

# Peer education for advance care planning among older people: volunteers' perspectives of training and community engagement activities

Jane Seymour<sup>1</sup>, Kathryn Amack<sup>1</sup>, Sheila Kennedy<sup>1</sup> Katherine  
Froggatt<sup>2</sup>

1. Sue Ryder Care Centre for the Study of Supportive, Palliative  
and End of Life Care University of Nottingham
2. International Observatory on End of Life Care, Lancaster  
University

(on behalf of the Peer Education Project Team)

(paper in press with *Health Expectations*)

# Setting the scene

- Changing demography: death at older ages, preceded by uncertainty / chronic disease/ often loss of, or fluctuating capacity
- The potential for 'advance care planning'<sup>1</sup> to aid transitions to palliative care
- Public awareness as a national priority (English End of Life Strategy – DH 2008)
- Many either do not wish or don't know how to talk- need for community initiatives
- Peer education: '*...sharing experiences and learning amongst people with something in common*' (Shiner 1999: 557)
- Peer education may aid attitudinal change at the community level

See:

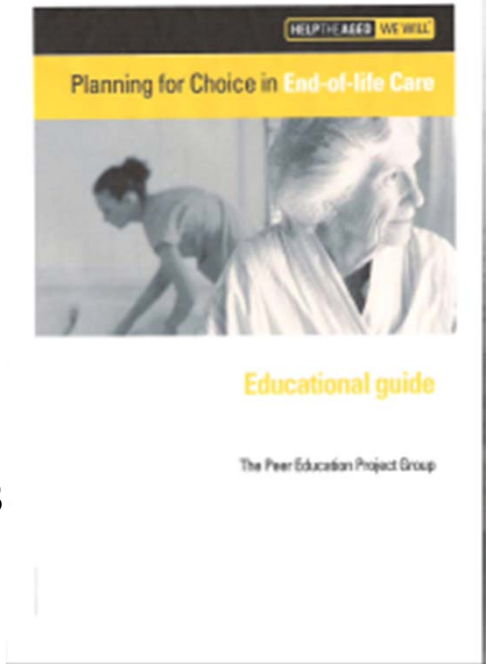
National End of Life Care Programme (in press) *Capacity, Care Planning and Advance Care Planning: A Guide for Health and Social Care Staff*. NEOLCP: Leicester

Fried TR and Drickamer M. Garnering support for advance care planning. *JAMA*, 2010; 303(3): 269-270

Shiner M (1999) Defining peer education. *Journal of Adolescence*, 22, 555-566

# Foundations

- Part of a programme of work<sup>1</sup>, specifically:
- A pilot project<sup>2</sup>:
  - Developed structured training programme<sup>3</sup>
  - 5 peer educators
  - Community based workshops
  - Development of booklet
- Listening Events <sup>4</sup>



1. For example: Seymour JE, Payne S, Chapman A, Holloway M. Hospice or home? Expectations of end-of-life care among white and Chinese older people in the UK. *Sociology of Health & Illness*. 2007; 29: 872-90
2. Seymour JE, Sanders C (on behalf of the Peer Education Project Group) (2006) *Planning for Choice in End of Life Care. An Educational Guide*. London: Help the Aged.
3. Sanders, C et al. (2006) Development of a peer education programme for advance end of life care planning. *International Journal of Palliative Nursing*, 12(5): 214-223.
4. Clarke A, Seymour JE. At the foot of a very long ladder': discussing the end of life with older people and informal caregivers. *Journal of Pain and Symptom Management*. 2010; 40: 857-69.

# This study

- Funded by the Burdett Trust for Nursing, with additional funds from Help the Aged. Two elements:
  1. A series of focus groups to explore end of life concerns <sup>1</sup>
  2. Revision of the training programme so that we could train a larger number of volunteers from diverse groups and localities

1. See for example: Almack K, Seymour J, Bellamy G. Exploring the Impact of Sexual Orientation on Experiences and Concerns about End of Life Care and on Bereavement for Lesbian, Gay and Bisexual Older People. *Sociology*, 2010; **44**: 908-24.

# Aims of the study

- To refine and extend an existing peer education programme for advance end of life care planning
- To recruit volunteers to the training programme and assess the acceptability of the refined training programme to them
- To study the level and range of community engagement by volunteer peer educators and the issues encountered by the peer educators for up to one year after the training programme.
- To add to conceptual understandings of how volunteers may be prepared to work as peer educators, according to their own aims and contexts

# A word about peer education

- ‘Peerness’- can mean a multiplicity of identities<sup>1</sup>
- May provide an alternative, or a complement, to ‘expert’ led education <sup>2</sup>
- Can strengthen a sense of identity and encourage change by role modelling <sup>3</sup>
- Can range from the structured to very informal
- But has been called ‘...a method in search of a theory’ <sup>4</sup>

1. Shiner M. Defining peer education. *J Adolesc.* 1999; **22**: 555-66.
2. Connor A, Ling CG, Tuttle J, Brown-Tezera B. Peer education project with persons who have experienced homelessness. *Public Health Nursing.* 1999; **16**: 367-73.
3. Peel NM, Warburton J. Using senior volunteers as peer educators: What is the evidence of effectiveness in falls prevention? *Australian Journal on Ageing.* 2009; **28**: 7-11.
4. Turner G, Sheperd J. A method in search of a theory: peer education and health promotion. *Health Education Research.* 1999; **14**: 235-47

# One theoretical framework

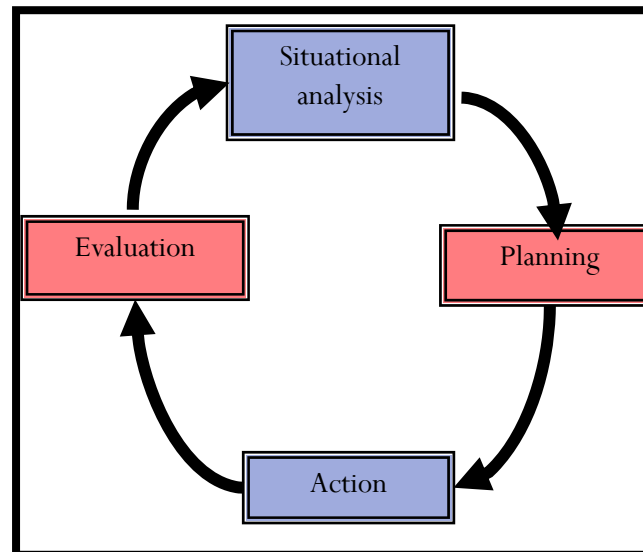
- Social identity
- Critical consciousness
- Social capital

See: Campbell C, MacPhail C. Peer education, gender and the development of critical consciousness: participatory HIV prevention by South African Youth. *Social Science and Medicine*. 2002; **55**: 331-45.

Freire P. *The Pedagogy of the Oppressed*. London: Penguin, 1970/1993a

# Methodology

- Participatory action research
- Worked with a core group of older adults already trained as peer educators (research partners)
- Ongoing action and reflection



# The focus of training

- awareness of issues about loss and communication and how these influence peer education;
- skills to prepare them to facilitate peer group or one- to- one discussions to raise awareness of ACP in their communities;
- awareness of appropriate resources to provide information to others about ACP and related end-of-life care issues.

# Structure of the 3 day programme



## Topics

- Palliative and end of life care: introducing key issues
- Understanding loss, grief and bereavement
- Advance care planning and other legal/ethical issues



## Approaches

- Peer education: what does it mean?
- Supporting ourselves and others
- Working with your peers: Action Planning



## Techniques

- Group work: dynamics, facilitating groups
- Communication skills

# The volunteers

- 32 people recruited from the preliminary focus group study, sampled via community groups
  - 24 'older' people; 8 community care staff
  - 22 women, 10 men
  - 8 under 55; 8 were 55- 64; 9 were 65-74; 3 were over 75
  - 2 black British; 30 white British
  - 17 rated their health as either 'excellent' or 'good'; 7 said their health was 'fair' or 'poor'
- (not everyone agreed to give demographics)*

# The community groups

- A 'Crossroads' Cancer and Palliative Team and their Bereavement Support Group –N England
- An umbrella organization comprising several self help groups-Midlands
- An African Caribbean Community Association in a city in Northern England
- A network of lesbian, gay and bisexual (LGB) older people living in various parts of England (London-Scarborough)
- A Seniors Forum in the North East of England.
- Senior Learners Group (NW England)

# Evaluation methods

Training

- Personal aims and concerns
- Evaluation forms and 'post it notes' end of each day

4 months

- Postal Questionnaire (24 respondents)

6 months

- Follow up workshop/ focus groups (20 participants)

12 months

- Interviews (12 with 25 participants)

# Perceptions of the training

- Preliminary aims and concerns:
  - *Speaking in groups; learning new information; finding out how to support others; gaining information for self and others; sharing learning.*
  - *In addition, some anxieties about subject matter and whether the role was feasible*
- Positive perceptions of the programme: sustained over one year
- Some 'gaps': *more on legal/ ethical issues; importance of support networks*

# Developing new understandings

## **Evaluative comments**

- *Meeting like minded people who all wanted to help other people- even though some obviously had difficult times themselves*
- *Enjoyed meeting a wide variety of people- hearing different points of view*

## **Reflections on learning about end of life care issues**

- *The diverse ways and extent to which other people think about end of life issues- I have learnt a lot*
- *That there are many ways in which we might use this information for ourselves and also with others*
- *Dying sounds a bit more complicated than I thought!!!*

## **Understandings and perceptions of the role of peer education**

- *Involves people with something in common learning together*
- *Can be done with individuals and with groups, as informal and as formal discussions*

# Immediate plans

- **Working with a community group**

*I plan to meet as part of a group to discuss the way forward*

*I hope to use what I have learnt and go forward with (community group)*

*I would like to participate within groups in my local area*

- **Finding a way forward**

*I would like to go away and re-read the information, think about the subject and look at how I can pass on information*

*I wish to find a way of working that matches my strengths and (more importantly) is judged reasonably effective*

- **Using it with family and friends**

*I hope to use it in my personal life, put it to family and friends*

*I will talk about the process of my dying with my family*

# Personal/ emotional implications: at one year

*"It is obviously a very delicate area and it gave me compassion ... a re-education as far as I was concerned because in my working life I was the person giving orders ... so it did educate me on getting down the people's level; I'm not up here talking down to them if anything I'm down here talking up to them and the training taught me to be more sympathetic with more compassion and I am very thankful for that" (Male Older volunteer, 12 months after the Programme).*

*"... on a personal note, I too have taken notice of what I've learned from here, and I've made all my arrangements, such is if I have to go. As I progressively get worse I might later on, hopefully a lot later on, have to go in a home because I don't have next of kin. And I have been out to talk, write down exactly what I want to know, [how] I want it done, so that for me has been a good thing as well, because I wouldn't know nothing about it had I not come here.... All I've got to do now is grow old gracefully " (Female older volunteer, six months after the programme).*

# Peer education activities

## At 4 months

- 21 people reported initiating a one to one discussion about end of life care.
- 7 people reported that they had either given, or planned to give, a talk or presentation to others.
- 2 people reported that they had worked together to arrange an 'information day' in their area.
- 14 people had sought out other relevant workshops or presentations to learn more about end of life care issues.

## 6- 12 months, and currently

- Those well embedded in a community group more likely to report success
- One subgroup gained funding to develop a resource portfolio
- Others taking part in local and national awareness raising
- Some found it difficult in spite of efforts
- Some had become ill or been bereaved: this stopped engagement.

# Two case studies

- *Older LGB group*

- began with their local support group, their friends and relatives

- extended to regional activities

- now (2010/11) have won lottery funding to continue

- gained support from national and local fora

- *Seniors forum*

- reported success in engaging at local level, because of direction of national policy

- then began to network nationally

- *I'll be quite frank, I certainly wouldn't have got as involved as I am if I hadn't have done it (the training). ... after the last training day we had a meeting we said well okay we'll go and meet these people and see what they're doing ... So we went and saw the hospice. We went and saw the PCT [Primary Health Care Trust]. We went and saw the Council. ... We literally pressed our PCT to get an (end-of-life care) strategy together ..; we said ...we're going to hold an information day and we will invite them to come and talk. So it pressurised them into having to have something ready (**Older volunteer, male, 12 months after the programme**).*

# Limitations

- A self-selected group of volunteers
- The evaluation of the programme depends on self-report data
- We don't know how peer education activities were received by peers
- We need some more funding to study outcomes of peer education in communities

# Discussion and Implications

- We tried to enable development on individuals' own terms/ situationally: '*an intervention in context*';
- Insights into mutual learning as a means to engage with a new health technology (ACP)
- Critical consciousness characterised by: *changes in personal style, awareness of new ways of learning; reflections on loss/ death; finding positive impacts in work/ life*
- Did not suit everyone and ability to sustain role varied

# Conclusions

- We have developed an acceptable training programme for volunteers who wish to be involved in raising public awareness of ACP issues
- Those linked strongly to community groups seem more able to develop and sustain peer education- 'identity' important
- Some volunteers were able access a wide network and 'catch' an important historical moment
- The personal impact of the training/ role is considerable
- Bereavement and illness may not be compatible with the role



A volunteer training programme about **Advance Care Planning**

# Acknowledgements

- With grateful thanks to all the volunteer peer educators who took a leap of faith in participating in this project.
- We gratefully acknowledge the invaluable help and assistance of the other members of the Peer Education Project team (Gary Bellamy, Amanda Clarke, Carmen Franklin; Merryn Gott, Muriel Richards, Caroline Sanders, Ivy Sharpe, Don Thompson and Maddie Welton).
- In addition, we are appreciative of the advice and support received from members of a project advisory group: Paul Cann, Age UK; Claire Henry, the National End of Life Care Programme; Jonathan Ellis, Help the Hospices, Professor Allan Kellehear, Bath University.
- One member of the advisory group was a service user, Andy Milward, who died shortly after the completion of the project. His passion in sharing with others his own experiences of illness and reflections on palliative and end of life care was inspirational.