

Title Page

**Title**

Paramedics and Serious illness: Communication Training.

Word count – [3033] excluding title page, abstract, references, figures and tables.

**Title**

Paramedics and Serious illness: Communication Training<sub>2</sub>

**Authors**

Dr Nikki Pease

Consultant in Palliative Medicine and Clinical Lead Serious Illness Conversation Cymru

Velindre NHS Trust

Cardiff, UK.

E-mail [nikki.pease@wales.nhs.uk](mailto:nikki.pease@wales.nhs.uk)

Tel 07825004956

Dr Jenifer Jeba Sundararaj

Professor of Palliative Medicine

Christian Medical College Hospital

Vellore, India.

e-mail [jenifermugesh@yahoo.com](mailto:jenifermugesh@yahoo.com)

Mr Edward O'Brian

Macmillan End of Life Care Lead Welsh Ambulance Services NHS Trust

Serious Illness Conversation Cymru Clinical Team

e-mail [Edward.obrian@wales.nhs.uk](mailto:Edward.obrian@wales.nhs.uk)

Dr Joanne Hayes

Medical Director and Consultant in Palliative Medicine

Serious Illness Conversation Cymru Clinical Team

Marie Curie Hospice Cardiff and the Vale

Penarth. CF64 3RJ

e-mail [Jo.hayes@mariecurie.org.uk](mailto:Jo.hayes@mariecurie.org.uk)

Dr Edward Presswood

Specialist Registrar in Palliative medicine, Wales Deanery

Serious Illness Conversation Cymru Clinical Team

e-mail [edward.presswood@wales.nhs.uk](mailto:edward.presswood@wales.nhs.uk)

Dr Samantha Buxton

School of Management

Swansea University

Bay Campus

Swansea. SA1 8EN

e-mail [s.l.buxton@swansea.ac.uk](mailto:s.l.buxton@swansea.ac.uk)

## Abstract

### **Objectives**

The need to empower Ambulance Service staff at the point of delivery of end of life care (EoLC) is crucial. We describe the delivery, outcomes and potential impact of the Serious Illness Conversation project delivered to Welsh Ambulance Service Trust (WAST) staff. Over an 18 month period, 368 WAST staff attended face-to-face teaching, which included serious illness conversation communication skills, symptom control and 'shared decision making'.

### **Method**

Data collected from WAST staff was used to gain insight on perception of their role and challenges within the context of EoLC, understand the impact of teaching on self-confidence and identify impact on the wider service. A mixed methods approach was used for data analysis.

### **Results**

WAST staff view themselves in several important roles, acting as 'facilitators' to patient centred, seamless care, providing support, liaison between services and practical help in patient care at the end of life. The difficult questions and situations pertaining to EoLC were related to discussions on death and dying and managing expectation. The predominant barriers identified related to communication. Quantitative outcomes on the six communication domains indicate statistically significant improvement in self-assessed confidence. The overall impact to the wider ambulance service suggests a trend toward better use of resources.

### **Conclusion**

The perceived roles and challenges identified by paramedics can help in customising training objectives. The initial outcomes from the on-going project with WAST demonstrate increased confidence in handling communication issues. Initial successive surveys suggest teaching is making a real life impact on patient care at end of life.

## Objective

Annually in England and Wales in excess of 500,000 people die. This is forecast to increase by approximately 10% to 574,000 by 2030.<sup>1</sup> With an increasing elderly population due to advances in medical treatments and care and many patients living longer with life limiting illness, the need for good end of life care is ever rising. However the recent Parliamentary Ombudsman report on death and dying<sup>2</sup> identified that patients and relatives are frequently dissatisfied with end of life care; specifically that there were issues around poor communication, inadequate symptom control, poor care planning and a failure to recognise that patients were dying, with subsequent failure to address their needs. In response, many central governments developed end of life strategies, integral to which are building and developing appropriate end of life care skills within the generalist workforce in primary care, secondary care and in the community.<sup>3&4</sup>

In recognition of this and with the hope of increasing patient engagement in serious illness treatment options and outcomes the Serious Illness Conversation (SIC) Cymru project was launched in December 2016. SIC Cymru is an 'all Wales' project supported by funding from the Welsh Government End of Life Board. Although the main aim of the project was to develop a sustainable strategy for delivering SIC training to healthcare professionals and support staff in Wales (i.e.

communication skills training), the project also sought to improve symptom control and support clinical decision making for frontline WAST staff. To this end the project covered SIC (communication skills training), symptom control for palliative care patients and 'shared decision making'.

This article presents the outcomes of the Serious Illness Conversation project delivered to WAST staff.

## Method

Between December 2016 and June 2018 (18 months), 12 identical format, interactive teaching sessions across Wales were undertaken (nine to practicing paramedics and three to final year paramedic students). Each session included four hours of face-to-face teaching on three main aspects; (1) serious illness conversation/communication skills, (2) symptom control at the end of life, which included identification that a patient is likely to be at the end of life and administration of medicines for symptom control and (3) 'shared decision making', the process and application of shared decisions regarding patient care or management, whereby an experienced physician (usually from primary care or palliative care) provides telephone advice /support to paramedics at the patient's home.

The project taught a 'toolkit' for SIC supported by a breaking bad news strategy that would be immediately clinically applicable to front line staff. The communication skills toolkit used had been written by the clinical lead for the project, Dr Nikki Pease (with co-author Baroness Professor Ilora Finlay), and taught both nationally and internationally for over 12 years by Cardiff University.<sup>5,6</sup>

Over the 18 month period, 218 paramedics (approximately 10% of WAST paramedic workforce) and 150 final year university paramedic students attended the training.

Qualitative and quantitative outcomes were used to ascertain both the impact of the teaching and gain insight into ambulance staff self-perception of role and communication within end of life care. Qualitative outcomes were captured within the serious illness conversation teaching per se when at 3 separate fixed points during teaching, attendees were asked to write short statements on 'post-it notes' to answer each of the following questions.

With regard to palliative and end of life care,

- what is your role?
- what are your difficult questions/ situations?
- what are the barriers to communication?

For each question, attendees were encouraged to write as many statements as they wished. The written statements were immediately collected and typed verbatim to form 3 separate word documents that were independently analysed by two of the authors (NP and JJ). Thematic analysis was used to identify, organise and report themes found in the datasets. The predominant themes identified are presented within the results section of this article.

Impact of the teaching was assessed in two ways. Firstly, the immediate capture, via questionnaire of attendees self-rated confidence in six different end of life communication domains. The anonymous questionnaire employed a 10-point Likert style rating scale, on which attendees self-scored their 'confidence', 1-10, [1 is not confident at all, 5 is neither confident or unconfident and 10 is very confident] in 6 communication domains. The same questionnaire was administered pre and immediately post teaching (appendix 1). The questionnaire included assessing the respondents'

confidence in: breaking bad news to patients; breaking bad news to relatives; communicating to patients that their future might be uncertain; discussing ceilings of treatment; discussing Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and discussing advance care planning (ACP).

Secondly, in an attempt to assess the impact of SIC training on WAST patient care within the 'real world' setting two reviews of practice were undertaken. WAST patient care records (PCR) are in a paper format that allows both free text and tick box options of specific criteria. One such criterion is to tick the box indicating that a patient is considered by the attending paramedics to be for 'end of life care' (EoLC). This option exists to both enable the paramedic crew to manage the patient outside of standard guidelines and allow coding of that episode of patient care. WAST coding was used to search and retrieve PCRs for patients 'managed' as EoLC. (Table 2) The reviews were undertaken prior to start of SIC teaching and repeated after 18 months of the teaching programme running across Wales. A period of 18 months was chosen as this was the initial funded period of the teaching programme.

For both reviews the free text of retrieved PCRs were read by an experience senior paramedic to ensure only patients who were 'predictably end of life' were included eg. patients in whom cardiac arrest was the primary reason for the 999 call were excluded, as were patients in whom the free text suggested a diagnosis of a life limiting illness, such as cancer or heart failure, however, there was little else to confirm the patient was at the end of life.

As the report is an exploratory evaluation of education and a review of practice formal ethical approval was not required.

## Results

### Quantitative outcomes:

Over the 18 month period, 218 paramedics and 150 final year university paramedic students attended the training. Before conducting any analysis, the data was cleaned such that only data where both the pre and post confidence scores were completed were included in the final analysis. Therefore, from the original 368 responses, 298 complete responses were included in the final analysis.

Once the data contained only complete pairs, a paired samples t-test was undertaken in SPSS to determine the significance of the difference between pre and post mean values for each of the six EoLC communication domains. Using the frequency of each pre and post learning scores, a histogram of each communication domain was created. (Figures 1-6) This allowed for a visual presentation of the change in learning scores to support the statistical data from the paired samples t-test.

The mean pre and post teaching self-score of confidence, standard deviations (SD) and p-value in each of the six domains are presented in table 1

Ambulance staff self-scores of confidence in: (n=298)	Pre-learning mean	Pre-learning SD	Post-learning mean	Post-learning SD	P-value
breaking bad news (BBN)	6.68	1.48	7.97	1.16	<0.001

breaking bad news to families	6.61	1.47	8.00	1.14	<0.001
communicating to patients that 'The patient's future maybe uncertain'	6.03	1.63	7.63	1.38	<0.001
discussing ceilings of treatment	5.38	1.96	7.18	1.71	<0.001
discussing Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)	6.39	1.84	7.83	1.56	<0.001
discussing advance care planning (ACP)	5.34	2.05	7.46	1.66	<0.001

Table 1 Tabulated outcomes of ambulance staff confidence in communication skill domains.

### Qualitative outcomes:

The ambulance staff provided responses for three questions relating to their perceived 'role', their 'difficult questions/situations' and their perceived 'barriers to communication' within the context of palliative and end of life care. Totals of 493, 549 and 596 anonymous answers were collected respectively.

#### **Question 1. With regard to palliative and EoLC, what is your role?**

Of the 493 statements collected, 217 (44%) referred in some way to ~~the need around~~ communication and 111 (22.5%) directly or indirectly to a supportive role.

The three super themes identified in terms of ambulance staff role were, communication, support and 'practical medical care.'

The role of communication centred around three sub themes. Firstly around consultation with patient/ relatives or friends on breaking bad news, DNACPR, providing information, assessing need and guiding them. The second was liaison with other healthcare professionals e.g. district nurses, local palliative care teams and police. The third was to signpost and guide families on their next step, or help navigate the health care system. Verbatim responses include:

*"Keep patients and family informed of what's happening", "Ask relevant questions re any plans/decisions that have been made", "Signposting family to appropriate support services ie. Bereavement support".*

Many ambulance staff identified their role as one of providing support in terms of supporting patient's preferred place of care/death, respecting patient's wishes, "be advocates of maintaining dignity and respect" and be a support to the family as a "shoulder to cry on". Many responses indicated that ambulance staff are comfortable ascertaining expectation regarding a patient's healthcare and on-going management, discussing treatment options and preferred care setting with them. Exemplified by quotes: *"Discussing the treatment options with patient and family and respecting their choices", "Supporting family if unsure what to do now/next".*

The third super theme was their role to deliver practical help and medical care in terms of symptom control, confirming death and transport of patients to appropriate care settings, e.g statements such as: *"Treating symptoms; making patients comfortable and pain free as possible", "Providing support in medications; administer medications".*

Interestingly although ambulance staff saw themselves in the role of conveyance, their professional responsibility was clearly multidimensional.

**Question 2. With regard to palliative and EoLC, what are your difficult questions/ situations?**

Of the 549 statements collected 360 (65.6%) questions relating to death, dying, prognosis and expectation around these was the predominant theme. Ambulance staff indicated that they were often asked direct questions such as *“Am I going to die?”*, *“How long has he/she got?”*

The difficult situations were associated with DNACPR discussions and stopping futile CPR. It is not uncommon for ambulance staff to arrive at a patient’s home where the family/friends have started CPR on a terminally ill loved one. Negotiating appropriately stopping CPR was identified as a difficult situation. Other areas of challenge were handling conflicts in patient and family wishes or between family members, uncertainty of clinical outcomes and mismatch of expectations.

**Question 3. With regard to palliative and EoLC, what are your barriers to communication?** Of the 596 responses to this question, 546 could be subdivided to patient related (36.3%) and health care professional related barriers. Patient related barriers were predominantly physical barriers like ‘language’ mentioned in 75 (13.7%) of statements and patient’s ability to understand ‘*mental capacity*’, ‘*sensory barriers hearing/sight*’ and ‘*disability*’. Healthcare professional barriers related predominantly to lack of confidence in communication and handling the different emotions of patient/ relatives mentioned in 173 of 546 (31.6%) annotations. Exemplified by annotations such as: *“emotional situations”*, *“irate relatives”*, *“Finding the right words to explain”*, and *“feeling the need of not wanting to be that person giving bad news by not being too direct”*.

	Pre SIC teaching (184 PCRs) Sept 2015 - Mar 2016	Post initiation SIC teaching (223 PCRs) April 2017 - April 2018
EoLC patients (meeting inclusion criteria)	78	131
Conveyed to Emergency Department	30 (38%)	29 (22%)
Conveyed to alternative	0	10 (8%)
Emergency ambulance (EA) only	68 (87%)	88 (67%)
Rapid Response Vehicle (RRV) only	8 (10%)	22 (17%)
EA and RRV	13 (17%)	20 (15%)
Just in Case Medicines* administered	0	8 (6%)
Shared decision making documented	33 (42%)	94 (72%)

\*End of life/anticipatory parenteral medicines

Table 2. WAST patient care record outcomes pre SIC teaching compared to outcomes following initiation of teaching programme.

Discussion

The qualitative outcomes identified give insight into the self-perceived role of paramedics in EoLC, their difficult questions and barriers to communication. This information has already informed future SIC teaching with the integration of clinical case scenarios to emphasise specific areas identified e.g. patient asking ‘how long have I got?’, uncertainty of outcome and mismatch in expectations. It is hoped that publication of paramedics self-perceived roles within EoLC will act as a foundation for future collaboration and research.

The authors acknowledge that the pre and post self-scoring of 'confidence' are in reality surrogate indicators of outcome from communication teaching. The fact that in each of the domains there is a highly statistically significant increase in confidence suggests that communication skills teaching is useful to the clinical setting and attendees leave the sessions more confident. (Fig 1-6) What cannot be inferred is whether the improved confidence in communication is sustained, to what extent there is sustainability of learning and whether 'refresher' sessions should be offered?

To help ensure maintenance of skills and acknowledging that only 10% of WAST workforce were able to attend face-to-face teaching, a bespoke, free eLearning modular programme, which offers 4 hours of training with content similar to the face-to-face programme (communication skills, end of life care and symptom control) was produced. The modules are interactive with quizzes and video clips to demonstrate various aspects of the Serious Illness Conversation.<sup>7</sup>

In the six months since the eLearning launch in January 2018, in excess of 500 ambulance staff have accessed the modules, of these > 350 have completed the 5-module programme. The shortfall in staff completing the programmes maybe because SIC training is not yet mandatory. What is not known is to what extent the staff undertaking the e-learning are 'new' to the SIC programme.

Although the project team were keen to ascertain whether SIC teaching had any measureable real-life impact, the only system of data collection/retrieval within WAST to measure this were sequential reviews of practice across Wales. Although these reviews have inherent limitations, in that relatively small numbers of PCRs had the EoLC box ticked and were subsequently requested, there was consistency of process. The authors, therefore, feel comparison of pre and post initiation of SIC teaching adds valid outcome data (table 2) and indicates a significant change to clinical practice.

Results indicate both a reduction in EoLC patients conveyed to emergency departments plus a trend towards a more appropriate emergency response vehicle attending. Crucially a RRV normally has one paramedic on board and is not a 'patient transfer' vehicle whereas an EA has two ambulance personnel and intent is response and possible transfer. Dispatch of the most appropriate vehicle ensures not only better resource allocation but also a more timely response as RRVs are often 'on scene' quicker.

The increased shared decision making documentation suggests paramedics value discussing EoLC patients with doctors. An output from this project is how the shared-decision making process can be further supported to ensure appropriate lines of accountability.

The initiation of administration of parenteral EoLC medicines is interesting as although giving parenterally medication is within a paramedic's role, prior to teaching the data suggests that EoLC medicines were not administered. Whilst it is not possible to attribute this change solely to the teaching, the timing is highly suggestive that the project has influenced practice. Of note is that paramedic training is to administer parenteral medication intramuscularly or intravenously whereas palliative care prescribing of parenteral drugs is via the subcutaneously route. Teaching discussed the rationale for this difference and the role of shared decision making in patient management.

A significant limitation in interpreting the impact of the two reviews of practice are that the PCRs reviewed are not specific to those who attended SIC teaching, (either face-to-face or eLearning) but rather an all Wales outcome which may be due in part to factors outside of this project. The authors recognise this and therefore one of the major outputs of this study is the identification of the need for better methods of data collection.



During the teaching clinical obstacles were identified, for example the Joint Royal College Ambulance Liaison Committee (JRCALC) national guidelines stated that paramedics should not administer morphine to patient with a systolic blood pressure of <90mmHg.<sup>8</sup> Patients nearing EoL will frequently have low blood pressure. The course team, therefore, worked with the authors of JRCALC to review and subsequent amendment of the EoLC chapter, such that the guidelines now include specific guidance on shared decision making and align with elements taught within the SIC teaching sessions. This indirect yet positive outcome evolved through this project.

## Conclusion

Within the SIC teaching attendees were taught a simple six point toolkit for communication<sup>5,6</sup> and how such a toolkit might be applied to the clinical setting; that as healthcare practitioners 'we are not born good communicators and that it is a skill we can all learn, refine and develop' and importantly terms like 'advanced communication skills' are unhelpful as they lead healthcare workers to believe they may not have the skills needed to communicate with EoLC patients. It is interesting that teaching a 'toolkit of communication' can improve confidence not only in breaking bad news but also in other communication domains, which are often key stages to patients' care and management. Understanding the perceived role, challenges and barriers for ambulance staff in the context of palliative and EoLC can help to further refine training to make it appropriate and relevant.

Outcomes for the retrospective review of PCRs indicates a trend that the teaching has a positive real life impact in terms of administering anticipatory medications, location of conveying patients and 'shared decision making' (between paramedic on site and doctor, either the patient's General Practitioner or palliative medicine clinician).

The combined outcomes have been major factors in the development of a four-year WAST, Palliative Care Wales and MacMillan collaborative project. The collaborative project seeks to both identify better methods of EoLC data collection within WAST, which will subsequently be used to inform the EoLC aspects of any new WAST e-record and to develop seven (one for each Health Board) specialist palliative care paramedics through Wales.

NP led the project design, delivery, data collection, analysis and review/revision of the manuscript in light of the reviewers' comments. NP, JH, EP and E O'B each contributed to the design of the project, delivery of the teaching, acquisition, analysis and interpretation of the data. JJS contributed significantly to the design of the work, analysis of the qualitative data, draft of the original manuscript and review and revision of the manuscript in light of the reviewers' comments. SB contributed to the design of the project, drafting the work, quantitative data analysis and interpretation. All authors are in agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

There is no funding to report for this submission. There are no competing interests for any author.

## Licence for Publication

The Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, an exclusive licence (or non-exclusive for government employees) on a worldwide basis to the BMJ Publishing Group Ltd to permit this article (if accepted) to be published in BMJ Supportive & Palliative Care and any other BMJ PGL products and sublicences such use and exploit all subsidiary

rights, as set out in our licence (<http://group.bmj.com/products/journals/instructions-for-authors/licence-forms>).

Competing Interests: None declared.

## References

1. Office for National Statistics (2017)  
<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2017> [accessed Oct 2018]
2. Dignity in dying 2015 Parliamentary and Health service Ombudsman.  
[www.ombudsman.org.uk/publications/dying-without-dignity-0](http://www.ombudsman.org.uk/publications/dying-without-dignity-0) [accessed June 2018].
3. Palliative and End of Life Care Delivery Plan (2017)  
<https://gov.wales/docs/dhss/publications/170327end-of-lifeen.pdf> [accessed Sept 2018].
4. End of Life Care in England, a briefing paper (2018) Policy Institute for Public Policy Research.  
<https://www.ippr.org/files/2018-05/end-of-life-care-in-england-may18.pdf> [accessed Oct 2018].
5. Nicola Pease (2017) 'Communication to promote life near the end of life'. Chapter 49 In Kissane D, Blutz B et al. *Oxford Textbook of Communication in Oncology and Palliative Care 2<sup>nd</sup> Edition*. Oxford University press.
6. Simon Noble, Nicola Pease, Ilora Finlay (2010) 'The United Kingdom General Practitioner and Palliative Care Model' Chapter 57 in Kissane D, Blutz B et al. *Handbook of communication in oncology and palliative care*. Oxford University Press.
7. WAST end of Life Learning courses <https://wast.onclick.co.uk/> [accessed October 2018]
8. Joint Royal Colleges Ambulance Liaison Committee. 'UK Ambulance Services Clinical Practice Guidelines 2016' Class professional publishing. [www.jrcalc.org.uk](http://www.jrcalc.org.uk) [accessed October 2018]

Figure 1 Ambulance staff self-scores of confidence in breaking bad news (BBN) to patients.

Figure 2: Ambulance staff self-scores of confidence in breaking bad news to families.

Figure 3. Ambulance staff self-scores of confidence in communicating to patients that 'The patient's future maybe uncertain'.

Figure 4. Ambulance staff self-scores of confidence in discussing 'ceilings of treatment'.

Figure 5. Ambulance staff self-scores of confidence in discussing DNACPR.

Figure 6. Ambulance staff self-scores of confidence in discussing advance care planning (ACP)