VOLUNTEERS AT LIFE’S END - VALE IN THE COMMUNITY

AN EVALUATION

Sheila Markham, VALE Project Lead

Introduction

The aim of the VALE in the community project was to offer trained volunteers to act as companions to patients who were largely alone, in their own homes as the preferred place of death and in the last 72 hours of life. The volunteers were all either qualified health professionals, or had extensive experience of caring for dying patients; the sessions offered were almost exclusively during out of hours, with the patients being referred by either the GP or District Nursing team caring for them.

It was hoped that making end of life companions available to support and reassure patients and potentially, anxious family members or carers, would enable patients to achieve their preferred place of death, and to avoid inappropriate or unnecessary hospital admissions. Significant numbers of people who die in hospital have no medical need to be there and might have been cared for elsewhere had appropriate support been available. The National Health Service (NHS) is increasingly under pressure for resources and acute bed availability; there is a stated goal that patients should be able to receive care close to or at home. A further factor is that a substantial number of complaints received by the NHS involve end of life care in hospital; reduction of this number must surely indicate improvement in end of life experience for patients and those close to them.

Following interest from the clinical commissioning group (CCG) a large group practice in a rural market town was approached, and agreed to participate in the pilot. The practice has 26 GP members, and works with a single District Nursing team; the patients live both in the town and in surrounding rural villages.

The evaluation planned to capture quantitative data which includes numbers of volunteers appointed and trained, numbers of patients referred, hours of companionship given by the volunteers. Also data
from the practice and CCG which gives number of deaths, place of death and achievement of death in place of choice.

Qualitative data was also collected, by means of questionnaires to volunteers at the beginning of the training, evaluation of the training programme, use of reflective diaries, and questionnaires to volunteers and to family members, if appropriate, and to referrers at the conclusion of the pilot project.

The entire project was funded for one year, by grant from the St. James’ Foundation, through Hospice UK.

The project aimed to examine the use of trained volunteer companions at the end of life in patients’ own homes, the impact of this on the volunteers, and the need for such a service.

BACKGROUND

The current perception in end of life care is that the majority of people would prefer to die in their own home (Gomes, et al 2013,) That an individual should be able to choose where they die has become a quality marker in end of life care (Department of Health, 2009). However, the majority of people still die in hospital (ONS in NeoLCIN, 2014).

This figure is predicted to rise over the next fifteen years, with deaths at home falling, while care home as a place of death also rising. (Gomes and Higginson, 2008). There is much literature concerning choice of place of care and of death; however, there is substantial variation in both the quality of some of the evidence, and in the content, as, inevitably, much of it rests upon the views of healthy adults who must predict their future feelings, and who, naturally, wish for a speedy and dignified death. (Pollock 2015). Most of us will die in old age, with co-morbidities and degenerative conditions which will require support over months or possibly years (Leadbeater and Garber, 2010).

What is not clear is the separateness of choice between place of care and place of death, and how the former is not necessarily also the latter. Conflating where people die with quality of death is likely to inhibit development of good end of life care – living well and dying well are
very different. ‘Where’ had become a proxy for ‘how’ (Wood and Salter, 2013).

The End of Life Care strategy emphasises the opportunity for choice at the end of life, with emphasis on home being a quality marker. Hospital is considered to be fraught with the risk of poorer care than could be delivered in other care settings (ONS, Voices Survey, 2014) Evidence shows that patients who have an advanced care plan, discussed with professionals and relevant family or significant potential or actual carers, have a greater chance of achieving both their preferred place of care and of death. (Maimoona et al, 2015)

This, however, could be changing. NHS England’s document ‘Actions for End of Life Care 2014 – 16’ states; ‘importantly, we signal a shift in focus from ‘place of death’ to the broader ‘experience’ of end of life care.’

Thus, effective advanced care planning – another pillar of the End of Life Care strategy, enhances the likelihood of patients dying in their preferred place (Gomes et al 2015) and can and should capture any changes to the decision made at the outset of the journey towards death.

The majority of patients who have a preference recorded nominate home as their preferred place of care – often assumed to be preferred place of death too, though they should be reminded that this decision can and ought to be revisited whenever they feel the need. (Capel et al 2011) CCGs support the national strategy promoting choice, which has also economic and resource implications for an NHS struggling with massive demand and underfunding.

The emerging evidence that preferred place of care is not necessarily the preferred place of death could be relevant to the findings of this small project which might demonstrate that providing home-based support at end of life is not a crucial factor for all patients. (Holdsworth et al 2015)

The grant bid was built on the premise that patients who lived alone were more likely to be admitted to hospital at the end of their lives, even if the preferred place of care was home. (Hanratty et al 2013) It was anticipated that the additional support provided by a volunteer
could prove influential in enabling the patient to remain in their own home. The other relevant factor came from the work of the ‘No One Dies Alone’ program, which originated at the Sacred Heart Medical Center, Oregon. (Clarke, 2001) This provides volunteers for in-patients who are dying, and have no one with them other than health care staff looking after them.

The VALE in the community project offered appropriately trained and supported volunteers to provide companionship and support to people who live alone, or to any family or patient needing extra support and reassurance. This would be available in the last 72 hours of life, and outside normal working hours – i.e., 6.00pm to midnight daily, and on Saturday and Sunday. These were considered to be times when additional support might be needed, as statutory services are either reduced or absent, and most befriending services also operate during the working day. Helping people achieve their preferred place of death, reducing inappropriate hospital admissions – and thus costs, reducing the number of complaints associated with end of life care (Parliamentary Ombudsman, cited in House of Commons 2014) were all given as pertinent reasons for the pilot project of Volunteers at life’s end – VALE – in the community.

Referrals would come from GPs, District Nursing teams and clinical nurse specialists in palliative care in the community. They would have clinically assessed the patient and judged the need to be for a companion, to be with them at a stressful and emotional time, to provide a calm, reassuring and supportive presence at the end of life. This offer would also encompass any family or significant other who might be present. Volunteers were recruited from health professionals, most of whom were semi-retired. All were keen to be able to spend time alongside a dying person, not being limited by time, and the need to carry out clinical tasks before moving on to the next patient. This was a companionate role, and strictly non-clinical; it in no way replaced any planned care from other agencies.

Successful use of VALE volunteers could enhance the patient experience at the end of life, and may help the bereaved family come to terms with their grief having been supported through the emotional ordeal of a loved one’s death.
The bid for project money anticipated working with the GP out of hours service. However, this covers a large rural county and a city with a very diverse population. The current out of hours service provider was experiencing problems and had been rated inadequate by the Care Quality Commission (CQC, 2015) and was thus deemed not to be in a position to work with a pilot project. The sheer size and scope of the area when considered with the time and resources allocated to the project necessitated selecting an area and potential partner likely to enable the development of the project within its resources.

A market town served by a single very large GP practice, with patients also in outlying rural villages and supported by a single district nursing team was within the CCG which had expressed interest in the project. The palliative care lead GP was approached and agreed to be a partner. The district nurse team leader was immensely helpful and enthusiastic. Both agreed that there was likely to be a need for such a service in the patient population.

Following advertising in community hospitals, GP surgeries, volunteer bureaux and the hospice shops, all in the target and surrounding area, ten volunteers were appointed. Eight completed the training – mostly nurses, with one semi-retired GP and one very experienced health care assistant, already an experienced volunteer with the hospice home visiting service.

The use of these volunteers in working with patients and families at the end of life, in a discrete small town and rural area will be evaluated.

Can trained volunteers be asked to stay alone and support patients and possibly anxious or distraught families, in their own homes - this during the last 72 hours of life, and in the “out of hours” periods? Is there a need for this service in this locality?

**METHOD**

Ten people requested application packs, nine were interviewed and appointed and 8 completed training. At the end of the first 3 months, 2 volunteers withdrew, for personal or professional development reasons. (See attrition chart, Appendix 1)
A steering group was established, which included members of the hospice senior management, the managers of the home visiting service and of outpatient services, the lead GP for palliative care, district nurse team leader, data manager from the CCG, and a volunteer who had also been a carer for a deceased relative.

Referral criteria were developed, and circulated to the steering group for comment. A project leaflet for patient information was created and scrutinised by the hospice reading panel. The hospice referral form was adapted to include an environmental risk assessment – considered essential as the volunteers may be visiting a lone patient late in the evening, possibly in a remote rural area.

A protocol was developed for lone worker protection, with advice on personal safety, and the need to telephone the hospice ward when they had left the patient’s home. A form was created for ward staff, which confirmed that the volunteer had phoned in, and with emergency contact details for the project lead/manager in case a volunteer should not make a call at the end of the visit, and be in potential danger.

At the outset of the two day training the volunteers were asked to complete a questionnaire. This asked for views about motivation, aspirations of what to give and what might be gained, the attraction of the role and of the organisation. (Appendix 2)

All the volunteers came from the area of the pilot, and wanted to work in that locality, or the nearby small town.

The volunteers were asked to complete a weekly availability chart for the following week. All were aware that being available did not equate with being called to work. All preferred to fill in slots on a weekly basis, as their lives were busy, and they were not necessarily free at the same time each week. This system was easily adopted and worked well; the Home Visiting service coordinator sent out emails at the beginning of each week, and later that week furnished volunteers, project lead and manager with the following week’s volunteer availability chart.

The volunteers were also asked to keep a reflective diary, in which to record their feelings and experiences. They received some guidance on this from the palliative care research consultant during the training,
including reassurance that any comments used in the evaluation would be anonymised, having been accessed only by the evaluator.

Regular support meetings were held, and much appreciated by the volunteers. They also had access to the project lead and Home Visiting service manager by email or telephone during the working week, and had both individuals mobile telephone numbers.

The project was launched to the GP practice by the project lead attending a regular palliative care meeting, to explain the project aims, discuss any queries and answer questions. Each individual doctor was sent a copy of the referral criteria, referral form and project leaflet. These were also made available electronically.

Several District Nursing team meetings were attended by the project lead, following a similar format. All potential referrers were made aware of the project contact details, and encouraged to contact the lead to discuss the appropriateness of referrals if they were at all unsure.

**FINDINGS**

The sole GP practice in a rural market town, serving also surrounding villages, had a population of 35,700 patients.

Annual deaths at home 14/04/2015 – 14/04/16 = 110

Annual deaths in hospital 14/04/2015 – 14/04/2016 = 114

All patients have a recorded place of death – reported by the GP practice.

It has not been possible to demonstrate achievement of preferred place of death. (data from data manager, GP practice)

The sole referral came from this practice: the preferred place of death was home and was achieved.

**DISCUSSION**

Thus 8 volunteers were trained and eager to work with patients - and nothing happened.
As the project was of such short duration, after 3 months without a referral, a decision was taken to widen the catchment. The project was made available to the neighbouring small market town, situated at the periphery of the CCG area. It was more difficult to access the GPs in this area, but one of the volunteers had a long history with the practice and continued to work with it in locum positions, so was a valuable 'inside informant'. The concept of the project was received enthusiastically by both the GP practice manager and the district nursing team. Both were supplied with the information in hard and electronic forms.

And still nothing happened. The project lead revisited the potential referrers where they were accessible – this being the district nursing teams. The GPs were difficult to access, even via regular meetings. Updating and reminding emails were sent to the practice managers who were the gate keepers.

Both district nursing teams articulated that they felt appropriate patients for referral would be more likely to be identified by themselves because of the frequency of visits and knowledge that they built up regarding the terminally ill patients on their caseloads.

In discussion with the teams during one of the frequent visits the nurses stated that the offer of a volunteer at the end of life was made on several occasions, but refused by the carers. Was this because introducing a stranger at this highly emotional time was too great an ask for the carer, if not the patient? Previous responses to a similar project, run in conjunction with a small group of nursing homes (Faull 2012) found that both patients and volunteers felt sufficient time to build a relationship with the dying person was beneficial to both.

Because of the paucity of referrals, discussion was initiated with the hosting hospice, to consider the use of the volunteers with inpatients who might benefit. Several years previously, a speaker from abroad had suggested that lay volunteers could help by sitting with dying patients. This had not been agreeable to the hospice staff, who considered it a matter of principle that someone was always with a patient at the end of life. However, increased complexity of patients for symptom management or end of life care, plus great demand on bed occupancy
resulted in volunteers as end of life companions being viewed as an enhancement of care for the patients.

The VALE scheme was promoted to ward teams through regular team meetings and handovers. Hard copy information was left with the team leaders for their information folders and was sent electronically.

At the same time, the project was made available to the two community hospitals in the target area. Both had dedicated palliative care beds, which were used by the local GP practices. Both were visited several times by the project lead, who informed ward teams of the aims and goals of the project and left the essential information with them. All potential referrers were strongly encouraged to contact the project team, by phone or email, to discuss any patient whom they thought might fit the criteria, to discuss the appropriateness of the individual situation.

Along with this extension of potential target areas, the time scale of the last 72 hours was extended too. If the referrer judged that the patient had begun on the dying journey, even though the end may not have been imminent, the patient would have been eligible for support from a VALE volunteer. The criteria was altered to reflect this change and new information sent to all referrers, as an aide memoir.

At last! A referral was received from a District Nurse (also a project volunteer herself) The system for contacting the available volunteer and handing over the information worked smoothly, as did the mechanism for complying with the lone worker policy guidance.

The patient was visited as planned, the family were gathered, by the volunteer, to the bedside to be with him as he died. The volunteer then helped with practical details such as contacting the on-call doctor to verify death, and then the undertaker of the family's choice, to arrange for the removal. When she felt that they were supporting and comforting each other, the volunteer left them, with thanks and gratitude expressed by all the family members. This was repeated to the District Nurse the next day when she made the bereavement visit, along with praise for the scheme that made this possible.
The volunteer made contact with the project lead the next morning, to say that she felt all had gone well, and that she had felt useful and valued, and was able to use her considerable clinical skills to identify that the patient was at the point of death, and get the family to the bedside as they had told her they wanted to be. She expressed satisfaction in being able to stay with them to help and reassure, and allow them to express their thoughts about the deceased and much loved family member, without having to rush off to another patient.

Why were there so few referrals?

It has been suggested that importing a stranger at the end of life is too abrupt.

However, when the criteria were widened to include patients who might need support though not at the end of life, this did not increase the uptake.

In the rural and agricultural area in which the project operated, families appeared to rally round to support the dying person and each other, refusing the offer of a volunteer. There is evidence to suggest that areas of severe deprivation may have greater need of such schemes (NEoLCIN 2012)

When the project lead addressed various professional teams and meetings to make them aware of the VALE in the Community project it was met with enthusiasm, and welcomed as a needed service. On most occasions the group spontaneously identified recent patients who would have benefited from the service, or consulted each other about patients on their current caseloads who might welcome the presence of a volunteer. The anticipation thus engendered in the project lead was alas, short-lived, as the proposed referrals failed to materialise.

Were there too few individuals who filled the project criteria? Was the support that people choosing to die at home already had sufficient for their needs?(Holdsworth et al 2015).

In an effort to elicit some opinion as to why patients were not being referred a simple questionnaire was emailed to all potential referrers or those managing the teams (appendix 3) No replies were received.
WHAT DID WE LEARN?

While there was much anecdotal comment, there was no hard evidence that the need for Volunteers at life’s end was a local need. There is published evidence that schemes offering support at the end of life organised by hospices have not enhanced the achievement of home as a preferred place of death. Having available support has not increased the slender chances of a person living alone to achieve death in their own home either. (Holdsworth et al 2015,)

Semi or fully retired health professionals who volunteered have a real passion for end of life care. They wanted to use their experience, still have a role, feel useful and make a difference. Their satisfaction was anticipated to come from being able to spend time with a patient, not having to move on to fulfil other, clinical needs.

This is a large and rewarding cadre of potential volunteers, who have much to offer patients who have life-limiting illness, and whose needs are often successfully met by trained, compassionate non-clinicians.

Volunteers are generous with their time in the service of patients; however, they are not keen to spend it travelling distances to areas where they are not familiar. Thus, volunteers would need to be recruited for discreet areas of the county, probably where they know the geography, characteristics of the locality, and feel comfortable, particularly outside the hours of daylight.

RECOMMENDATIONS

The additional training undergone by VALE volunteers can be offered to interested Home Visiting volunteers, to enhance the patient’s experience of a supportive befriender, who will be with them to the very end of life.

Thus a comprehensive home visiting service could be available to patients, when full assessment of need and wishes can be aligned to the skills and interests of particular volunteers who have received extended training.

Harnessing the passion many retired health professionals have for palliative and end of life care can enable the development of additional roles in both the community and hospice setting. Further training in
rehabilitation and promotion of independence may well be an area of interest for some, alongside the companion experience.

It may be worth examining what ‘Death Doulas’ do; some of the services they offer fill gaps in available palliative care services, and could well be the remit of trained volunteers, particularly those with a health background.

Once recruited and trained, volunteers are anxious to put their knowledge to good use. Not being used for long periods risks disenchantment and disillusion, as well as the concern about becoming de-skilled.

CONCLUSIONS

The VALE in the Community project which offered trained volunteers to be companions at the end of life had little uptake, despite increasing both the target population and the geographical area.

There could be several reasons for this: the newness of the scheme, expecting busy health professionals to remember yet another option when pressed for time. Ensuring that every potential referrer was aware of the project, and knew how to refer a patient – often an issue when so many doctors and nurses now work part-time.

Families and carers may dislike the idea of introducing a stranger at such a sensitive and emotional time. They may also want and need to do everything they can to manage to support the dying relative to achieve their preferred place of death. That the target area is settled and not subject to deprivation on an above-average scale may be influential.

There are health professionals who are keen to volunteer their time and use their great experience and skills in the service of dying patients. Making this concept part of the experience of end of life could have rich rewards for all parties.
REFERENCES


Care Quality Commision – CQC- Quality Report 2015 Leicester City, Leicestershire and Rutland. 14/05/15

Clarke S 2001 NODA Program Sacred Heart Medical Center. Peacehealth Oregon, USA


Faull C 2012 VALE Service Evaluation of the Pilot of a New LOROS Service in Care Homes. LOROS Hospice


Higginson I, Sarmento V, Calanzani N, Benalia H, Gomes B 2013. Dying at home – is it better: A narrative appraisal of the state of the science. Palliat Med December 2013 vol.27 no.10 918-924


House of Commons, The Health Committee. End of Life Care fifth report


National end of life care INTELLIGENCE NETWORK – NEoLIN analysis of ONS Mortality data What we know now 2014 Public Health England


Pollock K 2015 Is Home always the best and preferred place of death? BMJ 2015;351:h4855

Wood C, Salter J 2013 A Time and A Place. Sue Ryder, England
Appendix 1

VALE IN THE COMMUNITY

1. Recruitment prior to training
   • Number requesting application pack 12
   • Number applying 10
   • Number recruited 9

2. After training, before working on project
   • Number not completing training 1
   • Reasons for leaving training: After interview, no response to email or telephone contact, did not attend known training date.
   • Number completing initial questionnaire 8

3. Three months after project going live
   • Number of volunteers who have visited patients 0
   • Number exiting project 2
   • Number active but not yet used 6

4. Six months into project
   • Number of volunteers who have visited patients 1
   • Number exiting project 2
   • Number active but not yet used 5
   • Number of patients visited 1
   • Number of referrals 1
   • Number of referrals unable to respond 0
Appendix 2

VALE IN THE COMMUNITY

INITIAL VOLUNTEER QUESTIONNAIRE

At commencement of training programme.

Please answer these questions as fully as you are able. All this data will be anonymised when used in the reporting.

1. What motivates you to volunteer?
   *A passion for end of life care, feel useful and make a difference, use experience, give back and contribute*

2. What do you hope to give by volunteering
   *My experience, peace and comfort to patients and families, time*

3. What do you hope to gain by volunteering?
   *To still have a role, be useful, make a difference, time to be with a patient, share something significant, help and support*

4. What attracts you to this particular aspect of care?
   *Passion for end of life care, use of experience, contribute to community, make a difference to a neglected population, clinical role gives insufficient patient contact time,*

5. Why draws you to working with LOROS?
   *The reputation, value the work and research of the organisation*

   *Be part of the organisation*
Appendix 3

VALE in the COMMUNITY - a LOROS project

The VALE in the Community Service is a project and is offered to anyone whose preferred place of care at the end of their life is in their own home, in a community hospital or in LOROS hospice. Some patients do not have any family or significant other people to be with them at this time. Patients who live alone, have no family or whose families live at a distance are likely to benefit from the service. However, if the patient does have family present, the volunteer will support them, offering a calm, reassuring and supportive presence. VALE volunteers are trained to be companions for a dying person. The project aims to ensure that patients in the last hours, days or even weeks of life are given the support that they need.

The volunteers are not involved with any clinical or personal care for the patient, or the giving of medication. Their role is to be a companion to someone at the end of life. If the patient needs any nursing or medical intervention, the volunteer will contact the appropriate service, or ward staff, just as would a family member or friend.

A volunteer will be asked to visit a patient by either the GP, district nurse or Macmillan clinical nurse specialist, or member of the ward team. Volunteers usually visit patients outside normal working hours; this would be between 6.00pm and midnight and during the day on Saturday and Sunday.

- Are you aware of this service? Yes/No
- Have you referred any patients to this service? Yes/No
- If no, what were the reasons?
- Do you think that this service as a permanent option would be useful to you and your patients? Yes/No
- Any comments you would like to make regarding this pilot service?

For more information about this project please contact Sheila Markham, Project Lead; sheilamarkham@loros.co.uk or Andrew Lowden, Home Visiting Services Manager; andrewlowden@loros.co.uk or by telephoning 0116 231 8470 where the team will be happy to answer any questions or discuss referrals with you.