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Confidence in "end of life" care: developing and piloting an educational pathway for community nurses

Introduction

All individuals approaching the end of their life are entitled to high quality competent and compassionate care which is respectful and sensitive (National End of Life Programme (2011). End of life care (EoLC) is a term that has many varied interpretations, however intrinsically it includes physical, emotional, social and spiritual care that is required at any time in a person's life when their death or mortality is an issue (Froggatt et al 2006). The transition from palliative care to end of life care can be complex for staff (National Council for Palliative Care 2006**).**

Patients have the right to access high-quality palliative care services and should be enabled to exercise choice about their preferred place of care at the end of their life (National Council of Palliative Care, 2010). EoLC services should support people to live as well as possible until their death. Despite successive policy drives to improve the quality of EoLC (DH, 2008, 2007, 2010, 2011) substantial inequalities in how and where people die still exist. A large gap exists between where people prefer to die and where they actually die (Gomes et al 2012). Gomes et al (2012) also highlighted an increase in home deaths from 18.3% in 2004 to 20.8% in 2010.

District and community nursing staff deliver day to day 'generalist' nursing care to people living in their own home and it is acknowledged that district nursing teams play a vital part in caring for palliative care patients (Walshe and Luker 2010, Disler and Jones 2010). Indeed nursing staff are described as the lynchpins of community palliative care (Griffiths, Ewing and Rogers 2012), with both the volume and complexity of this work increasing over the last decade (Adamson and Cruikshank 2013, DH 2013, Queens Nursing Institute 2006).

In 2001, as part of the NHs Cancer Plan, the Department of Health launched a three year national education and support programme on the principles and practice of palliative care (DH 2001). By March 2004 some 1,700 district nurses (DNs) had participated in education programmes across England. A mixed methods evaluation of these educational programmes (Shipman 2008) reported that almost three quarters of respondents felt palliative care provision had improved, implying an increase in both confidence and competence. Some respondents, however, felt that they were not as knowledgeable or skilled as they had previously assumed and their self-confidence had been dented.

In 2008 the Department of Health produced the End of Life Care Strategy (DH 2008) highlighting the importance of developing workforce knowledge, skills and attitudes to improve the quality of EoLC. A year later common core competences and principles for those working with adults at the end of life were produced by the Department of Health working with the NHS End of Life Care Programme (2009). The seventh principle, relating to workforce development, recommends that both the organisation and the individual take responsibility for continuing professional development.

Caring for the dying can be stressful work particularly for nursing staff (Peterson et al 2010, Burnard et al 2008) generating complex feelings in nurses (Leishman 2008). Nurses therefore need to be offered development opportunities which enable them to identify and understand how they can continually improve their competence and confidence when delivering end of life care.

The educational pathway

The aim of the pathway was to increase both the confidence (through links to specialist nurses and mentoring) and competence (through access to a range of education /training opportunities) of participants in providing care for palliative care and end of life patients in the community.

The pathway took a learner centred approach underpinned by adult education principles and based within an ethos of practice-based learning (Steven 2009, Steven et al 2007, Lave and Wenger 1991). The pathway built on the 4 competency areas for end of life care identified by the Department of Health (DH 2008/9):

- Advanced care planning

- Communication skills

- Assessment and care planning

- Symptom management, maintaining comfort and well being

The project ran between February and November 2012 with a selection of 11 community nursing staff from across the area. All participants volunteered to participate and consented to be involved in the evaluation.

Ethics approval for the evaluation was obtained from the university ethics committee and NHS approvals were also obtained.

The pathway process (see Figure 1) involved participants linking with a mentor; undertaking a learning needs assessment; planning a course of action by choosing from a menu of educational activities; undertaking the activities. The 'menu' was developed to include both formal (accredited and unaccredited) and informal options and activities.

Training Needs Analysis

The 'NHS National End of Life Care Programme Training Needs Analysis (TNA) Questionnaire' (DH 2011) is described as a 'systematic gathering of information to find out employees' capabilities and to identify any gaps in the existing skills, knowledge and attitudes' (DH 2011 p2). The TNA was

developed via a national pilot and also forms the basis of an evaluation toolkit for end of life care learning events developed and used by the NHS and Nottingham University (Chady et al. 2012). Thus the TNA was deemed suitable and valid for use in this project.

The TNA covers overarching values and knowledge, and 4 EoLC competence areas:

1. Communication Skills

2. Assessment and Care Planning

3. Symptom management, maintaining comfort and wellbeing

4. Advance care planning

Mentors and mentees were also provided with documents offering guidance on the pathway process and opportunities and action planning.

Figure 1: Diagrammatic overview of the pathway
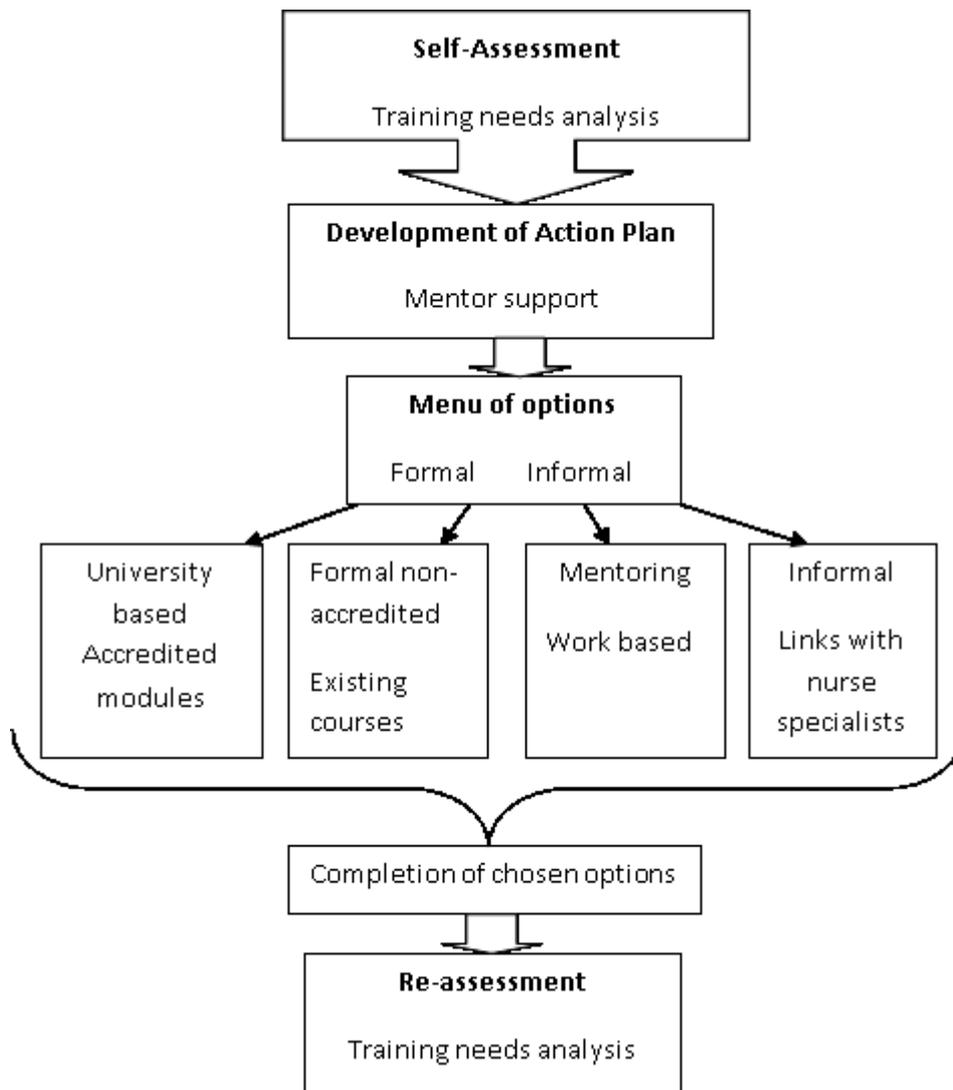
Participants

After receiving comprehensive information regarding the pathway and evaluation 11 nurses (6 DN sisters and 5 community staff nurses) from a range of employment and education backgrounds volunteered to participate. One team member acted as a point of reference liaising with mentors and participants throughout. Of the original 11 participants 3 withdrew (due to job/career changes and moves), leaving 8 to complete the pathway- these 8 are the focus of the analysis presented.

Experienced practitioners (i.e. palliative care specialist nurse (PCSN) and senior hospice nurses) from across the geographic area were recruited as mentors and attended two half day mentor preparation sessions. Mentor preparation was underpinned by the work of Connor and Pakora (2007) and Egan (2007). It was emphasised that the mentor relationship should be developmental and supportive and not a monitoring exercise.

Evaluation

In order to evaluate the pathway a mixed methods study was integrated into the project. A realistic evaluation (Pawson and Tilley 1997) methodology was employed allowing exploration of the context, mechanisms and outcomes.

Data collection involved:

• 	Interviews with nurse participants at three points

• 	One off interviews with mentors at the end

• 	Completion of the training needs analysis tool by participants at the beginning and end of the 'pathway' project,

• 	Collection of a copy of the participants' individual action plans.

Participants were also asked to consider keeping reflective notes on their educational experiences and to make these available to the researchers, however very few of those involved did so and data collected in this way was limited. Why few notes were kept was unclear and was not investigated, but may have been linked to time limitations, uncertainty regarding what was required or what was meant by reflection.

Data collection: Methods and timing	Start Feb 2012	Middle	End Dec 2012	Total
1:1 Interviews; Nurse participants (3 did not complete the pathway)	11	8	8	27
Mentors			7	7
Training Needs Analysis questionnaire	9		7	16

Table 1 Data collection details

(1 participant who completed an initial TNA withdrew - this data has not been analysed)				
Action plans	6	2		8
Reflective notes			2	2
Learning Logs		2		2

Semi-structured interviews lasting approximately 30-45 minutes were undertaken with participants at three points during the project allowing for detailed exploration of:

•   Participants perceived needs and feelings of confidence

•   Their experiences of the pathway

•   Reflections on the experience

The first interview acted as a baseline with subsequent interviews allowing for any changes or developments to be identified, explored and tracked. Where appropriate issues raised by respondents were followed up and incorporated into subsequent interviews, allowing exploration of previously unidentified areas of importance (Silverman 2001, Kvale 1996).

TNA questionnaires were completed by participants at the start and end of the project. The questionnaire is not designed as a measure of competence but relates to learning needs and confidence, and has been used effectively as the basis of an evaluation toolkit for end of life care learning events (Chadry et al 2012).

 Self-assessment of skills and competence is a highly complex issue (Yeo, Steven and Pearson 2009), and although competence was not measured, using the TNAs before and after, and in addition to the interviews, was felt to offer further insights into the potential changes and developments.

Interviews were transcribed verbatim, anonymised and analysed using an iterative approach drawing on grounded theory principles of constant comparative analysis (Strauss and Corbin 1990). The NVIVO software package was utilised for coding by the researchers using thematic analysis (Silverman 2001).
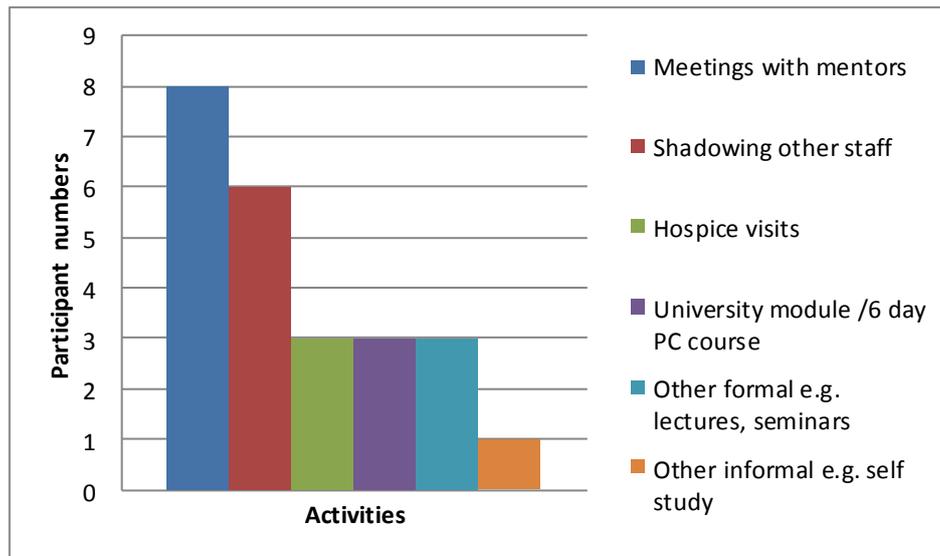
Findings

What they did

The TNA was seen as offering a structured way of considering confidence, personal strengths and weaknesses and training needs in relation to participants' roles in end of life care. Completion of the

TNA (either prior to, or during the first meeting with the mentor) was perceived as useful both by mentors and nurses, and acted as a focus for their discussions.

"It was a good document[TNA],it was very helpful, very insightful. (B2)

A range of activities were identified and undertaken by the nurses (see figure 2).

Figure 2: Educational activities undertaken as part of the pathway

Although mentoring formed a core part of the pathway, the organisation and frequency of meetings was at the discretion of those involved. Participants met their mentors between 2-5 times, with some spending a full day together and others a shorter period of time. All met their mentor at least twice. In general the mentor would plan, in collaboration with the nurse, a programme of educational activities aimed at addressing the identified training needs of the individual. Having someone to ask questions of, gaining reassurance and being offered support were seen as valuable in building and maintaining confidence in practice and was a key benefit of having a mentor.

Three participants made visits to hospices, with duration of visits varying between a full day, a half day or visiting solely to observe a ward round. Six participants shadowed specialist palliative care staff; these episodes ranged from a few hours to several days. Visits and shadowing were rated very highly by those interviewed and felt to offer participants opportunities to both observe the practice of experienced colleagues and engage in discussions about the care provision and planning.

Feelings of confidence

The TNA questionnaires asked *'What EoLC training do you feel you need to increase your confidence and competence?* and required the nurses to answer a series of statements by choosing to strongly agree, agree, disagree or strongly disagree. While responses were predominantly positive it was noticeable that 'disagrees' or 'strongly disagrees' were recorded for:

- All statements in the sections on communication skills and symptom management, comfort & wellbeing

- 4 out of 6 in the section on assessment and care planning

- 5 out of 6 in the section on advance care planning

- 3 out of 5 for overarching values and knowledge

Thus participants identified some feelings of low confidence across the entire range of areas of related to end of life care (EoLC).

Low levels of confidence were expressed in relation to communication skills, where 4 out of 8 nurses reported disagreement (1 strongly) with statement 1b and 1d (see table2). Furthermore for every statement there was some level of disagreement indicating that some aspect of communication appeared to be an area of low confidence for at least one of the nurses.

Table 2 : Responses to communication skills section of the TNA

Statements in the communication skills section of the TNA Responses at the start and end of the pathway by question		Disagree/strongly disagree	
		Pre	*Post*
1a	I feel confident to develop and maintain communication with people at the end of life, their families & others involved in their care about matters or situations related to end of life care	3	0
1b	I feel confident to listen to and talk with a dying person about issues surrounding their care and their death	4	1
1c	I feel confident to listen to and talk with friends and relatives of a dying person about their issues and concerns surrounding care at the end of life and death	2	0
1d	I feel confident to provide information and support about end of life in a range of formats, including written and verbal, as appropriate to the circumstances and the situation	4	0
1e	I feel confident to work with individuals, their families and friends in a flexible and sensitive way that demonstrates awareness of the	1	0

	impact of death, dying and bereavement.		
1f	I feel confident to recognise and respond to any variation over time, in individuals', their families' and friends' priorities.	2	0

The responses were similar for the section relating to symptom management, comfort & wellbeing (see table 3). However it is noticeable that the highest number of nurses expressing low confidence did so in relation to statement 3d. On inspection this statement can also be viewed as relating to communication issues i.e. giving advice and discussing anxiety. This perhaps highlights a central and difficult issue in EoLC – that of knowing how, and feeling confident to, communicate effectively and sensitively with service users and their carers and families (Charalambous 2010, Andrew and Taylor 2012).

Table 3: Responses to symptom management, comfort & wellbeing section of the TNA

Statements in the symptom management, comfort & wellbeing section of the TNA		Disagree/strongly disagree	
Responses at the start and end of the pathway by question		*Pre*	*Post*
3a	I am confident about helping an individual with their pain and other symptoms.	3	0
3b	I understand and can advise on coping strategies and therapies other than drugs to help people cope.	5	0
3c	I am confident to support a person in distress	2	0
3d	I am comfortable discussing a person's anxiety about the dying process and what will happen, be that the individual who is dying, their friends or family	4	2
3e	I am confident that I am able, in partnership with the individual, their family and friends, to develop, implement and monitor an EoLC plan which will meet the needs of the individual.	3	2

These findings are also borne out in the interviews, where participants identified a lack of confidence both in themselves and others in relation to communication and support.

> *'They [staff nurses] don't always feel that they have the confidence to do... Do more of the talking and the support side (A1)*

Some expressed a lack of confidence in dealing with "*difficult questions*" and specific situations including spiritual or psychological support. This lack of confidence was still present in the second interviews and in reflecting upon their perceived inability to communicate effectively participants used terms such as "*clumsy*", "*not streamlined*" or "*making a right mess of this*". However results from the post pathway TNAs showed an overwhelming movement towards 'agreement' and therefore higher levels of self-confidence, with only a single 'disagreement' recorded (see tables 2 and 3). In the final interviews participants reconfirmed communication as having been "*an issue*" but emphasised feeling more confident. Many described the power of learning about communication and symptom management from observing others (e.g. mentors, clinical nurse specialists, hospice staff), from talking with mentors and sometimes from undertaking other study (e.g. university).

> "*I had, an issue…with communication…But I think watching [mentor] and listening to the way she speaks to people… I feel a little bit more clued up …I think I've sorted the things out "(C8)*

There was an overwhelming sense of the pathway experience having been beneficial as one participant sums up,

> "*…It's been absolutely wonderful.. [the pathway] helped me look at where I was, and reflect and evaluate where I want to be and how I can get there. ..To do something about it and look where I can get the knowledge and skills from. So I think that it's been a really, really good experience*" (C4)

Although participants engaged in a range of activities and felt they had learned much and increased their confidence, a wider issue regarding access to educational and development activities emerged.

Legitimisation of educational activities

Getting time out of practice to meet mentors or undertake learning activities proved difficult and was often linked to workload pressures. One senior nurse spoke of her frustration of not being able to participate fully in the pathway nor attend meetings set up by her mentor. Such situations were often perceived as outside the nurses' control, for example influenced by staff sickness and the absence or limited availability of appropriate bank staff cover. Most participants encountered problems arranging or sticking to mentoring meetings, but found ways to get together even if meetings were not regular or required persistence on both sides.

> "*...we've both had quite busy schedules, so that's been difficult...getting as many regular meetings as we would like*". (B2)

Some felt it important to overcome difficulties rather than allow work commitments to continually impinge. One nurse described how a colleague urged her to continue with her meeting despite work commitments, while another described how the perceived benefit of being involved, both for the individual, their colleagues and ultimately the service users, was seen as outweighing workload pressures.

> "*We are low on staffing levels but, .. you just explain why you're doing it, how it's going to benefit where I'm working – not just for me, but for me as a Band 6 supporting Band 5s and developing them. The more knowledge I've got, the more I can support them and it's developing a future work force*" (B4)

Whilst it was recognised that set meeting times might not always work, it was suggested that some regular protected time may be beneficial and allow optimal use of available time. Where mentees were given protected time this was viewed as beneficial.

> "…she seemed really positive and excited that she was going to have some protected, definite time to be able to go and engage with stuff" (M10)

Interestingly, being released to attend modules delivered in a higher education setting appeared to be given greater credence than being given time to meet with a mentor.

> I think it's really difficult for people to assign time for meetings and study, that's not actually formalised – where you're not attending a classroom. And I think if someone is carrying a busy caseload, it tends to be the case load comes first. So the [pathway] is, sort of, second. Where if you have to attend a classroom at a certain time…" (M2)

Throughout the project it emerged that being involved in the pathway project had in effect legitimised participation in educational activities- be they formal (e.g. university modules) or informal (e.g. shadowing or hospice visits).

> "It's been brilliant because…It's given me the courage and…Well, sort of the reason to be able to go to the sister or a palliative care nurse or whoever, and just say "Oh can I do this because I'm on this palliative care research project" And I could have done all of these things before, but I probably wouldn't have put myself forward because I wouldn't have had that, kind of, extra reason to be able to say, "I'm in this scheme"…I think that it just gave me a, sort of,…a bit more of a reason to be able to feel that I could ask for things." (C5)

Thus the formal status of the project and its backing from the managers and the NHS Trust appears to have legitimised or sanctioned engagement in the activities offered. This perhaps indicates a need for greater visibility of managerial backing for such educational activities.

Discussion

Organisations are required to take responsibility for workforce development (DH 2008), with core competencies for the delivery of high quality end of life care available (DH 2009). A new vision for community nursing aims to ensure services have the right staff, with the right skills in the right place (DH 2013). The drive to have a competent workforce is apparent, although how nursing staff attain and maintain the necessary competence and confidence is not. The educational pathway reported in this paper offered community nurses a range of opportunities with the aim of increasing confidence and competence in end of life care. However this pilot study has limitations which require consideration. The pathway aimed to enhance both confidence and competence, but did not measure 'competence' in terms of skill performance or knowledge increase. Although participants reported a clear increase in their confidence in end of life care we cannot tell if, and for how long, such an increase may last. Furthermore, participants may have been those enthusiastic about EoLC and this together with the potential for participants to try to 'please' the interviewers; small sample size; and limited project duration, limit the generalisability of findings.

Notwithstanding the limitations we found that using the Training Needs Assessment tool, coupled with the action planning document as part of the pathway offered a valuable occasion for participants to explore their educational/training needs and possible ways forward. At the start of the pathway communication emerged as the main area of low confidence, spanning both communication skills and elements of symptom management. However the evaluation indicated a clear increase in confidence over the course of the pathway with participants learning and gaining reassurance from experienced colleagues. It is recognised that communication is fundamental to EoLC (DH 2011) and confidence in initiating conversations is crucial to delivering care tailored to individuals needs and wishes (Andrew and Taylor 2012, Sherwin 2011). Various communication skills courses exist or have been piloted, but many take place well away from clinical practice or focus on cancer (Barnes et al 2012, Andrew and Taylor 2012, Turner et al 2011), thus perhaps making them hard to access and harder to relate to personal practice experience. Indeed concern has been expressed regarding a need for greater access to developmental opportunities for community nurses in relation to communication in EoLC (Sprinks 2011 Charalambous 2010) and this seems borne out in our study.

While nurses in this study sometimes struggled to access opportunities, due to workloads and staffing issues, the pathway project legitimised their engagement in developmental and educational activities. Although we are unable to say if participants did more training when compared to their peers, their remarks regarding 'legitimisation' would seem to suggest this was the case. Backed by the NHS Trust the project was seen as giving credence to requests for time to meet mentors or attend sessions or visits. Sprinks (2011 p7)acknowledges these difficulties suggesting 'Communication training on end of life care is available, but ensuring staff have support and time set aside by employers to do the training is a problem'. However without the right education, development and support, staff can find delivering end of life care overwhelming (National End of Life Care Programme 2011 p8), while staff who are confident and competent in their role can benefit from increased morale and job satisfaction (Charalambous 2010).

The nurses involved in this educational pathway chose to engage mainly with mentoring and shadowing/visiting activities which offer convenient access to specialist knowledge and practice within a busy work schedule. While the research interviews may have themselves acted as a 'support' mechanism, participants felt they gained much from observing and talking to more experienced colleagues. This concurs with previous studies indicating that experiential learning (Kolb, 1984, 1988, Kemeny et al 2006, Yardley et al 2012), engaging in communities of practice (Andrew et al 2008), and direct contact with the reality of practice (Steven 2009, 2013) are powerful educational tools. Furthermore mentoring and clinical supervision have been shown to offer numerous benefits which cross the personal practice interface (Charalambous 2010, Steven et al 2008, and Oxley et al 2003). Indeed Charalambous (2010 p14) suggests that collegial support is needed in EoLC provision and that a 'well supported team will provide better care'. Such collegial support seems to have been gained by participants via the links provided by the pathway.

Conclusion

From this study it seems that providing community nurses with the chance to be involved in an EoLC educational pathway gave them development opportunities which were seen as 'legitimate' - suggesting nurses perhaps struggle to access such opportunities. Communication was a main area of

low confidence but increased over the course of the pathway seemingly facilitated by interaction with experienced colleagues. Mentoring emerged as a key mechanism, although making time to meet was a challenge for some.

It is clear from this study that the development of mentoring and support networks between community services and EoLC specialists holds potential and should be further investigated. A larger longitudinal study is needed to ameliorate the limitations and allow the duration of increased confidence and the extent of knowledge and skills gained to be thoroughly investigated. Notwithstanding the limitations it is clear that the nurses involved felt they had gained much benefit from participation in the pathway.

 Perhaps community nurses and their managers could lobby organisations for support in setting up such initiatives and greater access to opportunities. Good quality End of Life Care remains both a practice and policy driver whilst delivering patient care must take priority within the nursing workload, care needs to be delivered by confident, competent practitioners and that requires on-going educational and developmental support.

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