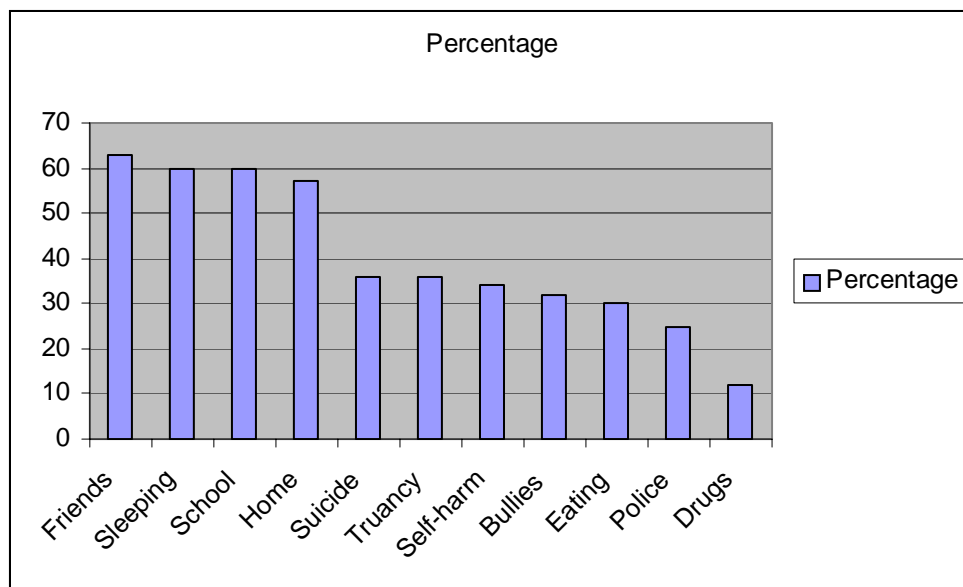
Problems

Young carers identify a range of problems in relation to their well-being. These include what might be regarded as fairly typical adolescent problems, such as problems with friends, at home and at school (Coleman 1990). In addition, one-quarter of all young people have had trouble with the police 'often or sometimes'. Some of these problems may also specifically arise out of the caring role, so for example, one girl aged 10-12 stated that she only had problems at home 'when mum's

been drinking'. Problems at home and at school are found to be common experiences for young carers (Dearden and Becker 2000).

Children and young people also report difficulties which may be seen as associated with mental health problems, including difficulty in sleeping (reported by 60 per cent of young carers), in eating (30 per cent), and most disturbingly, over one-third said that they had self-harmed (34 per cent) and thought of suicide (36 per cent). One 16 year-old wrote on the questionnaire, 'I never wanted to live'. Moreover, 12 per cent (n = 7) stated that they had taken alcohol or drugs to 'shut off'. One-third of all young carers reported problems with bullies. One 10-12 year-old boy recorded that he gets called names all the time and is 'afraid to go places in case I get beaten up; been threatened'.

Figure 1 Identified problems



Data from the interviews demonstrate not only the severity of some of the problems which young people experience, but also that it is impossible to separate out adolescent concerns from either life experiences in general, or the impact of being a young carer in particular. Many of the children and young people interviewed outlined histories of family violence, poverty, homelessness, drug abuse and loss over and

³ In analysis, 'just recently' was taken to mean in the last 6 months; 'as long as I can remember' was taken to mean from 5 years of age.

above their experiences of being young carers. 16-year old Lea⁴ illustrates this well. Asked what things worry her and get her down, she replied:

'How my mum is and all that, and my life being such a mess since I was younger and all that.'

The interviews furthermore give insight into the nature of the problems themselves. Just as in the questionnaire survey, many of the young people interviewed described difficulties with friends, at home and at school. They also shared problems with sleeping, most of all in relation to getting to sleep when they go to bed at night. Susan (aged 17) went so far as to say that she used to be too scared to go to sleep:

'... in case anybody came in the door or if anything happened I always used to stay up and watch on my own and that. I just got really scared.'

Susan's fear was not a generalised anxiety; it was directly connected to the threat of violence from her mother's ex-partner. 15-year old Kenny's sleeping difficulties are less specific:

'Well it's just when I start to get to sleep, eh, I've got to keep on turning and tossing and things like that and it takes me ages to get to sleep... I just canny get to sleep, eh, just cause I'm no tired at the end of the day. I could stay up all night.'

Some young people also talked openly about problems in relation to self-harm and attempted suicide. Susan vividly described what it felt like to her:

'It was just through pressure, I just didn't feel comfortable in my inner self and was really upset and then I turned to, like, cutting myself and just being really, really, really bad...'

⁴ All names have been changed to protect the identities of informants.

13-year old Jenny also talked about self-harm, but this time described punching herself: *'I get angry with myself for being me and having my parents and stuff.'* She went on to say she has frequent panic attacks, where she cannot breathe and she feels as if she is having a heart attack.

Some young people let off steam by acting out, instead of by hurting themselves. Lea trashed and then set fire to her bedroom when she was upset. Kenny lost his temper with his friend at school, and the consequences were more than he bargained for:

'So I cracked him one, right, and he chased towards me and I picked up a cone we were using and I chucked it at him, right, and the teachers just grabbed him and the next again day you had him and all the school bullies put together came and surrounded me. He pushed me against the fence and put a knife in my stomach.'

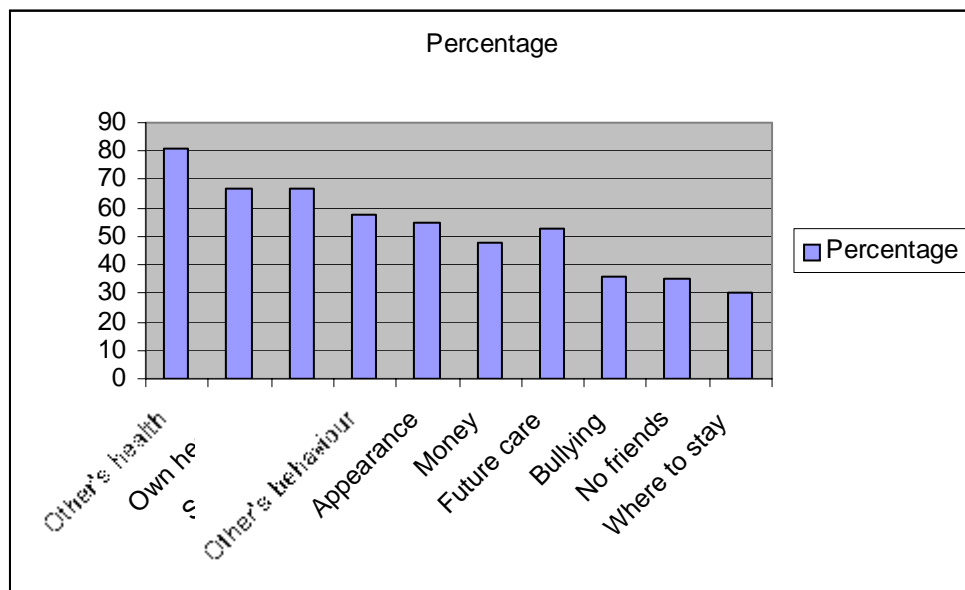
Worries

Young carers pinpoint a range of worries, some of which are commonly experienced by adolescents (for example, 55 per cent of all young carers worry about their appearance). Other worries can be wholly explained in terms of their lives as young carers. 81 per cent worry about the health of the person they care for, and 67 per cent worry about their own health. 58 per cent worry about the behaviour of the person they care for, and 53 per cent worry about who will look after them in the future. One young person added the poignant question, 'where would I be without my mum?'

Some worries are not specifically related to caring, but being a young carer brings an added dimension to the experience. For example, 68 per cent of young people reported that they worry about their school work, which may, in part, be related to having missed school to look after or be with a parent. Similarly, 48 per cent worry about money, and while this is a common teenage complaint, it may be compounded by financial difficulties caused by the reasons for caring. Over one-third of children worry about being bullied (36 per cent) and about not having any friends (35 per cent). 30 per cent also worry about where they stay.

All these factors are inevitably affected by the experience of being a young carer. For example, previous research on young carers illustrates that many children worry about their school work (Dearden and Becker 2000) and as many as 71 per cent of adults who had previously been carers in one study had been bullied at school, where bullying is defined as verbal, physical or emotional abuse (Bibby and Becker 2000).

Figure 2 Identified worries



Again, the interviews shed additional light on the broad picture which emerges in the questionnaire survey. 14-year old Stewart explained what he worries about:

'Just life, it's constantly worrying about my Mum, wondering how she is cause if she does, like, take a fit - cause she takes fits a lot – she's only had a couple in the last couple of months, but if she takes a fit she really canny do anything, she canny get out of bed and that, and we are all at school and my Dad's away to work so sometimes I phone home to see if she's all right...'

He went on to add that teachers at school put pressure on him and this is difficult for him. Nicky, although very much younger (aged 12 years), also worries about school, because she finds it hard to concentrate on her work, and sometimes falls asleep in class. In contrast, Jenny (aged 13) is delighted to be at school; it is a place of refuge, away from the cares of home and worrying about her mother's mental health.

Research indicates that schooling can be an extremely important protective factor for troubled children (Mortimore 1995), just as it is known that parental mental health problems carry a heavy emotional burden (Mahon and Higgins 1995).

Problems and worries

It is clear from the discussion already that there is a strong relationship between number and frequency of problems and worries. Drawing together the two themes, the following results emerge⁵:

- 67 per cent of young carers who express a low number and frequency of problems also have a low number and frequency of worries.
- 56 per cent of those with a medium number and frequency of problems have a medium number and frequency of worries.
- 74 per cent of those who identify a high number and frequency of problems also have a high number and frequency of worries.

Problems/Worries cross-tabulation		Worries		
		Low	Medium	High
Problems	Low	10 (67%)	3 (20%)	2 (13%)
	Medium	3 (11%)	15 (56%)	9 (33%)
	High	1 (5%)	4 (21%)	14 (74%)
Total		14 (23%)	22 (36%)	25 (41%)

This clearly demonstrates the existence of a high-risk group of young people who have both high problems and high worries. But the group with medium problems is also of interest. One third of those with medium level of problems actually describe themselves as having a high level of worries. This tells us that a significant number of young people (n = 9) exhibit more concern than the level of problems they have identified. Given the cumulative effects of stress (Rutter et al 1986), this group may be at risk of having more problems in the future.

⁵ A numerical formula was employed to distinguish number and frequency of problems and worries. Those responding with under 3 problems or worries were given a score of 1 (low problems or worries); those with between 3 and 6 a score of 2 (medium problems or worries); those between 7 and 11 a score of 3 (high problems or worries). In the case of 3 or more 'often' answers, this was also scored as a 3 (high problems or worries).

The impact of age, gender and ethnicity

Analysis suggests that there are definite age and gender factors associated with the reporting of problems and worries in relation to well-being. Older young people are much more likely to convey both problems and worries than younger children. This is not unexpected given that the problems they identify are commonly found to be teenage rather than younger children's problems, and that older young people are likely to be more expressive generally (Coleman 1990). Young caring has also been found, however, to have a negative impact on some young carers' transitions to adulthood, and this in itself should not be under-estimated (Becker et al 1998).

Worries/Age cross-tabulation		Age				Total
		5-9 years	10-12 years	13-15 years	Over 16	
Worries	Low	2 (15%)	6 (42%)	3 (23%)	2 (15%)	13 (100%)
	Medium	1 (5%)	8 (40%)	11 (55%)		20 (100%)
	High	1 (4%)	7 (28%)	10 (40%)	7 (28%)	25 (100%)
Total		4 (7%)	21 (36%)	24 (41%)	9 (16%)	58 (199%)

Further investigation demonstrates that some kinds of problems are specially implicated with age.

- 89 per cent of over-16s have sleeping difficulties; just as older children are more likely to state that they have eating problems, have self-harmed and that they worry about not having friends.
- Levels of truancy increase with age, and problems at school peak in the 13-15 years age-group.
- Interestingly, worries about bullying seem to decrease with age. While 3 out of the 4 young children (aged 5-9 years) and around one-third of all children aged 10-15 years said they worried about bullying, only one-quarter of those 16 years and over are worried about bullying.
- Getting in trouble with the police, predictably, rises with age, as does substance abuse, worries about money and concerns over physical appearance (by aged 16 and over, 44 per cent of all young people worry about their appearance).

- Older children are more likely to admit to worries about both the health and behaviour of the person they care for, and their own health, reflecting, perhaps, their greater understanding of health and illness generally (Hergenrather and Rabinowitz 1991, Kalish 1999).
- Thoughts of suicide also increase with age. However, given that 4 children in the 10-12 age-group said they have thought about suicide, this remains a cause for concern for all ages.

Girls are much more likely to describe both problems and worries than boys (84 per cent of all those with a high number of problems are girls, just as 76 per cent of those with a high number of worries are girls). This may again be explained in terms of girls' greater willingness to share their feelings and express emotions (Carli 1990). However, there may be additional gender issues in caring which make it possible that the experience of being a young carer is more troublesome for girls than boys. Studies of young carers suggest that gender is an important factor contributing to some children taking on care-giving roles in the first place (Dearden and Becker 1995). The difficulties which girls face may therefore be seen to reflect wider societal expectations placed on women (Tucker and Liddiard 1998).

		Worries			Total	
		Low	Medium	High		
Gender	Boy	Count	8	11	6	25
		% within Gender	32.0%	44.0%	24.0%	100.0%
		% within Worries	61.5%	52.4%	24.0%	42.4%
Girl		Count	5	10	19	34
		% within Gender	14.7%	29.4%	55.9%	100.0%
		% within Worries	38.5%	47.6%	76.0%	57.6%
Total		Count	13	21	25	59
		% within Gender	22.0%	35.6%	42.4%	100.0%
		% within Worries	100.0%	100.0%	100.0%	100.0%

Just as with age, some problems and worries have specific gender significance.

- Girls are more likely to report sleeping difficulties and eating difficulties (40 per cent of girls said they have problems with eating, compared with only 20 per cent of boys, and no boys said they 'often' had problems of this nature).

- Girls admit to more problems at school and higher levels of truancy, and they worry about their school work more than boys (76 per cent compared with 60 per cent, and they are more likely to state they worry ‘often’).
- Relationships with peers are another particular source of anxiety for girls. 72 per cent record problems in falling out with friends (versus 52 per cent of boys) and 58 per cent worry about not having friends (versus 20 per cent of boys). 70 per cent of all those who have severe problems with bullying are girls.
- Girls are much more likely to state that they have used drugs or alcohol to ‘shut off’, and to have self-harmed. Disturbingly, almost 50 per cent of girls have self-harmed at some time, and 19 per cent (almost 1 in 5) have often self-harmed. The fact that 20 per cent of boys admit to self-harming is also noteworthy.
- Girls are also more likely to think about suicide (over 50 per cent of girls, compared with 26 per cent of boys).
- Getting into trouble with the police is reported by twice as many boys as girls (36 per cent of boys and only 19 per cent of girls). In contrast, girls worry much more about their appearance than boys, and they worry more about money (which may have a connection with appearance in relation to money for clothes).
- Although most boys and girls are concerned about the health of the person they care for, girls are more likely to admit that they are worried about the behaviour of the person they care for and about their own health.
- Slightly higher numbers of girls worry about who will look after them in the future.

The interviews again bring flavour to the survey results. They demonstrate, for example, that concern about physical appearance is not just a girls’ issue. 16-year old James explained what he does not like about himself:

‘I dinna ken, I just think it’s my looks. And, like, my weight because, like, everybody in school, like, you’ve got to be the right weight and everything. So I’ve started to go to the gym and everything, but I just get on with it.’

The interviews, however, also provide overwhelming evidence for the conclusion that girls either have, or express, more problems and worries than boys. It is the older girls

who were interviewed who talk most fully about their experiences of solvent abuse, self-harm, sexual violence, and attempted suicide. Lea (aged 16) told her own story of what it is like to be depressed:

'I go and lie down and all I want to do is sleep or eat sweets and just keep my mouth shut...I just go into my room and lock my sister out and put the music on...Then one time it came all at once and then I just took an overdose. ... I got taken to hospital, but I never wanted to go in, but one of my friends, I phoned her first to tell her, then I had to go to hospital and see a psychiatrist and then I went home.'

It is the matter-of-fact way in which Lea recounts this event which makes it so surprising, and also so real. There is a sense in hearing the older girls' stories that they have accepted their lot, and they can see their future lives ahead of them.

The relatively low numbers of minority ethnic children who completed the questionnaires (n = 9) make comparisons across ethnicity difficult to substantiate. There does not appear to be a relationship between the numbers of problems and worries and ethnicity. However, looking at the picture in more detail, some similarities and differences emerge.

- Similar percentages of white and minority ethnic children express problems in relation to sleeping, eating, truancy, problems at home, self-harm, trouble with the police, substance abuse, worries about money and where they stay.
- Relationship with peers is of interest. While similar percentages of children fall out with their friends 'sometimes', a higher percentage of minority ethnic children and young people state that they 'often' fall out with friends (38 per cent compared with 16 per cent). Perhaps surprisingly, a similar ratio of white and minority ethnic children reported problems with, and worries about bullying.
- The numbers of minority ethnic children and young people reporting thoughts of suicide are too low to comment.
- Minority ethnic children and young people are more likely than white children to describe their appearance as a worry to them (75 per cent compared with 54 per cent), but again numbers here are low (n = 7).

- Minority ethnic children are more likely to state that they often worry about the health of the person they care for. They also worry more about their own health, and about who will look after them in the future (71 per cent as compared with only 51 per cent of white children). These findings may be related to reasons for caring rather than ethnicity, since a higher percentage of minority ethnic children report caring for someone with a physical disability (see also Shah and Hatton 1999).

The impact of length of time being a carer

The number and extent of problems and worries identified by young carers is influenced greatly by the length of time they have been caring for a family member. Almost all categories of problems increase according to length of time caring. This is most vividly demonstrated in the responses given to the questions relating to problems at school. 75 per cent of those who have been caring 'as long as I can remember' report having problems at school, as compared with 57 per cent of those who have been caring for 'quite a long time' and 33 per cent who have 'just recently' become carers. This finding corresponds with research evidence which indicates that young carers commonly experience educational difficulties associated with punctuality and attendance, poor concentration and difficulty in completing class work and homework (Blyth et al 1995).

Length of time is also clearly implicated in relation to recorded worries. None of the 4 young carers who said they have been caring 'just recently' have a high number of worries, whereas 50 per cent of those who have been caring for 'quite a long time' do, compared with 38 per cent of those who have been caring 'as long as I can remember'. It seems possible that young people who are carers may become less worried over time, as they understand more about the condition of the person they care for and they receive more help via the EYCP and other agencies. If this is indeed the case, then the youngsters who may need most support in relation to their worries are those who are in the middle range: they have been caring for quite a long time but have not yet either sufficient coping mechanisms or enough knowledge and understanding to deal with this.

Length of Time Caring/Worries cross-tabulation						
		Worries			Total	
		Low	Medium	High		
Length of Caring	As long as I can remember	Count	4	9	8	21
		% in Length of Caring	19.0%	42.9%	38.1%	100.0%
		% in Worries	30.8%	45.0%	33.3%	36.8%
Quite a long time		Count	6	10	16	32
		% in Length of Caring	18.8%	31.3%	50.0%	100.0%
		% in Worries	46.2%	50.0%	66.7%	56.1%
Just recently		Count	3	1		4
		% in Length of Caring	75.0%	25.0%		100.0%
		% in Worries	23.1%	5.0%		7.0%
Total		Count	13	20	24	57
		% in Length of Caring	22.8%	35.1%	42.1%	100.0%
		% in Worries	100.0%	100.0%	100.0%	100.0%

These findings make sense in terms of what is known about children who live with a parent with illness and also research into children and resilience. Altschuler (1997) indicates that problems affecting one person in a family inevitably affect other family members; faced with illness, the family has to adapt to considerable change in roles, structures and patterns of relating (1997: 40). Different illnesses bring different pressures, and hence different responses, and these change over time as family members learn to cope with, and anticipate manifestations and stages of the illness. Research into resilience and children points out that not all young people from ‘at risk’ family environments go on to develop problems; there are individual factors that serve to reduce or enhance the probability of them developing maladaptively when confronted by family stressors. Steele et al (1997) argue that one such factor may be a child’s use of coping strategies: in other words, they learn over time how to deal with stressors in the family.

Other implicating factors

Other factors analysed in relation to both general and specific problems and worries were as follows:

- Household composition: this was not found to have major significance in relation to either exacerbating or mediating problems and worries, although there was (perhaps not surprisingly) a slight tendency for those in single parent families to express more problems and a greater number of worries.
- Person cared for: the large number of different combinations of people cared for makes it difficult to make any clear statements about a link between problems and worries and the person (or even number of people) cared for. Moreover, the uncertainties about how the young carers were using the term ‘caring’ makes it difficult to separate out those who were naming the people they love, and those giving information about the person they care for.
- Reasons for caring: the picture here is not straightforward. 65 per cent of those who care for someone with a physical disability exhibit high levels of problems and worries; other reasons for caring throw up small numbers in each category. But issues already discussed in relation to the high non-response rate for this question must raise doubts about the accuracy of this figure. What is perhaps more notable is that having more than one reason for caring does not necessarily lead to a higher level of problems or worries. Clearly, having one reason for caring may be just as problematic as more than one, depending on the nature and severity of the problem.

Connections between specific problems and worries

Some problems and worries demonstrate high degrees of overlap in terms of responses, suggesting that there is a strong likelihood of a young carer who has one worry or problem also having the other. This is not unexpected in the questions which relate to school, and those concerned with peer relationships. Hence it is predictable that children and young people who report problems at school also admit to truanting and to worries about their school work. 78 per cent of those who often fall out with their friends also worry about not having friends, suggesting a volatile and inconsistent quality to their friendships. Similarly, there is a high correlation between being bullied and worrying about bullying. 89 per cent of those who state they have problems with bullying also often worry about being bullied; 90 per cent of those who have never been bullied do not worry about bullying.

There are also other problems and worries which have a clear relationship and which can be seen as high indicators of mental health concerns. Self-harm is one factor which increases with many other categories, suggesting that it may be an indicator of serious problems for the young carer:

- 57 per cent of those who have often self-harmed also often have problems at home.
- 86 per cent of those who have often self-harmed have also often thought about suicide.
- 100 per cent of those who have often self-harmed have also often taken alcohol or drugs ‘to shut off’.

There is also a highly significant relationship between a young carer’s worries about the health of the person for whom they are caring and worries about their own health. 89 per cent of those who often or sometimes worry about the health of the person they care for also worry about their own health (often or sometimes). In the same way, young carers who worry about the health of the person they care for also worry about who will look after them in the future. 89 per cent of those who do not worry about the person’s health have no worries about who will look after them in the future.

The inter-connectedness of problems and worries should be of great interest to those who are caring for, and working with children and young people. It is known that where problems in adolescence come all at once, young people are more likely to get into significant difficulties (Coleman 1990). Young carers who experience a coming-together of a number of worries and problems clearly have a high need for support in their lives.

Available avenues of support

The survey questionnaire invited young carers to write down the people they talk to currently when they have problems and worries. Results show that most young carers talk to a range of people, with their mothers at the top of the list (81 per cent), friends next (71 per cent) and Young Carers Project workers third (64 per cent). 10 per cent of all children only have one person they can talk to; one child has no-one.

Research on children's mental health indicates that the factor of overwhelming importance in terms of risk and protection for young people's mental well-being is the quality of family support (Aggleton et al 2000). It is encouraging, therefore, that so many children and young people in this sample are able to discuss their problems and worries with their parents, particularly their mothers. Over 40 per cent also name their siblings as people they can talk to. This suggests that while not all brothers and sisters are recognised as supportive, for a significant number this is indeed the case. As 17-year old Susan said wistfully, *'If it wasn't for my wee sister and my family...'*

Friends come high in the list of people who give support, and again the importance of friendships to adolescents is backed up in literature on mental health (Wright 2001). It is widely recognised that peer relationships take on greater significance during adolescence (Coleman 1990) and that having a number of good friends is vital in helping to steer a path through the teenage years (Rutter et al 1986). This study has shown that young carers' friendships can be volatile in character and young people worry about falling out with friends and also worry about not having friends. All the young carers who were interviewed spoke about how important friendships are to them, but they are not always easy to manage. As Kenny (aged 15) explained, sometimes when he is upset or worried, his friends think they are to blame and this causes tensions:

'You get really nippy with people ... like when you're with your pals, you can start shouting at them or just lose the head at them and they think it's up to them and it's no and it just causes a big cycle.'

16-year old Lea gives a similar account. She describes causing arguments with everyone when she is upset, and says that most young people do not understand this. Making a friend through EYCP has made a huge difference to her life, since she now has someone who understands something of her own experience. She does not need to keep things in any more, or to 'explode': *'but now I am talking more to my friend, but I just tell her everything now'*.

Asked what they like about the Young Carers Project, meeting other carers and young people came top of the list (88 per cent), closely followed by activities at the Project

(86 per cent) and trips and holidays (84 per cent). 68 per cent noted that they appreciate getting time off from caring, while 66 per cent like being able to talk to Project workers. 11 per cent of all children added 'having fun' and 'having a laugh' to an open question which asked them if there was anything they wished to add.

15-year old Kenny plays a key role as one of the young carers on the 'forum' at EYCP. This has given him greater self-confidence and a realisation that he has something to offer others:

'I think it's better here because when your talking here, like, the workers can ask you about advice an' all, like if they need help they ask you for advice and like at hame it's you've still like got the barrier. But in here it's like they make you feel just as important as they are so it makes you get on much better.'

All the children and young people who were interviewed were invited to say whether they felt that it would be a good idea for EYCP to have a trained counsellor on staff to help them. Kenny said:

'Aye, it would be. A lot of people could get things off their back, and make life less stressful.'

Conclusions

This research study has demonstrated that children and young people attending EYCP have significant problems and worries. These can be described in three ways:

1. Young carers have some problems and worries which are typical of adolescent concerns (worries about body image, friendships, relationships with parents, school, money etc.).
2. Some young carers worry a great deal about caring and the person they care for; they may also experience the usual teenage concerns.
3. Some young carers have had (or are experiencing) major disruption and loss in their lives (including family violence, sexual abuse and homelessness) in addition

to typical adolescent problems and their worries about caring and the person they care for.

It is clear that while the third group may seem to be most 'at risk', all three groups could benefit from the support and help of a counsellor. All the research evidence in this study (as in other studies of young carers) indicates that being a young carer may put additional pressures on children and young people at a time in their lives which is already stressful. Whether or not the problems they face are defined as 'mental health' problems is largely immaterial; most children and young people will not come to the attention of mental health experts such as psychiatrists and psychologists. But their problems are real enough, from what may be seen as relatively minor ones such as difficulties in eating or sleeping to major ones, including deliberate self-harm and attempted suicide. Given the stresses and pressures that already exist in families where someone is in need of care, it is likely that for at least some children, support may not always be guaranteed. This makes additional support, via projects like EYCP, all the more essential.

This study has shown that older young people and girls express more problems and worries in relation to their well-being, suggesting that they may have particular needs that should be addressed. In addition, both problems and worries increase with length of time being a young carer. While those who have most problems have been caring for longest, those who express highest worries are not those who have recently become carers, or even those who have been caring for 'as long as I can remember'. It is the group in the middle, those who have been caring for 'quite a long time' who describe most worries. Some specific problems have been identified as especially problematic. Self-harm, for instance, seems to be highly correlated with other areas of stress and difficulty, and should be seen as an indicator of potentially serious mental health problems.

The study has also demonstrated, more positively, that most children and young people who use EYCP receive much-needed help from family and friends, from EYCP workers, from other young carers and from the opportunity to take part in activities through the project – 'to have fun'. Nevertheless, all but one of the 61 carers

who took part in the study would like more help. Lucy (aged 9) was in no doubt why a counsellor would be a useful addition to the EYCP staff team:

‘...because if you kept it inside, it wouldn't be very helpful, for yourself and if you could talk to somebody about it you would probably get a lot of help.’

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Appendix 1

Children and Young People's Well-Being: Questionnaire

ABOUT YOU (please tick one box from each section)

How old are you?

5 - 9 years	
10 - 12 years	
13 - 15 years	
16 and over	

Are you a boy or girl?

Boy	
Girl	

How would you describe yourself?

White	
Black	
Asian	
Any other (please tell me more)	

Who do you live with?

I live with one parent only	
I live with one parent and brother(s) or sister(s)	
I live with two parents only	
I live with two parents and brother(s) or sister(s)	
I live with someone else (please tell me who)	

Who do you care for?

I care for one parent	
I care for two parents	
I care for a brother or sister	
I care for someone else (please tell me who)	
I don't care for anyone	

Do you know why the person you care for needs help? If you do, please tell me

--

How long have you been caring?

As long as I can remember	
Quite a long time	
Just recently	

PEOPLE YOU CAN TALK TO

**If you are worried about something, who do you talk to?
(please tick as many answers as you want to)**

Mother	
Father	
Brother or sister	
Friend	
Aunt or uncle	
Grandparent	
School teacher or guidance teacher	
Young Carers worker	
Social worker	
Psychologist or psychiatrist	
Doctor	
Youth club worker	
Help Lines eg Childline	
Anyone else? (Tell me who)	

**What do you like about the Young Carers Project?
(please tick as many answers as you want to)**

Meeting other children and young people	
Talking to project workers	
Having time off from caring	
Activities at the project	
Going on trips and holidays	
Anything not on this list? Please say more	

YOUR WORRIES

Sometimes children and young people worry about themselves and about other people.
Tell us about the worries that you have. (Please tick)

Do you ever	OFTEN	SOMETIMES	NEVER
Have difficulty sleeping?			
Have problems with eating?			
Have problems at school?			
Fall out with your friends?			
Get bullied at school or by others who live near you?			
Have problems at home?			

Have you ever			
Skipped school?			
Hurt yourself on purpose?			
Thought about suicide?			
Got into trouble with the police?			
Taken drink or drugs to 'shut off'?			

What do you worry about			
Your appearance?			
Your school work?			
Money?			
Where you stay now?			
Not having friends?			
Being bullied?			
The behaviour of the person that you care for? (what they say and what they do)			
The health of the person that you care for?			
Your own health?			
Who will look after you in the future?			
Anything else? (Please tell me more)			

WOULD YOU BE WILLING TO MEET THE RESEARCHER FOR AN INTERVIEW?

Your name Thank you for your help!

Children and Young People's Well-Being: Interview Schedule

1. Do you know why we are here today?
2. How did you feel about coming today?
3. I'd like to start by asking you to tell me a bit about yourself, since I don't know anything about you.
4. You know that the main thing we need to discuss is the things that worry you and what you do about them. Everyone feels sad and down sometimes. What are the kind of things that worry you or get you down?
5. Who do you talk to if you are unhappy or depressed or worried about something? (is this the same person you care for?)
6. Some children have friends they can talk to and some don't. What about your friends? How often do you see them?
7. When people are worried or depressed, this sometimes shows in the things they feel and the things they do. What about you?
8. Do you think it would be a good idea if EYCP employed a trained counsellor? Why?
9. Is there anything else you want to say?
10. How do you feel now?

Appendix 2

Descriptive statistics

1. Age

	Frequency	Percent
5 to 9 years	4	6.6
10 to 12 years	21	34.4
13 to 15 years	24	39.3
Over 16	9	14.8
Missing	3	4.9
Total	61	100

2. Gender

	Frequency	Percent
Boy	25	41
Girl	34	55.7
Missing	2	3.3
Total	61	100

3. Ethnicity

	Frequency	Percent
White	50	82
Black	2	3.3
Asian	3	4.9
Other	4	6.6
Missing	2	3.3
Total	61	100

4. Household Composition

	Frequency	Percent
One Parent only	9	14.8
One Parent and Siblings	22	36.1
Two Parents Only	4	6.6
Two Parents and Siblings	19	31.1
Other	5	8.2
Missing	2	3.3
Total	61	100

5. Person Cared For

	Frequency	Percent
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One Parent	25	41
One Parents and Siblings	9	14.8
Brother or Sister	8	13.1
Two Parents	6	9.8
Two Parents and Siblings	5	8.2
Other	4	6.6
No one	1	1.6
Missing	3	4.9
Total	61	100

6. Number of people cared for

	Frequency	Percent
One Person	32	52.5
Two People	16	26.2
Three or more people	8	13.1
Missing	5	8.2
Total	61	100

7. Reasons for Caring

	Frequency	Percent
Physical Disability	17	27.9
Learning Disability	1	1.6
Mental Health	2	3.3
Behavioural	2	3.3
Physical and Learning	7	11.5
Physical and Mental	1	1.6
Physical and Behavioural	4	6.6
Mental and Behavioural	3	4.9
Other	1	1.6
Missing	23	37.7
Total	61	100

8. Length of Caring

	Frequency	Percent
As long as I can remember	21	34.4
Quite a long time	32	52.5
Just Recently	4	6.6
Missing	4	6.6
Total	61	100

9. Talks to?

	Frequency	Valid Percent ⁶
Mother	47	81
Friends	41	70.7
Young Carers Worker	37	63.8
Father	28	48.3
Aunt or Uncle	26	44.8
Teachers	24	42.1
Siblings	24	41.4
Grandparents	18	31
Doctor	16	27.6
Social Worker	13	22.8
Youth Club Worker	11	19
Psychologist / Psychiatrist	6	10.3
Help Lines	5	8.6
Other	5	8.6
No one	1	1.7

10. Why I like the Young Carers Project

	Frequency	Valid Percent
Meeting other young carers	52	88.1
Activities at Project	51	86.4
Trips and holidays	50	84.7
Time off from caring	40	67.8
Talking to Project workers	39	66.1
Having fun	7	11.5
Other	4	6.8

11. Do you ever/have you ever?

	Often	Sometimes	Often + Sometimes	Never
Problems with friends	11 (19%) ⁷	26 (44%)	37 (63%)	22 (37%)
Difficulty sleeping	10 (17%)	26 (43%)	36 (60%)	24 (40%)
Difficulty at school	14 (24%)	21 (36%)	35 (60%)	23 (40%)
Problems at home	11 (19%)	22 (38%)	33 (57%)	25 (43%)
Thought of suicide	11 (19%)	10 (17%)	21 (36%)	38 (64%)
Has truanted	6 (10%)	15 (25%)	21 (36%)	38 (64%)
Has self-harmed	7 (12%)	13 (22%)	20 (34%)	38 (66%)
Problems with bullies	10 (17%)	9 (15%)	19 (32%)	40 (68%)
Difficulty eating	4 (7%)	14 (24%)	18 (30%)	41 (70%)
Trouble with police	6 (10%)	9 (15%)	15 (25%)	44 (75%)
Has taken alcohol/ drugs to 'shut off'	3 (5%)	4 (7%)	7 (12%)	50 (88%)

12. What do you worry about?

⁶ 'Missing' data has been excluded because it is not possible to separate out a 'missing' response from a 'no'.

⁷ All figures are rounded up to the nearest whole number. There are a small number of gaps where a young carer left a question blank.

	Often	Sometimes	Never
About the health of person cared for	26 (45%)	21 (36%)	11 (19%)
About own health	18 (30%)	22 (37%)	20 (33%)
About school work	12 (21%)	26 (46%)	18 (32%)
About behaviour of person cared for	12 (20%)	22 (37%)	25 (42%)
About appearance	16 (28%)	16 (28%)	26 (45%)
About money	11 (19%)	17 (29%)	31 (52%)
About who will look after you in future	11 (22%)	16 (31%)	24 (47%)
About being bullied	11 (19%)	10 (17%)	37 (64%)
About not having friends	8 (14%)	12 (21%)	37 (65%)
About where you stay	8 (14%)	10 (17%)	41 (70%)