



University  
of Glasgow

Johnston, B., Coole, C., and Jay Narayanasamy, M. (2016) An end-of-life care nurse service for people with COPD and heart failure: stakeholders' experiences. *International Journal of Palliative Nursing*, 22(11), pp. 549-559.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/132406/>

Deposited on: 2 March 2017

Enlighten – Research publications by members of the University of Glasgow  
<http://eprints.gla.ac.uk>

**Title: An End of Life Care Nurse Service for patients with COPD and Heart Failure: a qualitative study of stakeholders' perspectives and experiences**

**Authors**

1. **Professor** Bridget Johnston (Corresponding author)

Florence Nightingale Foundation Professor of Clinical Nursing Practice Research,

School of Medicine, Dentistry & Nursing,

College of Medical, Veterinary & Life Sciences,

University of Glasgow

57-61 Oakfield Avenue

Glasgow G12 8LL

Email: [Bridget.Johnston@glasgow.ac.uk](mailto:Bridget.Johnston@glasgow.ac.uk)

2. Dr Carolyn Coole

School of Health Sciences

University of Nottingham

Nottingham

NG7 2UH

e: [Carolyn.Coole@nottingham.ac.uk](mailto:Carolyn.Coole@nottingham.ac.uk)

3. Dr Melanie Jay Narayanasamy

School of Health Sciences

University of Nottingham

Nottingham

NG7 2UH

e: [Melanie.Narayanasamy@nottingham.ac.uk](mailto:Melanie.Narayanasamy@nottingham.ac.uk)

## **Abstract**

### **Background**

End of Life Care (EOLC) has historically been associated with cancer care, however demographic changes indicate that future provision must also cater for other long term conditions (LTC). An EOLC-LTC service, delivered by palliative care nurses, is currently being piloted in one area in the East Midlands with patients with cardiac and respiratory disease. In order to inform future commissioning, it is important to gain the views and experiences of those involved with the service.

### **Aims**

This study aimed to explore the views and experiences of the EOLC-LTC service from the perspective of patients and their partners.

### **Methods**

Semi-structured interviews were used as part of a case study design involving six cases. Each case consisted of the patient and their family member/carer, and key healthcare professionals involved in their care as identified by the patient. This paper reports on the findings from the interviews conducted with the six patients and their family member/carers. Data was analysed thematically. Ethical approval was granted by the Faculty of Medicine and Health Sciences Research Ethics Committee, University of Nottingham.

### **Results**

A total of 28 semi-structured interviews were conducted. Twenty-one interviews were conducted with six case studies. The following themes were identified: The experience of managing a long term cardio-respiratory condition; the nurse service; Building a close/therapeutic relationship/alliance and Fragmentation and integration.

### **Conclusions**

This study has shown that the EOLC-LTC service is welcomed and highly regarded by patients and their family members/carers, and the reasons for this. Further studies are required to explore the views and experience of other key stakeholders and to evaluate how well the pilot operates within the wider care pathway.

## **Key words**

**Evaluation; end of life care, nursing, respiratory, cardiac illness, heart failure, COPD**

## **Introduction**

As a result of the UK's ageing population (1), the number of deaths per year is expected to rise by 17% between 2012 and 2030 (2). In addition, many more people will be dying at an older age and will therefore be likely to have more complex needs and multiple co-morbidities as they near the end of life. These demographic changes will undoubtedly have a significant impact on the level and intensity of provision that is necessary. Therefore, End of Life Care (EOLC) services need to take into account the pressures of an ageing population that is living longer with increasingly complex diseases and co-morbidities (2, 3).

Historically, EOLC has been associated with those suffering from cancer, but future provision must also cater for the full range of other conditions that can be present at the end of life, such as long term illnesses (e.g. respiratory and cardiac diseases) or diseases associated with older age such as dementia, as well as multiple, co-morbid illnesses (4,5).

The drive for excellence in end of life care has been centred around five key priority areas (recognising, communication, involvement, support and planning, and doing) by the Leadership Alliance for the Care of Dying People (6, 7). Recognition that a person is at the end of life and identification of their needs and wishes is highlighted (7) and can instigate advance care planning, another important aspect of care. This involves people outlining their wishes about the future and the end of their life through structured discussion with staff and/or a formal document (6, 8, 9).

This paper reports on data collected as part of an evaluation of a pilot service providing generalist palliative care in the community to patients with COPD and Heart Failure – the End of Life Care Long Term Conditions Service (EOLC-LTC) The service consists of palliative care

nurses, an administrator and acute consultant support. The pilot was funded for an initial two year period from February 2014. The clinical role included:

- assessment and care planning for patients with complex palliative care needs;
- information on disease process, treatment, medication, local and national services;
- advice on symptom control; and
- psychological support for patient/carer.

The service accepts referrals from any health professional relating to the care of patients who are:

- aged 18+;
- registered with a GP within the local Clinical Commissioning Group
- have a long term cardio-respiratory condition and identified as being on the EOLC pathway, i.e. last twelve months of life.

## **Methods**

An exploratory, descriptive, qualitative design was used to explore the experiences and perceptions of the service from the perspective of patients, carers and healthcare professionals. Data were collected through semi-structured interviews with two groups of participants. The first group of interviews used a case study approach (Crowe et al, 2011), where the patient was the 'case'. The second group comprised key stakeholders who were unrelated to the cases. Interview guides were developed by the research team and included the perceived effectiveness of the pilot, barriers and facilitators to successful implementation and delivery, and how well the pilot was operating within the wider care pathway.

## **Sampling and recruitment**

Each case study comprised a patient together with a family member/carer and key health professionals involved in their care as identified by the patient. Patients were selected and approached by the nurses delivering the service using the following criteria:

- Considered to be in the last year of their life due to COPD / HF.
- Having the mental capacity to give informed consent.
- Physically able to complete a 30 minute interview.
- Established on the service caseload for at least three months.
- Having palliative care needs (past/present and ongoing).

Potential participants were given written information about the study by their nurse, who gained their verbal consent for their contact details to be given to the research team. A researcher then contacted the patient to answer any further questions about the study and to arrange an interview at the patient's place of residence. Written consent was taken on the day of the interview. Following the interview, patients were asked to identify others involved in their care who they thought might be willing to be interviewed. The researcher then contacted these individuals and where appropriate arranged the additional interviews, either at the home or workplace of the interviewee, or at the researcher's office base.

The second group consisted of approximately six key stakeholders (e.g. community nurses, hospital doctors, GPs). Potential participants were identified via members of the study team and through snowballing. The interviews followed the same procedure as that described above.

## **Data collection and analyses**

Interview data from both groups of participants were combined and analysed thematically (Braun & Clarke, 2006) . All interviews were conducted, transcribed verbatim and checked by the interviewer (CC). Data were entered onto a software management programme (Nvivo) and coded line by line by CC, who revised initial coding following constant comparison of the scripts. Initial themes and subthemes were identified by CC, then reviewed, revised and agreed with BJ and MN.

## Ethics

The study was reviewed and approved by the University of Nottingham Faculty of Medicine and Health Sciences Ethics Committee. The study was deemed a service evaluation and therefore excluded from NHS ethics approval.

## Findings

### Sample

A total of 28 semi-structured interviews were conducted. Twenty-one interviews were conducted with six case studies. Characteristics of the participants are shown in Table 1.

**Table 1. Characteristics of the case study participants (n=21).**

Patient Case	Patient details			Participants (total per case)
	Age	Condition	Gender	
A	80	COPD	F	Patient, spouse, GP, consultant, EOLC-LTC Nurse (5)
B	64	COPD	M	Patient, spouse, GP, COPD nurse (4)
C	69	COPD	M	Patient, spouse, community nurse (3)
D	59	COPD	M	Patient, spouse, GP, consultant (4)

E	73	COPD	M	Patient, spouse, EOLC-LTC Nurse (3)
F	83	COPD	F	Patient, EOLC-LTC Nurse (2)

Seven stakeholder interviews were conducted. Participants comprised four community nurses, a representative of a self-help group, a hospice nurse and a GP.

Identifiers and categories for each participant are shown in Table 2.

**Table 2. Identifiers and categories for each participant.**

Identifier	Category	Identifier	Category
Patient A	Case Study Patient	COPD nurse	COPD nurse of Patient B
Patient B	Case Study Patient	CONS1	Consultant of Patient A
Patient C	Case Study Patient	CONS2	Consultant of Patient D
Patient D	Case Study Patient	EOLC Nurse1	EOLC Nurse of Patient A
Patient E	Case Study Patient	EOLC Nurse2	EOLC Nurse of Patient E
Patient F	Case Study Patient	EOLC Nurse3	EOLC Nurse of Patient F
Spouse A	Spouse of Patient A	CN1	Community nurse of Patient C
Spouse B	Spouse of Patient B	CN2	Stakeholder community nurse
Spouse C	Spouse of Patient C	CN3	Stakeholder community nurse
Spouse D	Spouse of Patient D	CN4	Stakeholder community nurse
Spouse E	Spouse of Patient E	GP4	Stakeholder GP
GP1	GP of Patient A	HF nurse	Stakeholder Heart Failure nurse

GP2	GP of Patient B	Hospice nurse	Stakeholder Hospice nurse
GP3	GP of Patient D	Self-help rep	Stakeholder rep of self-help group

Four main themes were identified. These themes and their subthemes are shown in Table 3.

**Table 3: Themes and subthemes identified through analysis of interview data.**

1	The experience of managing a long term cardio-respiratory condition	
	i	Unpredictability
	ii	Individual presentation
	iii	Comparison with cancer care
	iv	Emotional/social component
	v	Accessing routine care
2	The EOL-LTC Nurse Service	
	i	Referral
	ii	Knowledge and understanding of the service
	iii	Qualities of the service
3	Building a close/therapeutic relationship/alliance	
	i	Spending time with the patient
	ii	Qualities of the nurses
4	Fragmentation and integration	
	i	Complexity of service provision
	ii	Perceived drawbacks and limitations of The Nurse Service
	iii	Out-of-hours cover

	iv	Role clarity
	v	Communication/information with other services

Each theme and subtheme is summarised with illustrative quotations (Table 4). To avoid identification of the nurses by their gender, the term s/he has been used where necessary.

## **The experience of managing a long term cardio-respiratory condition**

The majority of the interviews concerned patients with COPD rather than those with heart failure. However, as one of the main symptoms of heart failure is also breathlessness, the interview findings are considered transferable to both conditions. COPD was considered to be a complex condition; however, despite this, it was perceived that patients and carers often have limited knowledge of how to manage COPD and are not necessarily gaining all the information or support they need from routine healthcare.

### *Unpredictability*

COPD was described as a condition that can deteriorate quickly. Patients' needs may therefore arise suddenly, and often outside office hours:

*And then it all goes a bit messy, as it can do with patients with COPD, things change very quickly and rapidly. [Stakeholder interview, second Community Nurse]*

It was therefore perceived as vital that patients and their carers were prepared for such an eventuality, and any decisions/wishes regarding end of life communicated effectively to the emergency services.

### *Individual presentation*

Unless an individual patient is well known to the attending clinician, it was observed that the severity of the condition may be difficult to assess. Prescriptions may be issued routinely, for example, when a patient may, in reality, be gradually deteriorating over time. An in-depth knowledge of what is 'normal' for an individual patient can guide the clinical reasoning of the clinician, leading to a more appropriate decision as to their management and resource use, such as whether or not a hospital admission is required:

*I mean we'd been called out because the patient's perceived severe breathlessness, but on examination they weren't actually having an exacerbation. They'd obviously just done a little bit too much that day. [Case study interview B, COPD nurse]*

### *Comparisons with cancer care*

Comparisons of COPD with cancer care were made by the participants. The symptoms of COPD were perceived by some to be more disabling than lung cancer, whilst support for patients comparatively limited, with the condition leading to frequent hospital admissions:

*Actually, my patients with COPD often have more disabling symptoms than patients with cancer, and yet again without this new service there was a real disparity in what I could offer. [Case study interview D, Consultant]*

The necessity to combine an acute approach to exacerbations alongside a longer term palliative approach was considered more complex to manage.

### *Emotional/social component*

The significant anxiety related to patients' fear of their symptoms was highlighted by participants; primarily fear of not being able to breathe, but also fear of pain. These anxieties were observed to result in lack of confidence, leading to panic attacks and depression, with patients becoming housebound and isolated. This led to an increased demand on family and carers which in itself became an additional concern for the patient:

*They know what's going off like at night time, nobody else is there... I hate it because she (patient's wife) goes to work and sometimes she doesn't get home until nine o'clock at night and then she has to come home and look after me and I don't like that. It gets me down. [Case study interview D, Patient]*

### *Accessing routine care*

Participants described the difficulties associated in accessing routine care for this client group. Patients and carers reported being unable to make timely GP appointments (particularly their 'own' GP), and experiencing delays in obtaining prescriptions. Attending hospital or practice appointments could be a struggle, and unnecessary hospital admissions, particularly at weekends, were seen as distressing for, and by, patients. Patients and carers were reluctant to ask for help. Community services did not necessarily visit at a convenient time:

*They come when they like (district nurses). And sometimes they don't come, sometimes they do; it's morning, dinner, night. [Case study interview C, Spouse]*

Patients felt unsupported, and clinicians were concerned about 'abandoning' patients. Although community matrons and district nurses and specialist nurses were valued, they were not perceived to have the necessary experience, expertise, remit or time to meet these patients' needs. Changing healthcare practice, such as the increasing emphasis on seven day working, longer shift patterns, increased caseload, and large catchment areas was a barrier to continuity and an in-depth knowledge of the patient. There was a view that routine community services were constantly 'firefighting' and that case management generally 'no longer exists'. This was echoed by patients who were frustrated when clinicians had little knowledge of their medical history:

*if you go to a strange one (GP) you start right at square one again so he doesn't know the full extent of the problem. [Case study interview A, Patient]*

## **The EOL-LTC Nurse Service**

### *Referral*

Feedback from the nurses employed by the service suggested that a method of triaging referrals might enable the nurses to respond more appropriately to the needs of the individual. Those making regular referrals to the service usually did this by phone, which they reported as relatively straightforward. However, others were less sure of the procedure:

*I don't know, nobody's really explained that to me so if I was going to (refer), the only way I would know to do that would be to go through the Health Point and ask them to do it that way, but whether that's the right way or not I'm not sure... I'm not sure at what stage and what sort of level we start thinking about referring. [Case study interview B, GP]*

Clinicians who were unable to contact the service by phone, particularly those working evening and weekend shifts, found the process less satisfactory.

Participants described the difficulties associated with deciding whether, and when to refer a patient to the service. Some patients were perceived to have difficulty in acknowledging and accepting that they – or their loved one - might be in their last year of life, or equated end of life care with imminent death. Discussions around end of life care were considered to be more difficult with patients with COPD, partly due to the trajectory of the condition. This uncertainty could also extend to patients with other long term conditions:

*Cancer, it's easy. Yes, it's spread and we haven't got any therapy which works. You've come to a cliff edge and you are identifying that you're going to be possibly end of life... That kind of clarity and cliff edge is not there with heart failure, it's not there with COPD, and certainly not there with liver failure...and frailty...[Stakeholder interview, GP]*

Making the decision as to whether a patient is in their last year of life was also considered challenging as clinicians might question whether there was another treatment option that could

be pursued. Clinicians might therefore postpone or avoid such a decision, leading to non-referral, or a delayed referral. The opportunity to discuss the referral with a nurse from the EOLC-LTC service was perceived to facilitate this process. However, if the reasoning for the referral had not been made clear to the patient, this could prove awkward for the nurse. Referrers also expressed frustration that the service was not available in all areas of the city.

#### *Knowledge and understanding of the EOLC-LTC service*

Knowledge and understanding of the service was variable. Although patients and their carers gave very positive feedback about their care, few reported knowing about the service in any depth, and generally referred to the name of their own nurse, or to the service by the short four-letter acronym of the organisation funded to the service.

Stakeholders also frequently used this acronym. Although there seemed to have been publicity about the service initially, participants gave the impression that more was required:

*I mean I think if people, if a lot of doctors knew about it, I think they would they would obviously use it a lot more, and it's probably just because not many people are aware of it... I presume like long term conditions, I would assume, severe asthma or heart failure or diabetes but I don't know if I've got the wrong end of the stick, is that right?*

*[Case study interview B, GP]*

The generalist community nurses reported not having been consulted or sufficiently informed about the service:

*I think we were never told about it to be honest. We just saw adverts for the jobs.*

*[Stakeholder interview, first Community Nurse]*

There was some confusion as to which organisation was delivering the service, and the health conditions it was aimed at. There is already a team of community nurses delivering generalist

end of life care through another provider in the same area. The need to address this uncertainty/confusion was acknowledged by the nurses from the EOLC-LTC service, however they reported having difficulty in finding time to actively market the service in primary care, instead relying on informing other clinicians through their patient caseload, and on consultant referrals.

### *Qualities of the Service*

Particular elements of the manner in which the service was delivered were highly valued by patients and clinicians alike. Patients expressed their confidence in the service, and liked having the same individual nurse allocated to them, who they could get to know well. Although occasionally the nurses had to cover for each other e.g. annual leave, patients were accepting of this as the team were seen to work closely together and share the same approach to treatment. With other services several different individuals might visit the patient, and treatment approaches and management might be contradictory, which was a concern of carers as well as patients. Continuity of care was therefore valued.

*F: Because when you've got different people coming they're all, they all think different ways of sorting him out, And then you think, I'm thinking perhaps I shouldn't have done that, perhaps I should have done that. [Case Study interview E, Spouse]*

However, some community nurses felt that the introduction of the EOLC-LTC had reduced the continuity of their own service.

Patients valued the reliability and dependability of the EOLC nurses, were confident that they would visit as requested / arranged and do what they had promised. Others involved with the patient's care also appreciated this consistency and had a high level of trust in the team. Patients perceived the EOLC-LTC nurse as the main clinician (key worker) managing their care, and other clinicians identified a case management approach as being key to the service.

*I expect [the EOLC-LTC nurse] to liaise with me, but the patient doesn't have to think about anybody else. So from the patient's perspective in my opinion it becomes, and this is what I expect from the service, I get a single point, a named person that they can ring, speak to, get advice, will do an assessment and liaise with other health services if needed. So it's very much of that personal contact. [Stakeholder interview, GP]*

The EOLC-LTC nurses were perceived as able to expedite prescriptions, facilitate more flexible hospital appointments, and liaise with GPs and consultants on the patient's behalf. Having a regular pre-booked visit from the nurse, often on a weekly basis, meant that the onus was not always on the patient to ask for the nurse to call, and encouraged patients to feel empowered to request more contact if they feel it necessary.

*I used to feel a bit awful if I had to ring (the EOLC-LTC nurse) up you know but they always said don't, don't, you know, just ring, ring up. And (the EOLC-LTC nurse) says the same, just ring, don't worry about it. [Spouse D]...That's what they're there for. [Case Study interview D, Patient]*

Patients and carers also appreciated having some control over when the nurse visited compared with other community nursing services. Patients described how they saw the EOLC-LTC nurses as delivering a comprehensive service that could and would help with *anything* and *everything*.

### **Building a close/therapeutic relationship**

#### *Spending time with the patient*

The frequency and consistency of the EOLC-LTC nurse visits helped a close relationship to develop between the nurse, the patient and their family and other support networks. Clinicians

also acknowledged the importance of building this relationship. A visit from the EOLC-LTC nurse was a source of pleasure and of therapeutic value in itself for the patient and their partner:

*M: And (the EOLC nurse) comes, you know, like I say, once a week and s/he keeps her very happy... S/he's a ray of sunshine walking through the door - there's quite a lot of banter together between them, you know. [Case Study interview A, Spouse]*

The ability of clinicians to 'have time' and to share this with their patients was valued by patients and clinicians. The EOLC-LTC nurses were perceived to have this time; however, there was some frustration expressed by other clinicians that they did not have a similar amount of time available, and doubts about whether the EOLC-LTC nurses' time was being used appropriately. Some, for example, questioned whether the collection of prescriptions was an appropriate use of a specialist's time, whereas others felt this was an unmet need as patients and/or carers often struggled to do this.

*They had time to sit and go and fetch prescriptions and that kind of thing, not quite band 7 work. [Stakeholder interview, first Community Nurse]*

It was common for patients and carers to describe how they felt able to *talk about* and to talk about *anything* with their EOLC-LTC nurse. This communication was facilitated by the closeness of the relationship and knowledge of the individual and their family. This included discussions about Advance Care Planning, which could be revisited, as appropriate to the individual. Some patients needed several opportunities to talk about their wishes and make plans. This approach was valued by others involved with the patients' care.

*Well sometimes, like with this patient in particular, we had already discussed - I think it's the GP's role to discuss resuscitation and all that first. But these guys went back, they reiterated and they took it further. [Case Study interview D, GP]*

The process of decision-making in condition management was referred to by patients as being one made together with the EOLC-LTC nurse and their family – plans were perceived as being made jointly, rather than being imposed.

*S/he asks us both what we both think, which is helping because it's not leaving the wife out... Yeah, s/he listens to what you have to say, then we'll meet in the middle. If it's different then we find a solution between us, that's between all three of us, not just me..., because yeah, it's me that's got the illness but it affects her as well... [Case Study interview D, Patient]*

#### *Qualities of the nurses*

Participants commented positively on the communication skills of the EOLC-LTC nurses, their gentle and professional approach, their ability to develop rapport with patients, and to liaise effectively with doctors. Their ability to address the patients' psychological needs was particularly commended.

*S/he just seems to have a very good rapport that seems to – s/he's very easy to like on the phone anyway and very easy to, you know, s/he's just got a nice manner and I could imagine that s/he would really listen to the patient. And I think s/he's dealing a lot with his anxiety, which is really good, because s/he's addressing every part of it, not just the COPD. So I think that for me is really good that s/he is sort of doing a lot of work with his mental health side of things as well. [Case Study interview B, GP]*

The nurses were perceived as having particular skills in helping patients manage their symptoms in order to increase, or maintain the quality and richness of their remaining lives, rather than trying to prevent or alleviate symptoms per se. They did this through various means, including challenging patients' thinking processes, using medication to best effect,

teaching relaxation techniques, referring for day care and addressing other health problems that might arise.

*And s/he put, s/he put things to me that really made me think... S/he came at it from a different angle which I didn't, I'd never heard before... I mean I've been out about seven times this year, so with (the EOLC nurse's) confidence I've been out at night time, weekends. [Case Study interview B, Patient]*

On a practical level the nurses were seen as a prompt and responsive point of access to other services, such as obtaining adaptive equipment, completing benefit claims etc. Their experience and skills were seen to facilitate independent clinical decision-making, rather than reliance on protocols.

Patients also described how the EOLC-LTC nurses increased their knowledge about and ability to manage their symptoms by *explaining* how different approaches could help them. Patients described how well they thought the nurses were able to assess their particular needs – not only those relating to their primary health condition – and to quickly identify any changes in these needs.

*F: As soon as s/he walks in s/he'll say you've had a bad week haven't you? M: Because s/he doesn't miss a thing does s/he? [Case Study interview C, Patient and Spouse]*

This was confirmed by clinicians.

*You know, sort of s/he can, s/he realises when s/he's sort of gone as far as s/he can go and s/he's been sort of, you know, we've been discussing what the next plan is as every stage, and then s/he's sort of organised the admission when s/he's realised that actually there's no more that s/he could do, and there was no more that I could do either. So actually to be aware of when, you know, there is no more is pretty good as well. [Case Study interview B, GP]*

Patients had absolute confidence in the EOLC-LTS nurses, and in their clinical knowledge and skills, which helped to reassure them. They also appreciated the honest approach they perceived to be taken by the nurses when discussing their condition with them.

*I'll say you're not hoodwinking me are you (name of EOLC nurse)? S/he'll say no I'll tell you the truth. S/he always tells me the truth. You know, I wouldn't like (the EOLC nurse) say it was fine and it wasn't. [Patient F]*

The EOLC nurses were seen as being knowledgeable about the patients' health condition and professional in their manner.

*What is different? I think s/he is very very professional first of all. When s/he comes back to me with any requests or anything else, s/he normally does all of the patients, s/he evaluates all patients' needs and etc. It's not only physical but other aspects as well. And when s/he comes to me s/he comes with very, very clearly formulated questions. And it might be two or three questions and that's it. It's a very brief consultation, s/he explains everything, what s/he thinks, what is going on and then s/he asks me for my opinion and that's it. [GP1]*

## **Fragmentation and integration**

Participants discussed generally the range and scope of services for this client group, and highlighted the need for cohesion and clarity of provision.

### *Complexity of service provision*

A wide range of services are available to, and accessed by, patients with chronic cardiorespiratory conditions. Participants described how this complexity can be difficult for patients and staff to be aware of and to understand.

*Because if I was diagnosed I wouldn't know what was available like hospice. Referral to the hospice for respite, there's so many things out there that are available for patients that you just don't know are there. [Stakeholder interview, Self-help group representative]*

#### *Perceived drawbacks and limitations of the EOLC-LTC Service*

Although there was much positive feedback about the nurses, there were also perceived limitations to the service. The nurses themselves acknowledged that they were unable to work as closely as they would like to with other healthcare providers, for example GP practices, due to the demands of maintaining a case management role. Other community nursing services were concerned that the EOLC-LTC service had led to disintegration of care and needed to make more efforts to involve the generalists.

*It has fragmented care in some instances. That we've (district nurses) been pulled in at the end when it all goes a bit pear shaped and, you know, because the (EOLC-LTC) staff haven't got the same access to immediate support, it makes life difficult for them... we don't want (them) to come in the way of the patient accessing services when they need them. [Stakeholder interview, second Community Nurse]*

The EOLC-LTC nurses were not perceived to have the same access to immediate support services, or to have the skills to provide active end of life interventions that some clinicians had expected them to.

*Things like referring to the fast track if a patient needs carers urgently. The (EOLC-LTC) nurses can't do that. So they would ring us and say 'this patient needs to be put onto fast track, I think they need carers' and whatever - they can't do that. They wouldn't set up a syringe driver. [Stakeholder interview, third Community Nurse]*

It was also seen as a disadvantage that the team were not following the same local organisational policies and procedures as other community nursing services. Some interviewees feel that the service would have been better developed within the existing community nursing team, rather than through a different provider.

*Again, it's down to the patients I suppose isn't it? It's, let's say I would, it would have been beneficial had our team grown. Because then we're working, all working together, and that would have been for the benefit of the patients. [Stakeholder interview, first Community Nurse]*

There were concerns about the risk of too many services being involved in managing the needs of this client group, which could be confusing and distressing for patients. This was perceived by patients as well as health professionals.

*I think too many cooks for one broth so to speak. [Case Study interview D, Patient]*

The identity of the EOLC-LTC service within Nottingham City was perceived to be less clear than in other areas of the county, and there were reports of resentment and misunderstandings from some participants stemming from the way in which the service had been introduced. It was reported that there had been some initial attempts to address these issues, but it was apparent that these had not been completely resolved.

#### *Out-of-hours cover*

The EOLC-LTC service is limited to office hours, and the nurses themselves acknowledged that at times they would like to be able to offer an out-of-hours service. However, most participants did not perceive the current practice to be a problem as long as patients had been provided with sufficient information and education about how to manage their condition themselves and/or how to access emergency services when necessary.

*It's about educating the patient, it's about planning what would happen if you called at three o'clock in the morning... [Case Study interview D, Consultant]*

There was a view that a slightly longer working day might facilitate liaison with GPs and increase referrals.

*Our hours are really office-y and I think that makes you unavailable. And also I think that, you know, if GPs can't get hold of you or they feel like you leave at midday, which 4.30pm in GP-land is midday, they're not going to call again because you're not helpful. [Case Study A, EOLC Nurse]*

There were differing experiences of the arrangements made by the EOLC-LTC nurses for out-of-hours cover. The nurses acknowledged the importance of making timely requests to other services to make out-of-hours visits where necessary, however it seems there have been occasions when this could have been managed or communicated more effectively.

*So often they've been seeing these patients on a regular basis, we don't know about that patient, and it comes to five o'clock on a Friday night or at a weekend, we get a call out from whoever, we don't know the patient or we don't know that patient's deteriorated. [Stakeholder interview, third Community Nurse]*

### *Role clarity*

More clarity on roles and communication routes was perceived to be required to avoid fragmentation, and clinicians feeling that their role or service is under threat. Acknowledging the skills of both generalists and specialists, and to minimise any gaps in services was also perceived as important. Some of this confusion of roles is thought to be due to the different service structure within the city, as compared with other parts of the county.

*I think in other areas it works fantastically well because their service matrix is made up differently than it is in the city. In the county they don't have palliative care beds and end of life care team, everyone knows...what her role is, or his role is. [Stakeholder interview, second Community Nurse]*

Some clinicians questioned that EOLC-LTC nurses were engaged in the *touchy feely* aspects of patient care, that the nurses were spending more time with patients only because of their small caseload, and they questioned whether this level of input could be sustained. Some community nursing services felt that their role was being eroded, and that services were not as 'seamless' as they might be. Other community nurses also saw it as their remit to be providing a range of holistic support, in addition to 'hands-on' nursing care. There was a perception by some that the EOLC-LTC nurses felt they needed to justify their role by managing patients themselves rather than involving other clinicians.

However, a degree of overlap was considered inevitable by some, and only perceived to be a problem if there was a duplication of roles. It was acknowledged that clinicians needed to avoid 'silo working' and to work across boundaries.

#### *Communication with other services*

Good communication between different services delivering care to this client group was seen as essential, but there were some doubts and uncertainties as to whether, and how, the different teams liaised with each other. There was a perception that it was more onerous for the EOLC-LTC nurses to communicate with other services due to organisational and locational barriers.

*They're very good, you know, patients love them, and I think they provide a great support, but the communication between us isn't good and it's quite frustrating.*

*[Stakeholder interview, third Community Nurse]*

The different teams recognised that they needed to communicate and work together more effectively in the future, and that all parties needed to take responsibility in driving this forwards. Participants/interviewees emphasised the need for sharing information across the services, primarily through the clinical computer system 'SystemOne'. There was uncertainty expressed by some of the participants/interviewees as to whether this sharing of information always took place and that there was a need for better sharing of information between the EOLC-LTC team and other services. The EOLC-LTC nurses were seen to be at a disadvantage in this process because they were employed by a different service provider, and did not initially have access to the same system when the service was set up.

Theme 1	
i	Unpredictability
	Individual presentation
	Comparison with cancer care
	Emotional/social component
	Accessing routine care
The EOL-LTC Nurse Service	
	Referral
	Knowledge and understanding of the service
	Qualities of the service
Building a close/therapeutic relationship/alliance	
	Spending time with the patient

	Qualities of the nurses
Fragmentation and integration	
	Complexity of service provision
	Perceived drawbacks and limitations of The Nurse Service
	Out-of-hours cover
	Role clarity
	Communication/information with other services

## **Discussion**

This paper has reported on a service evaluation of a pilot service providing generalist palliative care in the community to patients with long term end-of-life cardio-respiratory conditions.

- Pros and cons of pilots
- Pros and cons of different 'providers' and integration of service
- Case management approach and 24/7 healthcare
- Comparisons with cancer care
- Terminology – end of life, palliative
- SystemOne and communication
- Limitations – patients selected by nurses, patients reluctance to identify other 'carers' (e.g. friends, neighbours, family other than partners) who were not healthcare professionals

## ***Service activity***

The interview findings revealed widespread agreement that this patient group has unmet needs, particularly, regarding clinical and support needs in the last year of life. These needs include managing the unpredictability of symptoms, the anxiety associated with breathlessness and its impact on carers, and difficulties experienced in accessing routine, expert, person-centred care.

The pilot service was seen to be largely successful in addressing these needs. Patients and carers valued the regularity, continuity and convenience of the nurses' visits. The nurses were seen to have the time and ability to develop both an effective relationship with patients and carers, and a good understanding of the individual patient's health condition. Treatment plans and decisions were made with the patient and their carer, rather than for them. The nurses were seen as professional, reliable and consistent, to have a high level of expertise in holistic assessment, symptom management and clinical reasoning.

The findings indicated that the service was making an impact on key end-of-life service outcomes such as unnecessary hospital admissions and GP visits, however, there were also questions raised as to how else these services might be evaluated, and suggested the need for patient-related outcomes (PROMS) such as quality of life, self-efficacy, comfort, dignity comprising ongoing evaluation.

### ***Referral to the service***

Interview findings revealed a number of potential obstacles to referral. These included organisational factors such as the usability of the referral system, knowledge – and visibility - of the service, and the referral criteria. However, referral decisions were also determined by the clinical skills and confidence of the referrer. Potential referrers might be reluctant to consider making a referral for a number of reasons. This might be because: they were unsure when a patient was in their 'last year of life'; they were uncertain as to whether there might be another treatment intervention available that had not been considered; or that they were

unwilling to broach the subject with the patient. Clinicians' lack of understanding of the meaning of 'end of life' and their difficulty in recognising when a patient had reached this stage have been reported elsewhere, in relation to COPD (28) (and Heart Failure (29). As the recent definition provided by the British Medical Association (2) is less specific than that provided by the NICE commissioning guidelines (30) stating that – 'the end of life care phase may last for days, weeks, months or even longer'.

Referrers therefore needed not only to be aware of, and confident in the service, but also confident in making the decision that no further active treatment is indicated, and discussing this with the patient.

There was also a suggestion from the EOLC-LTC nurses that the referral procedure could indicate the speed of response advised by the referrer such as the use of a 'traffic light' or triaging system.

### ***Integration with other community services***

Although in many ways the pilot demonstrated success, the interview findings indicated that there were problems in embedding/integrating The Nurse Service within existing community nursing services. Insufficient initial cross-agency consultation and planning prior to implementation of the service had resulted in confusion as to its role and remit. If not necessarily leading to duplication of services, there were concerns about existing roles being eroded. There was perceived to be greater fragmentation and lack of clarity of services which are in themselves already considerably complex. Generalist nurses felt that they were not being involved in a patient's care until too late, without sufficient opportunity to build up a relationship with the patient.

These issues had resulted in some resentment, with questions being asked about the skills and grading of the EOLC-LTC nurses, and whether these were appropriate to the role. The identity of the service was considered to be less clear than in other areas of the county, and

appeared to be hampered by the lack of a well-defined name that would distinguish it from the generalist community nursing services..

Interview findings suggested that extending the service to include patients with other end-of-life palliative care needs might facilitate greater understanding of the role, however cardio-respiratory conditions were seen to be the priority, and extending the remit might dilute the impact of the service further.

These problems in implementation seem to have been compounded by the difference in organisational policies and procedures between the EOLC-LTC service and existing community nursing services, including apparent initial lack of access to SystemOne, and concerns about whether patient information was being 'shared' effectively, particularly as the EOLC-LTC service was reliant on community nursing to cover out-of-hours. The potential advantages of extending the delivery of the service outside of office hours appeared to be outweighed by the disadvantages of reduced continuity, and that a more 'seamless' service should be possible by services working together across boundaries more effectively. However, there was a view that the current hours worked by the nurses could be lengthened slightly to facilitate communication with GP practices.

## **5 Conclusions and recommendations**

In conclusion, there is general agreement that a nurse led, case-managed end-of-life care service is needed for patients with cardio-respiratory conditions in Nottingham City, and that the nurses employed by The Nurse Service are widely respected and appreciated. In particular the service is greatly valued by patients and carers. However, the effectiveness of the service would be improved by greater integration within existing community nursing services. By increased promotion and visibility of the service, greater clarity of the nurses' role and remit, and improved education and communication regarding how palliative and end of life care is defined and understood.

## References

1. Age UK. Later Life in the United Kingdom. London: Age UK; 2015
2. National Institute for Health and Care Excellence (NICE). End of Life Care for Adults  
<http://www.nice.org.uk/guidance/QS132011>.
3. Oliver D, Foot C, Humphries R. Making our health care systems fit an ageing population. London: The King's Fund; 2014.
4. Barnato AE, Cohen ED, Mistovich KA, Chang CH. Hospital End-of-Life Treatment Intensity Among Cancer and Non-Cancer Cohorts. *Journal of Pain and Symptom Management*. 2015; 49(3): 521-9.e5.
5. Social Care Institute for Excellence (SCIE). Dementia Gateway: End of life care. London SCIE; 2013.
6. Leadership Alliance for the Care of Dying People (LACDP). One chance to get it right. London: Department of Health, 2014a.
7. Leadership Alliance for the Care of Dying People (LACDP). Priorities of Care for the Dying Person. London: Department of Health, 2014b.
8. Mullick A, Martin J, Sallnow L. An introduction to advanced care planning in practice. *British Medical Journal*. 2013; 347.
9. The gold standards framework. Advance Care Planning  
<http://www.goldstandardsframework.org.uk/advance-care-planning>
10. Oxenham D, Finucane A, Arnold E, Russell P. Delivering preference for place of death in a specialist palliative care setting. *BMJ Quality Improvement Reports*. 2013; 2.
11. Murtagh FEM, Bausewein C, Petkova H, Sleeman KE, Dodd RH, Gyles M et al. Understanding place of death for patients with non-malignant conditions: a systematic literature review. Final Report: NIHR Service Delivery and Organisation programme; 2012.
12. Gomes B, Calanzani N, Higginson IJ. Local preferences and place of death in regions within England 2010. London: Cecily Saunders International; 2011.

13. Wilson E, Morbey H, Brown J, Payne S, Seale C, JS Administering anticipatory medications in end-of-life care: A qualitative study of nursing practice in the community and in nursing homes. *Palliative Medicine*. 2015; 29(1): 60-70.
14. Wilson E, Seymour J, Morbey H, Payne S, Brown J, CS. Anticipatory prescribing in end-of-life care. *Nursing Times*. 2014; 110(44): 24-5.
- 15.