

Volunteering for the Future: The Impact on Young Volunteers of Volunteering in Paediatric Palliative Care

Rosalind C. Scott, Children's Hospice Association Scotland, Kinross, Scotland

Denise Burgin, Children's Hospice Association Scotland, Kinross, Scotland

BACKGROUND

The children's hospice movement in the UK is still relatively young with the first children's hospice, Helen House, being established in Oxford in 1982. Children's hospices are purpose built buildings offering respite and palliative care to children and young people suffering from life-threatening conditions and support to their families. Palliative care for young people with life-limiting conditions is described as "an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on the enhancement of quality of life for the young person and support for family and friends and includes the management of distressing symptoms, provision of respite and care through death and bereavement" (ACT ; R.C.P.C.H. 1997). The aim is to help the children and young people to live life as fully as possible and achieve hopes and dreams in the time they have left.

Less than 11 percent of children using hospices have cancer. Many have a range of other complex, life threatening conditions such as, duchenne muscular dystrophy, cystic fibrosis; Batten's disease, mucopolysaccharidosis and neurological conditions such as severe cerebral palsy (ACT et al.1997).The period of time that children and families stay varies from hospice to hospice, and is dependent on the child's specific needs, condition and the circumstances of each family. On average it is for periods of 3 - 5 nights on several occasions throughout the year, up to approximate-

ly 21 nights. The demand for hospice/respite care has increased considerably in recent years and consequently there are now more than 27 children's hospices with many more in the planning stages.

The maintenance and continuing development of all hospices relies heavily on voluntary income as only a small proportion of their funding comes from statutory sources such as the National Health Service and Social Services. It is of great concern therefore that the "National Survey of Volunteering in UK" (1997) identified a "sharp reduction" in levels of participation by young people aged 18 - 24 years and more negative views of volunteering among the younger generation than older age groups. Further research was funded by the Institute of Volunteering Research (Gaskin 1998) to explore young people's understanding of voluntary work and their view of its relevance to them. Attention was focussed on the conditions and incentives which would attract them to voluntary work and the best ways of publicising and marketing volunteering opportunities. Some of the key findings were a need for flexibility and ease of access to volunteering opportunities, which is still considered to be a barrier. Young people also stated that volunteering should be "enjoyable, satisfying and fun."

Culbertson (2003) speaking about youth volunteering in America, argues that the greatest hurdle to supporting youth volunteering over the next decade is the generally disapproving perception of adults about

Ros Scott is Head of Voluntary Services at the Children's Hospice Association Scotland, and has an extensive background in volunteer management in palliative care, both the adult and paediatric sectors. She is currently Chair of InVOLve, the Professional Association for Volunteer Managers in Palliative Care for UK and Ireland, Vice-Chair of the Help the Hospices Advisory Panel on Volunteering, and part of the Executive of Scottish Association of Volunteers Managers. She also leads the Association of Children's Hospices Volunteer Managers Group.

Denise Burgin, currently works as an independent nurse consultant. She has many years of experience in paediatric/child health nursing as a senior nurse/ward sister, in paediatric medicine and oncology and also as a nurse tutor, lecturer in child health nursing. Her current interests relate the involvement of volunteers in children's care environments and to the emotional impact of grief and loss.

youth. He believes that adults have a “misperception” about young people and underestimate their capacity to deliver meaningful and effective [voluntary] service. Most importantly Culberrson cites research sponsored by the “Independent Sector” and “Youth Service America” (2002) which indicated that adults who engaged in volunteering in their childhood give more money and volunteer more time than those who began in later life.

THE STUDY

Rachel House, currently Scotland’s only children’s hospice, opened in March 1996. It is well supported by 140 volunteers of all ages including young volunteers aged between 16 and 21 years. Initially there was concern that young volunteers might experience difficulty working alongside people of a similar age, who were not expected to live until adulthood. Particular concerns were expressed about their vulnerability when a death occurred in the hospice. It was decided therefore to undertake a study to explore the impact on young people of volunteering in a paediatric palliative care environment. The purpose of the study was to explore the experience on young volunteers (age 16-21 years) of working in a children’s hospice environment; to identify the extent of involvement of young volunteers in children’s hospices throughout the U.K. and to determine the attitudes of children’s hospice professionals towards their involvement. The sample comprised the total population, at the time of the investigation, of two distinct groups: Group A: young volunteers aged 16–21 years, who were or had been involved within Rachel House children’s hospice at the time of the study or within two years of the time of the study (n=16); Group B: other children’s hospices in the U.K. listed in the “Association of Children’s Hospices Directory” (n=18)

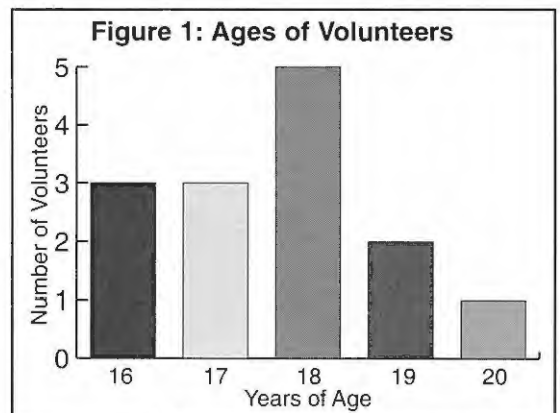
Two questionnaires were developed and used to gather information from the two groups. Postal questionnaires were sent to Rachel House young volunteers. The hospice questionnaires were sent to the member of staff with responsibility for/interest in volunteers. A subsequent follow up telephone interview was conducted with a small selected sam-

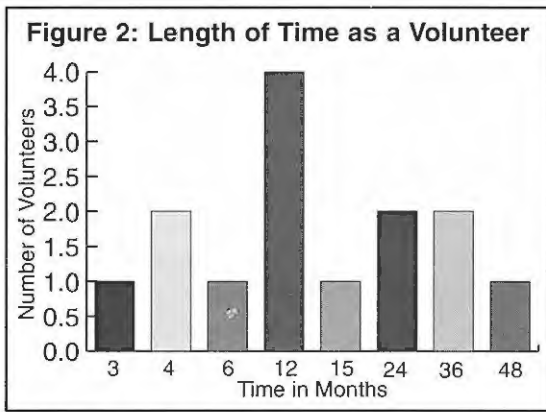
ple (n=3, 27%) of young volunteers. The purpose was to explore in more depth some of the responses made within the questionnaire.

Informed consent was obtained from all participants initially and throughout the process. They were also informed of their ability to “opt out” at any time. Confidentiality and anonymity were assured to all participants. There was an awareness throughout the study of the sensitivity required when discussing issues of loss, death and bereavement.

Fourteen completed questionnaires were received representing an 88% response rate. The data obtained from the questionnaires was analysed both qualitatively and quantitatively. The findings were grouped under headings related to the questions asked. The age of the volunteers ranged from 16 to 20, with the mean age being 17.6. (Figure 1 demonstrates the age range of volunteers). The period of time that volunteers had been with the hospice varied from 3 – 36 months (Figure 2). The roles that volunteers undertook included helping in the kitchen, helping with meals, helping with housekeeping and working with the activities team with affected children and their siblings.

In relation to their experience of the environment, 86% (12) of young volunteers had not found the paediatric palliative care environment a difficult area in which to work. This was attributed to the reassurance and support of experienced staff and volunteers; opportunities to talk about their experiences; and the friendly atmosphere and openness of the hospice staff. Fourteen percent (2) had initially found the environment difficult because of the similar ages of the children and also found it difficult to accept that the





children would die. However these respondents indicated that although it had taken time, they had settled into the environment. The majority 72% (10) felt that the introductory period of the induction training had adequately prepared them for the impact of volunteering in a paediatric palliative care environment.

Attendance at the quarterly support meetings had been difficult for young volunteers with only 14% (2) making use of these sessions. Those who had not attended these meetings cited other commitments and lack of time as the main reasons. One respondent did not feel the need to attend, whilst another feared s/he would be the only young person there. They suggested meetings be held at evenings and weekends; sessions which were specifically for young people and a young volunteers' social evening.

At the times when there were deaths in the hospice, 79% (11) of the young volunteers felt that they received the support needed. Young people reported that opportunities to talk; the caring, reassurance and support of experienced staff and volunteers; the family spirit; the friendly atmosphere, and the openness of the environment were important at these times. One respondent (7%) had not found adequate support and indicated that knowing that they could talk to someone would have helped. Subsequent contact with the Chaplain had been very helpful to this volunteer. All (100%) respondents indicated that their experiences had been very rewarding. A few put forward suggestions for improvement, which included more contact with children; more appreciation from staff; and a certificate of achievement.

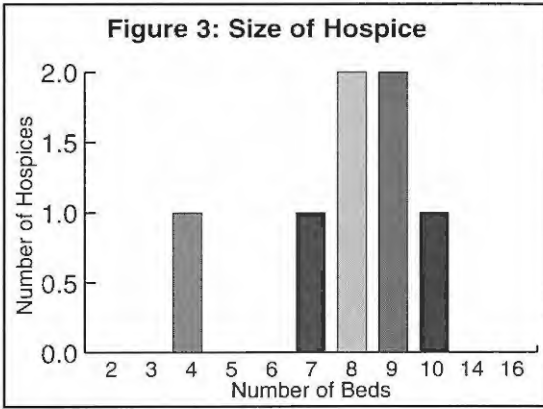
FINDINGS FROM TELEPHONE INTERVIEWS WITH YOUNG VOLUNTEERS

Seventy-nine percent (11) of respondents indicated in the initial questionnaire that they would be willing to take part in a further telephone interview. Information obtained by telephone supported the above findings. These interviews, however, highlighted that working with an experienced volunteer partner was very important. This they felt gave confidence and one to one support. Also, the practical aspect of the induction period was identified as being of most value. They felt that this was the only way to find out what volunteering would really be like.

The role of the volunteer co-ordinator was specifically identified as a key role in the support of young volunteers. It was suggested however that more emphasis be given to support in the recruitment and introductory stages of volunteering. Young people reported that they had learned a great deal and had overcome their fears about interacting with the hospice children and their families. Key learning included the fact that there were many misconceptions about children's hospices and that it was "OK" to be happy in such an environment. Young people indicated that through their volunteering experience in a children's hospice, they had gained valuable insight into an area of life of which they had no previous experience.

FINDINGS FROM QUESTIONNAIRES TO HOSPICES. GROUP B

Of the questionnaires sent to other hospices (19), 10 were returned, a 53% response rate. Figure 3 demonstrates the number of beds within each of these establishments. Only 3 hospices involved young volunteers. They identified a range of roles involving young volunteers which included pool aides, housekeeping, befriending, helping with mealtimes, helping with activities with children, and office duties. No specific support needs for young volunteers were identified. They were found to cope well in an environment of loss and bereavement. All identified the value of young people working with an older, more experienced, mentor as a key factor. It was felt also that most young people

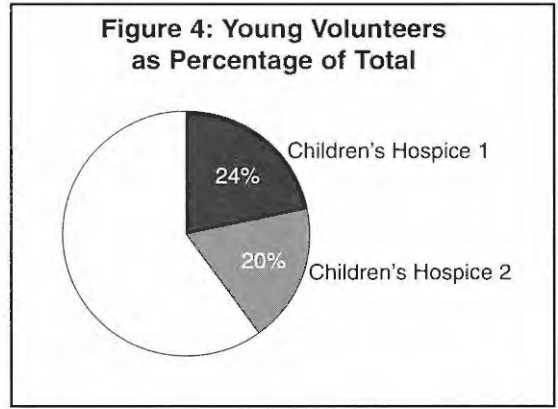


had thought through their wish to volunteer carefully before application and that careful selection and training helped to ensure success. Specific issues identified included the failure of young volunteers to notify hospices of their lack of availability and also the fact that they would like to keep the young people involved as volunteers for a longer period of time.

Children's hospices reported that the involvement of young volunteers ensured that the hospice community reflected the range of ages within the community as a whole, and broadened the diversity of skills within the volunteer team. They reflected that young volunteers were usually mature, motivated, bright, cheerful and an asset to the hospice. The hospices that did not include young volunteers in their organisation cited a number of reasons for their non-involvement. These included: concern about the similarity in age to the young hospice users resulting in greater support needs, and a lack of a volunteers co-ordinator to supervise volunteer input. Hospice policy was given as another reason. Figure 4 represents the number of young volunteers as a percentage of the total number of volunteers in children's hospices. This figure demonstrates the low level of involvement of young volunteers.

DISCUSSION AND CONCLUSION

This study involved a very small sample which affects the statistical significance and generalisability of the findings. It is, however, reflective of the small number of children's hospices and the number of young volunteers participating at the time of the study. It is clear that children's hospices and young vol-



unteers derive significant mutual benefit from each other. It appears that concerns about the difficulties which may arise because of the similarity in age between young volunteers and children using hospices is totally unfounded. The range of roles undertaken varied considerably and highlights the fact that young volunteers do not necessarily have to have close contact with hospice clients in order to offer a valuable contribution. The variety and flexibility of roles available means that young volunteers can adjust the amount and intensity of involvement according to their developing confidence and experience.

Contrary to previously held beliefs by many hospice professionals/personnel, the majority of young volunteers did not find the paediatric palliative care environment a difficult place to work. Factors associated with this positive finding were supportive staff and a friendly, open environment. Two respondents, however, did find their experience difficult because of the similarities in age of the client group and difficulties around the time of death. Although these respondents reported that they did eventually settle into the environment, it would be interesting to explore if these could have been identified at the selection stage and more support offered.

The majority of respondents felt that their introductory induction training had prepared them for their role. Other commitments and a lack of time, the reasons given by those unable to attend support meetings verifies the findings of Gaskin (1998) who identified flexibility and ease of access as some of the key factors affecting young peoples willingness to participate in volunteering. The suggestion made by respondents of holding these

meetings at weekends or in the evenings should be explored. Reassuringly everyone indicated that their experiences had been very rewarding and the ideas for improvement such as more appreciation from staff and certificates of achievement could be implemented with relatively little effort or expenditure. The findings in relation to the involvement of young volunteers in other hospices, demonstrates that they are being excluded or only involved at a peripheral level. This is a very important finding as it may support Culbertson's (2000) contention that adults have disapproving perceptions of youth.

Those children's hospices that did involve young volunteers identified that they had coped well and were very positive about their experiences. Key factors to success appears to be, careful selection, flexibility of training opportunities and meetings, ongoing support and working alongside older more experienced volunteers. The young people of today are the volunteers of the future and failure to capture their interest and involve them at an early age could pose significant challenges to all organisations that rely on voluntary support in the future.

IMPLICATIONS FOR FUTURE PRACTICE

It is clear that if organisations are to succeed in developing effective volunteer programmes involving young people, negative attitudes to young volunteers must be identified and challenged. Positive attitudes should be encouraged by education, the sharing of good experiences and successful strategies.

Organisations should assess their volunteer programmes to identify areas where young people could make effective contributions or contribute in a more meaningful way. There is a need for adults/professionals to have confidence in the abilities of young people and to recognise their capacity to cope in challenging environments. Effective management includes: active recruitment, selection, matching, training and support strategies to aid their introduction and development is vital.

Criteria for the selection of young volunteers should be developed and used in all recruitment situations. A support strategy

specific to the needs of individual young volunteers should be identified, documented and monitored by the volunteer co-ordinator during the introductory training period. The availability of ongoing support which is flexible and that young people know how to access, should be reinforced at each meeting. Organisations need to think imaginatively about methods of the delivery of training. These might include: one to one mentoring or coaching by experienced volunteers and innovations such as web designed training.

Young volunteers need a voice, both individually and collectively within organizations and their views need to be heard. This could be achieved through representation within organizations and on committees locally and nationally. Young volunteers are the future. They must feel valued and appreciated or we risk losing them to volunteering forever.

REFERENCES

- Armstrong-Dailey, A., Zarbock, S., (2001). *Hospice Care for Children*. (2nd ed.) New York: Oxford University Press.
- Association for Children with Life Threatening or Terminal Conditions and Royal College of Paediatrics and Child Health. (January 1997) *Report of the Joint Working Party*.
- Culbertson, S. *Youth Volunteering and Service Learning – Tapping the Fountain of Youth*. *Dialogue* Vol.5. August 2003 Association of Volunteer Administration www.AVAintl.org/profession/dialogue.html
- Doyle, D. (2002). *Volunteers in Hospice and Palliative Care. A handbook for volunteer service managers*. London: Oxford University Press.
- Gaskin, K. (1998) *What Young People Want from Volunteering*. *Institute for Volunteering Research*.
- Wooley, H., Stein, A., Forrest, G.C. & Baum J.D. (1989) "Staff Stress and Job Satisfaction at a Children's Hospice". *Archives of Disease in Childhood* 64 pp114-118.