“A Friend in the Corner”: Supporting people at home in the last year of life via telephone and video consultation – an evaluation

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Abstract

Objective: To evaluate a 24/7, nurse led telephone and video-consultation support service for patients thought to be in the last year of life in Bradford, Airedale, Wharfedale and Craven.
Method: Activity and other data recorded at the time of calls were analysed. Interviews with 13 participants captured patients and carers perspectives.
Results: Between April 1st 2014 and March 31st 2015, 4648 patients were registered on the Gold Line. 42% had a non-cancer diagnosis and 46% were not known to specialist palliative care services. The median time on the caseload was 49 days (range 1-504 days). 4533 telephone calls and 573 video consultations were received from 1813 individuals. 39% of the 5106 calls were resolved by Gold Line team without referral to other services. 69% of calls were made outside normal working hours. Interviews with patients and carers reported experiences of support and reassurance and the importance of practical advice.

Conclusion: A nurse led, 24/7 telephone and video consultation service can provide valuable support for patients identified to be in the last year of life and their cares. The line enabled them to feel supported and remain in their place of residence, reducing avoidable hospital admissions and use of other services. Providing this service may encourage health care professionals to identify patients approaching the last year of life, widening support offered to this group of patients beyond those known to specialist palliative care services.

Key Words: telemedicine; videoconsultation, end of life care; carers.

Background

For many people with life-limiting conditions, the last year of life is characterised by rapidly changing needs requiring intervention from a variety of professionals across primary and secondary care [1,2].Typically, most of that time is spent at home, although place of death is most likely to be hospital in England and Wales [1–3].

In relation to care coordination, the most recent VOICES survey suggested that the proportion of bereaved carers who considered that community services worked well together had declined over the past 3 years [4]. Many complaints relating to end of life care arise as a result of events that occur outside GP surgery hours [5] and many unplanned hospital admissions occur out of hours. This is not only costly to the NHS but also represent significant disruption to the people who are admitted [6]. At these times, patients encounter health professionals they do not know and who have varying levels of palliative care expertise [7,8]. A current priority for research (as identified by patients, carers and clinicians) is exploring the best ways to provide palliative care support outside working hours to avoid crises and help patients to stay in their place of choice [9].

Telehealth is an umbrella term which refers to the delivery of health-related services and information via telecommunications technologies, including telephone and video links. It involves the remote exchange of data between a patient and healthcare professionals to facilitate diagnosis, monitoring, and management of conditions [10]. The adoption of telehealth is a key priority for the Department of Health's "TEC" policy [11].

A review of telehealth in palliative care in 2010 [12] was expanded to include international studies and to include papers published up to February 2015. Four further studies were found, including two integrative reviews [10,13–15], incorporating telehealth initiatives such as mobile phone apps for symptom management and video-conferencing between hospice and oncology. Many hospices provide telephone support for patients, this is usually restricted to people known to them whereas the majority of people who are thought to be in the last year of life are not known to specialist palliative care services [16]. Palcall, a service providing 24-hour telephone advice from a hospice for any patient with palliative care needs [17] still had more than 80% of patients referred by specialist palliative care and did not report patient views.

This is the first reported evaluation of a palliative care telehealth initiative which focuses on patients not known to specialist palliative care and includes patient and carer experience.

Description of service

Gold Line service is a 24/7 single point of contact for any community patients identified to potentially be in their last year of life. It offers care co-ordination, advice and support to the patients

and their carers, provided by a nursing team based at the teleconsultation hub in Airedale general hospital .

Using the Gold Standards Framework [3,4], support and training has been provided to primary and secondary health care teams to help in identification of such patients and to support the sensitive conversations needed at this time. If a patient is identified as likely to be in the last year of life they are offered inclusion on to their primary care teams GSF register and are eligible to receive the Gold Line service. By using the GSF as the criteria for access to the Gold Line, this service is available to many more people than if it was offered solely to patients referred to the specialist palliative care services.

In the area , all GPs, community nursing services, specialist palliative care teams and the telemedicine hub/Gold Line team use Systm1 as the patient electronic record which makes sharing of information across boundaries possible following appropriate consent procedures. The electronic record has an Electronic Palliative Care Co-ordination template (EPaCCS) embedded within it to allow recording and easy sharing of useful information such as patient preferences for care and support and other treatment decisions or advance care plans (see, www.tpp-uk.com).

The Gold Line is staffed by senior nurses who are experienced in using teleconsultation skills to support care home staff and residents and community patients with long term conditions as part of a different, related service. The team has also received additional training in communication skills and general palliative care principles and palliative care and acute oncology emergencies. Access to the service for patients and carers is either via telephone, or a video app on an iPad. Referral to the service enables the team to access the patients full electronic health record (with appropriate consent) to inform and enhance care advice. Once the nurse has dealt with a call they record the reason the call was made and outcomes of the call in the patient record using a standard checklist.

Calls to Gold Line may result in (1) direct advice (2) referral to another professional, or (3) admission to hospital or hospice.

Methods

Data on timing and nature of contacts with the Gold Line and the resulting actions taken was gathered from the electronic patient record.

In addition, eight patients and five carers who had been given access to the Gold Line service were asked by a nurse who coordinated the Gold Line service whether they would participate in an interview. Information sheets and consent forms were sent to the patients' home and followed up two days later with a telephone call from a study researcher.

Interview participants were asked questions related to their experiences of using the service, using a semi-structured approach that enabled exploration of any additional topics raised. Interviews were

digitally audio-recorded and transcribed verbatim, and scripts were analysed for broad themes. Comparison of themes was carried out individually and then between members of the research team in order to minimise the risk of bias. Sections of the script were highlighted and allocated to the identified themes. Findings are presented that relate to the activity and outcome data and that address experiences relevant to the main benefits and problems of telehealth identified in the literature review.

Ethical approval was obtained in June 2014 by the National Research Ethics Service Yorkshire and the Humber (Leeds East) - (REC Reference 14/YH/0166 IRAS ID: 149772). The Health Research Association decision tool determined that the quantitative data was service evaluation and formal ethical review was not required for the collection of this data.

Results

Referral numbers (1st April 2014-31st March 2015)

- Patients referred to Gold Line = 4648
- Proportion referred patients *not known* to Specialist Palliative Care Services = 45.2% (2102/4648)
- Number of deaths =1429
- Days on caseload: median=49, mean=88, range (1-504 days)
- Total number of calls: 5,106 telephone (573 video-consultations) relating to 1,813 individual patients
- Sixty nine percent (3523/5106) of calls occurred out-of-hours

Table 2 : Age of patients who died

Age range (years)	Number of patients
<29	7
30-39	11
40-49	34
50-59	87
60-69	220
70-79	355
>80	715
Total	1429

Avoiding use of other services

The Goldline team member taking the call judged that 189 hospital admissions, 198 A&E attendances, 405 GP visits and 186 community nurses visits were potentially avoided during this 12 month period .

Service user profile

A review of patients (n=1,138) on the caseload (including those who died, n=160) in the 6 weeks prior to 31 March 2015 were analysed. 46% (526/1,138) had cancer; 42% (481/1,138) non cancer diagnosis and 12% (131/1,138) missing data. Of the patients who died only 13% (21/160) died in hospital.

Table 3: Disposition at the end of each episode of care

Remains in place of residence	4500
Admitted to hospital	9
Admitted to hospice	2
Attended emergency department	18
Reported death	19
Other e.g. ambulance called to assess	20
Missing data (this data was only collected for the later part of the year hence the high number of unrecorded dispositions)	538
Total	5106

Table 4 - Onward referral outcomes of patients accessing Gold Line

Community Nursing team	1878
Palliative Care Services (Specialist nurse and consultant)	154
Chemotherapy Help Line	25
Out of hours GP	848
In hours GP	234
No onward referral (direct resolution of issues)	1967
Total	5106

Qualitative Evaluation

Five patients (and carers, where appropriate) who have been given access to the Gold Line service were recruited to a parallel qualitative evaluation of the service. They were purposively selected via the Hub, to include men and women of different ages and with different life-limiting conditions. All but one were interviewed in their own home, with a single interview occurring in hospital. A bereaved carer was also included in the sample. Interviews were transcribed verbatim and thematic analysis undertaken by the team.

Demographics of the participants who were interviewed are detailed in table 1. Some were seen twice, some were seen with their carer and one carer was seen without the patient.

Table 5 – Participant Demographics

	Diagnosis	**Lived alone?**	**Revisited**
Patient 1	Cancer, bipolar disorder	N	Y
Carer 1			Y
Patient 2	Mesothelioma	Y	N (died)

Patient 3	Cirrhosis	N	N (died)
Carer 3	Also a patient - (lymphoma and dementia)		
Patient 4	Cancer, anxiety	Y	Y
Carer 4			Y
Patient 5	Dementia (unable to consent to interview therefore carer only)	N	N (not appropriate)
Carer 5			N
Patient 6	Cancer, diabetes	N	N
Carer 6			Y
Carer 7	Cared for wife (breast cancer)	N	N
Patient 8	COPD, depression	Y	Y
Patient 9	COPD, anxiety	N	N

Out of hours support

Carer 5 described how she used the Gold Line at around 6 am, having been awake all night Eventually her partner became worse and so she contacted the Gold Line for advice.

> **Carer 5:** *The doctor was very quick, very good…somebody in there, they called the doctor for me and he straightaway come here.*

Others stated that they would be most likely to use it out of hours, or if there was a change in their condition:

> **Patient 2:** *"that's how it was introduced to me, as an out of hours service. I don't know if it's a day or night service"*

Emotional support and practical advice

Participants reported the emotional support and advice they received at difficult times as well as the value of talking to someone in the night when they had trouble sleeping or felt on the verge of panic.

> **Patient 9:** *"the iPad is invaluable for me… I panic and I can't breathe … It sounds silly, but even something to distract my attention, saying "oh, I'll ring the iPad" and I can say "I can't breathe." And they can physically see how bad I am breathing… You know there's someone there, at the end of that, that answers straight away. It's amazing, it's made my life a heck of a lot easier. It really has, it's invaluable to me, it really is. Priceless, it is."*

Some of those who had used the service expressed the view that part of the value of the Gold Line existed in just knowing it was there.

> **Patient 2:** "*Sometimes, I'm up having a cup of tea because I'm not feeling too good. And I think "shall I make a phone call? No, I'll see how I get on after I've had my cup of tea." So it's actually saved phone calls... It is like a crutch, basically... I sometimes sit down, have a cup of tea, ten minutes, and I'm ready to go back to bed again."*

Preventing admissions

There were positive reports of how the Gold Line had liaised with other services on behalf of patients or carers.

> **Carer 3:** *So I got on the iPad and I said, "look at that!" (laughs) and she [nurse] could see that he was wandering about, distressed, disorientated, quite aggressive, quite agitated. … She had a word with him, told him to sit down, that I would give him some medicine for the pain. .. 'I'll get the nurses to come out and have a look'. And that's exactly what happened ...the nurses came and they had a look at everything and they took a water sample and then they said they'd send for the GP...and put him on antibiotics straight away. The next morning he were 90% better. So to me, it keeps people out of hospital, it gives you security.*

Expediting appropriate admissions

In cases of uncertainty as to the best course of action, the Gold Line offered an opportunity to arrive at a calm and considered decision, rather than a panic reaction.

> **Carer 1 (2nd interview):** *"We were sort of trying paracetamol because his temperature was starting to go up, and so the nurse on the other end of the iPad was talking us through "has the temperature come down? Is he responding to the paracetamol?" And eventually, with discussion with them, we decided I should take him into hospital."*

Working together

Views on how services worked together varied.

> **Carer 7:** *"I can see just how hard it is to get all of those different services to point at one person, but it's not, I mean, I don't know how many they had on the go at one time, I mean, twenty, thirty, a hundred? I don't know. A lot more. And yet, to me it felt like everything was focused on me and on P, and to achieve that is quite extraordinary."*

> **Carer 1:** *"I know there are some parts of the system that don't link up, like the hospital computer system and the GPs computer system, I'm not sure that they all link up between Trust 1 and Trust 2 as well."*

Continuity of care

Over time, patients and carers got to know the Gold Line nurses, and developed rapport.

> **Patient 9:** *"You get used to seeing the same faces and you bond with them, because they're always there when you're poorly, and they reassure you, so you get a bond with them. You feel safe with them, you know? And my records are all there in front of them, so they know who I am, they know what I'm on, they know what I take, I don't have to explain it to every single person I speak to, they already know. "*

Impact on the home environment

One of the participants (telephone line only) said that he would consider the iPad to be an invasion of privacy and stated a preference for the telephone line.

> **Carer 3**: *I think in some ways the separation, there was an element of control, because what we wanted was privacy, so bringing somebody else [in] then would be an invasion of your*

privacy.

An example of the Gold Line at the end of life

Carer 7 described in detail the last night of his wife's life, she was sleeping only occasionally and having periods of restlessness. From an earlier conversation with the Gold Line, he described how he knew that she was not going to get better, that she was dying,

> **Carer 7:** *"But because I spoke to the Gold Line about something, and I said, I think I just asked the question "is this what I think it is?" And I think all they said was "yes, probably". But again, that helped, just that somebody could tell me what was, reassure me that what I was seeing and experiencing was, wasn't something different that may be needed addressing in a different way....."it meant that I could just be in the moment with her. It gave me sort of control over my feelings, which ultimately meant that she was looked after better than she would have been"*

Discussion

Through combining quantitative and qualitative data we report on a service that was experienced as personalised, responsive, safe and efficient. It was predominantly accessed "out-of-hours" for practical advice, symptom management, reassurance and emotional support.

Crises out of hours can lead to hospital admissions. Patients and carers valued the direct advice offered to them at these times. The Gold Line provided access to emergency services and GPs by evading the standard processes which participants felt were depersonalised and time consuming, a perception upheld by others [7,8]. Sometimes admission to hospital is appropriate and desirable for the patient and carer. The focus should not be on reducing admissions *per se*, but on reducing admissions that can be safely avoided.

The Gold Line offers, in the minds of our participants, the opportunity to elude the structural barriers to accessing responsive care by enabling faster responses by GPs, District nurses and A&E departments because a 'specialist' service has enabled it.

Both patients and carers commented on the friendliness and responsiveness of the Gold Line staff. The fact that patient information was instantly available was appreciated, as service users were not required to repeat information with unknown telephone operators at a stressful time.

A priority for those using the face-to-face service is ease of use. There were no concerns with the actual use of the application, although there were concerns around wireless connectivity, reflecting earlier findings by Johnson et al [13].

The face-to-face nature of the iPad was found to be very helpful in that the service user could directly show what was happening to themselves or their relative. Being able to see staff was reassuring. This finding supports, in part, the work by Johnson et al [13] and Stern et al [14]. However, this evaluation did also highlight that not all wanted face to face contact, views about the relative "privacy" offered by the two options differed, with some people wishing to control visual access to the home (see [15]).

The population served by the Gold Line include groups known to face challenges in accessing palliative care; notably the elderly and those with a non-cancer diagnosis. Previously published data highlights that only about 30% non-cancer patients [18,19] and less than 20% of older patients [16] are appropriately identified for palliative care. Quantitative data was collected retrospectively and limited by current reporting systems; electronic data for deceased patients is only available for analysis for 6 weeks after death
You could put something here about having a service encouraging use of GSF. But not sure you need it in this paper at all.

Limitations of the Study

This evaluation includes interviews with a small sample of service users who were accessing support from Gold Line. Due to funding and time constraints, interviews were limited to two visits. As a result limited insight into the changes in use of the service across the illness trajectory has been obtained. Some potential participants were too unwell to participate when the time came to meet with them and some had died before the follow up interview. Figures on 'avoidance' of healthcare capture a subjective assessment made by the person attending the call who felt that no onward referral was required.

Conclusions

The Gold Line provides a personalised service that is particularly valued out-of-hours. Patients and family members reach out to the Gold Line to provide practical advice, support and calm reassurance. This support can prevent or reduce a crisis, facilitate timely and appropriate intervention, help manage symptoms and prepare family members for an expected death.

Furthermore, this service was particularly used by the elderly and those with non-cancer diagnoses. In addition nearly half the patients were unknown to specialist palliative care services; further extending the reach of the palliative care to a different population. We postulate that linking

identification to a specific service improves clinicians readiness to consider identifying patients who are potentially in the last year of life.

Concerns about medicalising the home environment, reported in the literature, were only manifest in an anxiety that the Gold Line, and in particular the iPad facility might intrude on privacy. But in general the technology was seen as a giving access to authoritative help from "a friend in the corner". Having a telephone or iPad link to known and trusted service providers offers the opportunity to have intimate care at a distance.

The Gold Line is extendable to other areas from the current call centre. Extension to other centres could be as part of a randomised controlled trial comparing Gold Line to usual care and include a health economic evaluation.

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Conflicts of interest

There are no conflicts of interest

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