



FEATURE ARTICLE

# Young, gifted, and caring: A project narrative of young carers, their mental health, and getting them involved in education, research and practice

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**ABSTRACT:** *Young carers are a global phenomenon. The UK estimates it has in excess of 175 000 young carers, the onset of their caring role often occurring between 8 and 10 years of age. Of these, 17 000 are caring for a parent who has severe mental illness, a significant factor for children entering the health and social care system, as up to 60% experience mental health difficulties themselves. This paper reports on the outcome of a participatory project aimed at better understanding the needs of young people. A World Café event was hosted, bringing together those involved in promoting the mental health of young people in a partnership consortium. The event was led by young service users and carers. Important issues raised by the young carers were being excluded from being included; stuck in the here and now, ignoring the future; a hole in the net; and ensuring the hidden is on the agenda. The World Café gave the university the privilege of insight into what local young carers need to improve their mental health, and more importantly, how we can utilize our skills to help them achieve their goals.*

**KEY WORDS:** *Involvement, mental health, nurse education, participation, young carer.*

## INTRODUCTION

This paper draws upon the work that has been developed in a large School of Nursing and Midwifery in the north west of England. This work has seen the development and establishment of a range of innovative approaches, recognized nationally and internationally, to service user and carer involvement in nurse education and research (Happell & Roper 2007; Stickley 2006; Warne & McAndrew 2006). While our efforts to date have focused

on embedding adult service user and carer knowledge into higher education activities, as part of a wider participation strategy, the time had come to extend this area of good practice to include young people under the age of 18. There is a strong commitment within our School to ensure that the voices of young people are heard, so they can effectively contribute to finding ways in which their well-being, and in particular, their mental health, can be improved.

In an attempt to widen participation and give voice to young people, it was important to bring together all those who were involved locally in promoting the mental well-being of young service users and carers. One approach to initiating such participation was to host a World Café event that would provide a platform to create important opportunities for collaboration between young service users and carers, the voluntary sector, health and social care practice, and education. Key objectives of the event encompassed exploration of opportunities for future

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Accepted June 2011.

collaboration in promoting greater understanding of the mental health needs of young people, strengthening representation of young service users and carers with mental health needs within our School's overall participation strategy, and further the research agenda for young people whose mental health might be or is compromised. These opportunities would build upon the work already initiated in promoting participation, ensuring that young service user and carer knowledge is embedded in education, research, and clinical practice (Warne & McAndrew 2004). For the purpose of this paper, the focus will be on young carers, exploring how caring impacts on their mental well-being, and what they consider might be the best ways of improving their situation.

### Young carers and their mental well-being

Young carers, that is, those providing care under the age of 18, are a global phenomenon (Becker 2007; Moore 2007; Robson 2004). In the UK, the 2001 census estimated that there were 175 000 young carers, with the onset of the caring role occurring for many children between the ages of 8 and 10 years (Office for National Statistics 2004). Many of these young carers, both girls and boys, are caring for a close relative (parent, sibling) who has a long-term health problem and/or is disabled. More than half of these young carers are living in a single-parent family situation, and often the burden of responsibility for other family members rests with the young person (Dearden & Becker 2004).

Young carers are involved in caring for people with a diverse range of health problems; for example, cancer (Gates & Lackey 1998), HIV/AIDS (Robson 2004), and chronic physical illness (Lackey & Gates 2001). Research suggests that 29% of people being cared for by young people are suffering from a mental illness, and in the UK, approximately 17 000 young people are living with a parent who experiences severe and enduring mental illness (Dearden & Becker 2004). While parents with a mental illness need support and help in recognizing their responsibilities as parents, their children also have to have their needs addressed (Social Care Institute for Excellence (SCIE) 2009). In the UK, parental mental ill health is a significant factor for children entering the care system. Child-care social workers report parents with a mental illness and/or a substance misuse issue account for 50–90% of their caseload (Office of the Deputy Prime Minister (ODPM) 2004). It is also estimated that, in the UK, between one-third and two-thirds of young people whose parent has a mental illness will experience mental health difficulties themselves (SCIE 2009).

Regardless of diagnosis or type of illness, young carers engage in caring activities that range from minimum assistance on an occasional basis through to sole responsibility for an individual's everyday care needs and/or those of the family. Factors that might influence the level of care required have been identified as the family's economic status, their social environment, lack of outside support, specific circumstances, such as the separation of parents, the process of being socialized into adopting a caring role, and the convenient availability of children within the home (Aldridge & Becker 2003).

In the UK, over the past 15 years, three national surveys regarding young carers have been undertaken. Since the initial survey in 1995, subsequent surveys completed in 1998 and 2004 showed improvement in some areas in the lives of young carers, but in other areas, there remains cause for concern (Dearden & Becker 1995; 1998; 2004). One such area is the increase in the level of emotional support that young carers are providing (Dearden & Becker 2004). While providing emotional support for others, the young people often experienced difficulties with stigma and isolation, schooling (from poor attendance to being bullied), lack of time for leisure activities, and a lack of recognition for their contribution to the family (Butler & Astbury 2005). When a parent has a mental illness, these problems are believed to be exacerbated, requiring a heightened need to ensure integration between mental health services and child-care services (Department of Health 2000; 2011). Given the juxtaposition of trying to provide emotional support for significant others, while social barriers prevent one's own emotional needs being met, it is not surprising that young people are themselves vulnerable to their mental health being compromised. Indeed, a number of research reports have identified strong links between increased risk of mental health problems per se, and more specifically, increased rates of depression in adulthood and alcohol and drug misuse among young carers (Cree 2003; ODPM 2004; Shifren & Kachorek 2003).

Gladstone *et al.* (2006) suggests that if the lives of young people living with or caring for parents with a mental illness are to be improved, recognition of personhood, personal agency, and intergenerational relationships are fundamental. Pakenham *et al.* (2007) emphasized the need to focus on interventions for young people that address the building of social support, cognitive appraisal, and the development of coping strategies, such as problem solving, support seeking, and support acceptance. While such provision is commendable, for some, caution needs to be exercised, as such activities might have the unintentional impact of rewarding young

carers, and thus, reinforce their caring role. It is suggested that providing high levels of care could be harmful to the young carer's own health, education, and life opportunities (Bibby & Becker 2000; Dearden & Becker 2004). These latter concerns have resulted in the ethos for some organizations, for example Barnados, to reduce levels of support in an attempt not to re-enforce young people in the caring role.

Addressing the needs of young carers who have a parent with a severe or chronic illness is a complex challenge. Young people should not be considered unwilling partners in providing care to their parent/s, and this is often demonstrated through their commitment, resilience, and skill (Aldridge 2006; Aldridge & Becker 2003). Indeed, the literature reports that the positive aspects of caring include increased self-esteem, early maturity, and a close relationship bond between child and parent (Aldridge & Becker 2003; Noble-Carr 2002).

However, in the UK, difficulties in addressing the needs of young people with a caring role can be problematic. Stanley *et al.* (2003) note this to be the case particularly for young people caring for parents. Likewise, assessment and access to interventions that would enhance their quality of life was, and to a certain extent remains, difficult (Stanley *et al.* 2003). In part, addressing such needs has been filled by funded charitable projects. In the UK, there are now a variety of projects offering various interventions to support young carers, the main aim being to provide them with access to services that offer support in terms of their caring role. Such support includes access to someone who will listen to them, talk about their experiences of living with and/or caring for their parents, and help them to create connections with peers who they can share their experiences (Grant *et al.* 2008). Also, rather than services taking responsibility and ownership of the young carer's support needs from the parent, focus is placed on interventions that enable and empower the whole family to make their own changes. The promotion of the whole family approach is built on the principles of promoting resilience and the well-being of all family members, together with the extended family network, is recognized as an important protective factor in developing resilience (Glover 2009; Social Exclusion Unit Taskforce 2008).

Failing to address the needs of these families has significant public health implications for the young carer and their parents. Their needs are complex and heterogeneous in nature, requiring diverse and sensitive interventions to enable them to address the issues that challenge and compromise their mental well-being. Since a wide range of interventions are provided through a variety of

services, the project team thought that bringing together local providers of young people's mental health services and those voluntary organizations who offer support to young people who have taken on the role of carer, would facilitate future conjoint working in terms of research, education, and practice. Through such collaborations, it is hoped that the services for this group of people could therefore be improved, and the young people can hopefully enjoy better mental health.

## METHODS

This paper draws upon methodological approaches most closely associated with participatory qualitative research. Internal university funding was sought to develop new and strengthen existing collaborative partnerships with local community groups that support young people and have a specific interest in their mental well-being. The team submitting the bid agreed to host two World Café-based events, one in December 2010 and another in July 2011. The events aimed to bring together a multiagency audience to explore the scope for collaborative working opportunities and prioritize the agenda for improving the mental well-being of young people, initially within our local community. The bid was successful, and this paper will now focus on young carers and the first of the two events.

A 'World Café' is an inclusive, participatory process that provides a platform for conversations between people and organizations about issues that concern them. Implicit in the notion of a café is an informal environment where people can meet for a table discussion of the things that have meaning in their lives. It is a way to capture the narratives being used by, in this instance, the young people, in articulating their experiences. As the World Café event is facilitated, the young people's conversations can be linked and built on. As people move between groups sharing ideas and discovering new insights, the capacity for effective action in pursuing common aims can be increased (Brown & Isaacs 2005).

As part of the participatory process, our first World Café was led by two presentations from local young people's groups: 'Florescent Adolescent' (five young people who were currently attending Mental Health day services) and Vocal (six young carers who are members of VOCAL—The Forum for Young Carers in Salford). The age range of these young people was 13–17 years of age. Both of the groups delivered an excellent presentation to an invited audience of approximately 50 people, with representation from secondary education providers,

statutory services (foster care, Youth Offending Services, Children and Adolescent Mental Health Services, the voluntary sector (Princess Royal Trust, 42nd Street, Brook), and from the Schools of Nursing and Midwifery, Social Work, Psychology, and Public Health at the University of Salford (Salford, Greater Manchester, UK). This was an audience made up of nurses and social workers working in a variety of care settings, voluntary agency workers, school teachers, and professional educators, all directly or indirectly providing services to children and young people.

Following each of the presentations, there was a short question and answer session. Following this, the audience had a short break while the project team, in collaboration with the young presenters, identified areas for the table discussion arising from the question and answer sessions. At the start of the day, each member of the audience, together with the presenters, was allocated a number representing the table discussion group they would initially be in. The project team ensured that there was a mix of people in each group to give maximum experience and hopefully a diverse discussion with regards to each of the identified topics. Each group was asked to dedicate approximately 30 minutes on each of the four topics and to capture their thoughts on flipchart paper. Once completed, the posters were displayed, and during the lunch period, people could add their own questions, comments, or ideas to any of the posters. Following lunch, a more formalized feedback session was facilitated to draw together the messages from each of the discussion groups. The day ended with 'key messages' being identified and recorded.

As stated earlier, for the purpose of this paper, we will focus on the presentation made by Vocal and the issues specifically important to them as young carers and their mental health. Outcomes from the 'Fluorescent Adolescent' group have not been included here as their concerns were those that addressed their experiences of being 'cared for', rather than as 'carers'. However, this work will be reported elsewhere.

### Raising young carer issues: Vocal presentation

The presentation started with an overview of the statistics related to young carers in Salford and an outline of the impact caring responsibilities have on young people's health and well-being. In keeping with some of the research identified earlier, it was also acknowledged that, locally, the number of young people caring for adults/parents with mental illnesses is rising.

Vocal then shared not only their own very personal experiences of caring for parents, grandparents, and sib-

lings, but also the experiences of other local young carers who they had surveyed for the presentation. With the aid of a short film that they had made, interspersed with standing up and narrating personal stories, they explained to the audience the massive impact these experiences had on their lives. Vocal explained the impact of caring on their physical health, including 'coughs and colds that linger', being 'too busy to go to the GP (general practitioner)', and the guilt they felt about passing on coughs and colds to those they care about and for. In addition, Vocal also expressed their experience of 'feeling tired all the time'. In terms of their social well-being, examples, such as 'we don't look any different', 'mates do not exist', 'my boyfriend dumped me: what's the point of having a girlfriend who can't go out?', and 'it's my little sister who has to cover me so I can have a bit of time to myself', clarified the level of isolation these young carers often experience. The impact of these experiences on their psychological well-being became evident when Vocal voiced phrases, such as 'I have no one to talk to', 'I look after him, but who will look after me', 'I hate my life: I'm 15', and 'I wish I was dead'.

On a more positive note, Vocal went on to explain how their support group gave them 'a time and place to relax', an 'opportunity to feel like any other young person', and a place 'where others really understood what you are going through'. With regards to the latter, this was further explicated by comments, such as 'now I know I am not alone', 'they do not force you to talk', and 'they understand how you are feeling'.

On completion of their presentation, the group presented the audience with copies of a book they had written to celebrate 10 years of the Salford Young Carers Service. The book, *Still Here, Still Proud* (Vocal 2010), highlights the issues faced by young carers in the city, reaffirming to the audience the real threat to the mental well-being of young carers, and subsequently, their determination to improve the services and access for young carers.

Vocal's presentation was emotionally evocative. Following the presentation, questions raised by the audience ranged from the fiscal, for example: 'Is the funding for your support service secure?' to the demographic: 'If we are only managing to help a small percentage of young carers, how can we discover others who need help?', to the personal: 'What do young carers need in order to enhance their quality of life?'.

The project team, together with the Vocal group, then established which of the issues raised were believed to be a priority to address with people attending the World Café. The following four areas identified were:

1. Excluded from being included; professional decision-making.
2. Stuck in the here and now, ignoring the future; failure of others to understand the effect that caring has on young people's futures.
3. A hole in the net; lack of appropriate support for young carers.
4. Ensuring the hidden is on the agenda; recognizing who the young carers are.

## FINDINGS

### Excluded from being included: Professional decision-making

This section can be divided into three aspects of communication: listening and understanding, speaking in tongues, and information exchange. The presentation given by Vocal prompted the audience to readily admit their failure to understand the impact that caring has on the lives of young people. Managed discussion among the audience also revealed that communication between organizations required significant improvement if young carers are to be offered a comprehensive service. Particular issues that were identified included lack of age-appropriate communication and professional versus lay communication. Despite being the main carer, the young people told stories of being excluded from decisions relating to themselves and those they were caring for, being dismissed by professionals as unimportant, and indirectly excluded through the use of 'professional' and/or adult language. Two of the young carers reiterated how they were told of their relative being discharged from hospital, but that no one explained to them about changes in the person's medication regime, which had previously (before being admitted to hospital) been the young carer's responsibility.

The young carers described themselves as 'the forgotten'. Their interpretation of this was being forgotten undermined them as people. On hearing their stories, the professionals in the audience were keen to ensure that the young people knew about services they could access that might provide them with extra support. There was also clear frustration from the audience that the young people had not already been informed of available services. This led to further debate regarding where to best place such information that would ensure available services reached the right audience. For example, as many young people use public transport, one suggestion was a young people's services contact page in the free paper provided on all local transport.

### Stuck in the here and now, ignoring the future: Failure of others to understand the effect that caring has on young people's futures

As the discussion progressed, it became evident that young carers' needed rapid access to services, that is, access to what they need, when they need it. The young carers explained how a long wait added to their stress, and that if help arrives when the crisis has already taken hold, they feel angry, frustrated, and unable to communicate with those who might be able to offer help. This led to a discussion about advocates for young carers who could be there and help them when they are feeling unsupported and/or challenged by the professional milieu. Again, stories were reiterated regarding the variability in skills from professionals; some taking the young carer to one side and asking how they can help, while others just 'speak to parents', 'tick their boxes', and 'leave without anything changing'. The frustration this often created highlighted the importance of having a place to go for support and escape. More specifically, the young person's education appeared to be integral to this category. A range of ideas were put forward, from needing a trusted person to help with practical issues, for example, picking up siblings from school so that they do not have to leave their own lessons early, strategies for late submission of work, through to a flexible system of education that recognizes their caring responsibilities and builds in support to enable carers to maximize their potential.

### A hole in the net: Lack of appropriate support for young carers

The issue of support manifested in a variety of ways. There was a general concern that although pockets of good support exist, the system lacks consistency. For many young carers, having fun appeared to be an important aspect that contributes to their mental well-being. However, while providing opportunities for such support mechanisms, it was also acknowledged that the young people needed a safe haven to discuss their very personal issues; a time when they can be their 'real self'.

The discussion around this feedback very much involved the young carers' experiences at school and with the voluntary agencies. For the young carers, school appeared to be a place that could easily align itself to insecurity. Young carers described how they are often bullied in school, and as they are not able to rely on their parent/s for support in dealing with this, their vulnerability is heightened. With regards to bullying, there was a felt need for teachers and other students to do more in terms of being supportive. This raised another important question: do adults sometimes need to take control?

There appeared to be a dichotomy with regards to this question. For some, there was a strong contention that the state should recognize that it has a vested interest in looking after young carers, given that they save the taxpayer a great deal of money. This furthered the argument for the promotion of young carer services and a need for young people to be informed of what is being said and/or decided about them with regards to their caring role. However, this again raised the subject of advocacy and how it might be more pertinent for young carers to be supported by an advocate. Such an advocate would be someone who is more familiar with the paternalism inherent in many health and social care organizations, and as such, can act as a 'buffer' for the young person.

### **Ensuring the hidden is on the agenda: Recognizing who the young carers are**

In the main, this final part of the feedback related to schools and the education system. The consensus was that 'if there is a problem out there, it doesn't have to be hidden. Risk-averse cultures lead to "hiding" when the opposite is needed'. There was some discussion around the notion of 'privileged knowledge', that is, the young people themselves being able to recognize others in a similar situation and how such knowledge could be utilized. For example, school teachers need to recognize particular behaviours, such as withdrawing from others. The idea of developing a 'checklist' or guidance for adults (nurses, teachers) in a position to help young carers who need support was raised; the belief being that any such checklist should be developed in collaboration with young carers.

It was felt that school assemblies or lessons could provide good opportunities to raise the subject of young carers and the issues that are important to them. It was felt that teachers and pupils alike had to start promoting mental well-being in school from an early age, and part of that well-being was accepting young people for who they are, which might include having responsibility for other family members. Emphasis was placed on the importance of dealing with issues of stigma associated with caring and there needing to be options for support within schools. It was agreed that a contact in school is needed; this could sometimes be an individual, but often many people will be needed, as caring is a complex issue. It was thought important that schools need to focus their priorities and be able to recognize pupils within the context of their own different life circumstances. Teachers and school nurses are pivotal to this process and to ensure the 'emotional' well-being of young people, and in particular, those with a caring role.

From the feedback, the following key messages were identified:

- Organizations need to listen, engage, and have meaningful communication with young carers
- Young carers need practical and emotional support
- Young carers need a safe place to go where they can relax and where they will be listened to
- Young carers need to be at the centre of discussions impacting on their lives
- Schools need to be flexible in order to meet the needs of young carers
- Young carers are best placed to educate the educators regarding their experience and the recognition of other young carers
- There is a clear need to secure further funding in order to continue and expand vital services, with recognition of the importance of 'spreading the word'
- Actions speak louder than words

## **DISCUSSION**

The four topics arising from the young carers' presentation and the audiences' response reflect issues that have arisen in previous literature relating to the impact of being a young carer on one's mental health. The implications of this impact for health and social care professionals should not be underestimated. The complex challenge in addressing the needs of young people caring for a parent and/or significant other with a severe or chronic illness can be overwhelming in terms of their mental well-being (Gladstone *et al.* 2006; Moore 2007). First, it is important to note that the young people who presented at the World Café were not unwilling partners in providing care to their parent/s, and as reported in the literature, this was demonstrated through their commitment, resilience, resourcefulness, and skill (Aldridge 2006). It is important that professionals are mindful of this when negotiating the development of services to meet the needs of young carers. Indeed, the young presenters showed evidence of early maturity in terms of knowing what they wanted in order to improve their lives (Aldridge & Becker 2003; Noble-Carr 2002).

While national projects have made good inroads with regards to helping young people who have caring responsibilities, it is clear that more work needs to be done. Some of the difficulties identified over the past 15 years, for example, stigma, isolation, and being bullied, continue to exist (Butler & Astbury 2005). While addressing such issues is not easy, professionals can learn lessons from these and other findings (Pakenham *et al.* 2007), notably

the importance of helping young carers' to build social support, recognize personal stressors, and develop coping strategies that can be easily accessed. Likewise, heed can also be taken of Gladstone *et al.*'s (2006) personhood and the significance of professionals recognizing the young carer as a person in their own right, who should be shown respect for not only what they do, but who they are.

The needs of young carers and their families are complex and heterogeneous, requiring a range of diverse and sensitive interventions made by a multiplicity of organizations. Addressing the issues outlined earlier requires change in education and health and social care at the macro (policy level), meso (service provision level), and micro (the individual level) level, and to do so will require collaborative multiagency working if we are to improve the mental well-being of young carers.

For our School, the day resulted in strengthening pre-existing, and developing new relationships with young carers and the organizations with which they have involvement. In harnessing such relationships, a number of tangible outcomes from the event have been achieved. These include the development of three research applications for funded projects. These have been submitted to funding bodies, and some of the young people will engage as co-researchers on the projects. The young people have now become part of the School's service user and carer group. This will give the young person greater opportunities to acquire a range of communication and other skills, as well as making a (paid) contribution to the work of the School and the wider University. The School and University is strongly committed to widening participation for those individuals who might consider coming to the University, but whose economic and or social position might make this more difficult. Events, such as that reported upon in this paper, greatly contribute to achieving these aims, regardless of whether these young people choose to access university education at a later date or not.

## CONCLUSION

The prolific emotionality engendered in the audience when listening to the young carer's presentation was palpable. The consequence was one of immediate vociferous discussion and debate, all needing to simultaneously defend and acknowledge by way of response. Bringing together local services has been an insightful experience. National projects, most of which are delivered at local level, have been instrumental in advocating on the part of young carers and ensuring that their voice is heard. As a university, the World Café gave us the privileged position of insight into what local young carers need to improve

their mental well-being, and more importantly for us, how we can utilize our skills to help them achieve their goals.

## ACKNOWLEDGEMENTS

To those who made this paper possible. Emma Jolly, Toni Bleakley, Florence Olatunji, Ashley Harrison, Ashley Owen, and Jon Cullen. Thank you for having the courage to share and for your inspiration.

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