

# '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 'Gold Line', 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** Data on the time and nature of all calls between 1 April 2014 and 30 March 2015 were obtained from the patient Electronic Records. Interviews with 13 participants captured patients and carers perspectives.

**Results** To date, 3291 patients have been referred to the Gold Line. During the study period, 42% of registered patients had a non-cancer diagnosis and 45.2% of service users 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 made involving 1813 individuals. 39% of the 5106 contacts were resolved by the 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 from the Gold Line and the importance of practical advice was emphasised. Current data (year to October 2015) show that 98.5% of calls (4500/4568) resulted in patients remaining in their place of residence.

**Conclusions** 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 for their carers. The line enabled them to feel supported and remain in their place of residence, hence reducing the pressure for avoidable hospital admissions and use of other services. Providing this service may encourage healthcare professionals to identify more patients approaching the last year of life, widening support offered to this group of patients beyond those known to specialist palliative care services.

## BACKGROUND

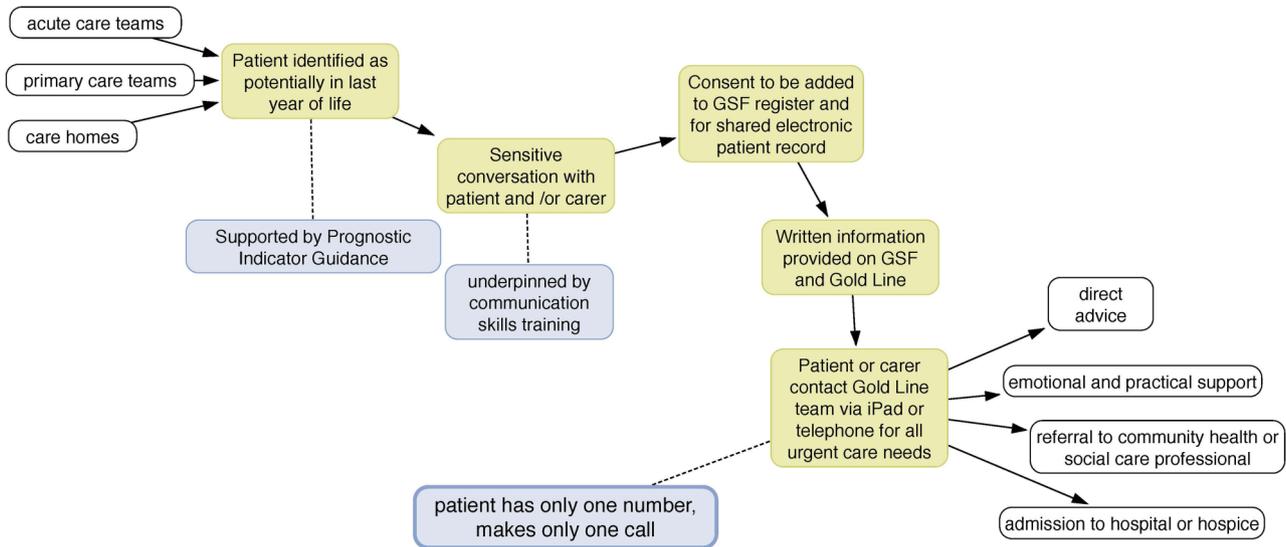
For many people with life-limiting conditions, the last year of life is characterised by rapidly changing needs requiring intervention from a variety of professionals across primary and secondary care.<sup>1–3</sup> Typically, most of that last year is spent at home, although the most common place of death is hospital across the UK and internationally.<sup>4–6</sup>

A major challenge during this time is care coordination. The 2014 VOICES survey (an annual survey of bereaved people in the UK) suggested that the proportion of bereaved carers who considered that community services worked well together had declined over the past 3 years.<sup>7</sup> Many complaints relating to end of life care arise as a result of events that occur outside GP surgery hours<sup>8</sup> and many unplanned hospital admissions occur out of hours. Unplanned hospital admissions are not only costly to the NHS but also significantly disruptive to the people who are admitted.<sup>9</sup> During these admissions, as in all out-of-hours contacts, patients are likely to encounter health professionals they do not know and who have varying levels of palliative care expertise.<sup>10 11</sup> A current UK research priority is to explore the best ways to provide palliative care support outside working hours to help patients to stay in their place of choice.<sup>12</sup>

Telehealth is an umbrella term referring 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

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## Research



**Figure 1** Gold line service.

diagnosis, monitoring, and management of conditions.<sup>13</sup> The adoption of telehealth is a key priority for the Department of Health's 'TEC' policy.<sup>14</sup>

A review of telehealth in palliative care published in 2010<sup>15</sup> was taken as a starting point and then expanded by the authors to include both international studies and papers published up to February 2015. Four further studies were found, including two integrative reviews,<sup>13 16–18</sup> incorporating international 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.<sup>19</sup> An example of a service originating in a hospice is Palcall, in Scarborough, UK. This provides 24 h telephone advice to any patient local to the hospice with palliative care needs. More than 80% of referrals to its advice line came from specialist palliative care practitioners.<sup>20</sup>

The study we present is the first reported evaluation of a palliative care telehealth initiative which includes the perspectives of patients who are not known to specialist palliative care services

#### Description of the service

The Gold Line service (figure 1) is a 24/7 single point of contact for any community patients identified as potentially in their last year of life. It offers care coordination, advice and support to the patients and their carers and is provided by a nursing team based at the teleconsultation hub in Airedale General Hospital. The service is provided to people in the Bradford District. This includes Bradford City, Airedale, Wharfedale and Craven, together covering a

population of around 500 000. These areas comprise an area of urban deprivation and ethnic diversity, villages and towns with low deprivation and high proportions of older people and a rural hinterland reaching into the Yorkshire Dales.

Using the Gold Standards Framework (GSF) support and training has been provided to primary and secondary healthcare teams to help identification of appropriate patients and to support the sensitive conversations between team, patient and carer 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. Having the GSF as the criteria for access to the Gold Line has meant this service is available to many more people than if it was offered solely to patients referred to specialist palliative care services.

All GPs, community nursing services, specialist palliative care teams and the telemedicine hub/Gold Line team use System1 as the patient electronic record which enables sharing of information between professions and across services boundaries following appropriate consent procedures. This 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 <http://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 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. All referrals are accepted on to the Gold Line caseload. Once the nurse has dealt with a call they record the reason for the call, and outcomes, using a standard checklist.

Calls to Gold Line may result in (1) direct advice (2) referral to another professional, (3) emotional or practical support or (4) 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 2 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 were service evaluation and formal ethical review was not required.

## RESULTS

### Referral numbers (1 April 2014–31st March 2015)

- ▶ Proportion of referred patients *not currently involved* with Specialist Palliative Care Services=45.2% (2102/4648) (use of Specialist Palliative Care is needs-based, so patients may be referred for a period and then discharged)
- ▶ Number of deaths=1429
- ▶ Days on caseload: median=49, mean=88, range (1–504 days)
- ▶ Total number of calls: 5106 telephone (573 video-consultations) relating to 1813 individual patients

- ▶ Sixty nine per cent (3523/5106) of calls occurred out-of-hours

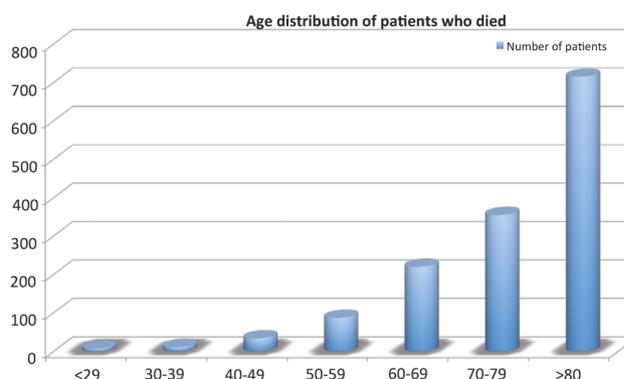
### Service user profile

A review of patients (n=1138) on the caseload (including those who died, n=160) in the 6 weeks prior to 31 March 2015 was undertaken. Forty six per cent (526/1138) had cancer; 42% (481/1138) had a non-cancer diagnosis and 12% (131/1138) missing data. Thirteen per cent of deaths occurred in hospital (21/160). [Figure 2](#) shows the age range of patients who died during the study period. [Figure 3](#) illustrates onward referral outcomes for patients accessing the service.

More recent data were analysed to identify disposition at the end of calls due to missing data in the 6-week study period. For the year to October 2015, there were 6515 calls, of which 475 were to report a death. [Table 1](#) shows the disposition at the end of the call for the remaining 6040 calls.

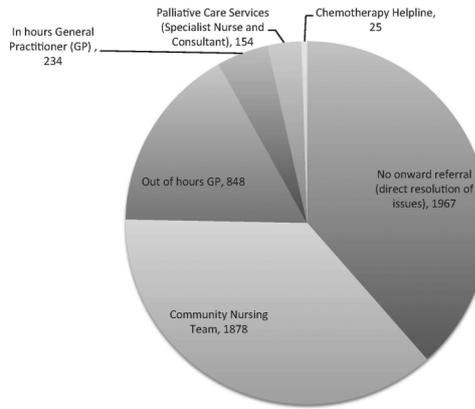
### Qualitative evaluation

Eight patients and six carers who were given access to the Gold Line service were recruited to a parallel qualitative evaluation of the service. They were purposively selected to include men and women of different ages and with different life-limiting conditions. All but one were interviewed in their own home, with one hospital interview. A bereaved carer was also included in the sample. Interviews were transcribed verbatim and thematic analysis undertaken by the team. Participants ages ranged from 43 to 88. Genders were equally represented in the sample. The life-limiting diagnoses included cancer (n=6), chronic obstructive pulmonary disease (n=2), cirrhosis (n=1), diabetes with renal impairment (n=1) and dementia (n=2). Two patients had two or more life-limiting conditions, and three patients had concurrent mental health problems (depression, anxiety and bipolar disorder). One female participant lived alone; all others lived with a spouse or partner. Carers were spouses other than in one case where a patient's daughter was the main carer. One carer was seen without the



**Figure 2** Age range of patients who died.

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**Figure 3** Onward referrals.

patient. Four participants were using the iPad to access Gold Line; the remainder accessed the service via telephone.

Following the first interview, patients were offered a second visit in order to ascertain whether the ways in which Gold Line was used changed over time. In six cases no second visit was possible due to deterioration, death or a change in place of care. Patients and carers were able to choose whether to be interviewed alone or with their carers.

#### Out of hours support

Carer 5 described calling at around 6:00 after her partner became gradually more unwell overnight:

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

All participants described at least one call made out of hours, and some considered it to be a solely out-of-hours service:

**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

**Table 1** Disposition at end of call (year to October 2015) (total=6040)

| Disposition at end of call           | Call numbers | Percentage |
|--------------------------------------|--------------|------------|
| Remained in usual place of residence | 5742         | 95.1       |
| Not recorded                         | 114          | 1.9        |
| Referred to A&E                      | 85           | 1.4        |
| Ambulance called to assess           | 44           | 0.7        |
| Hospice admission                    | 27           | 0.4        |
| Hospital admission                   | 21           | 0.3        |
| Other                                | 7            | 0.1        |
| Total calls                          | 6040         | 100%       |

A&E, accident and emergency.

#### 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.

Although some participants felt the iPad offered an additional benefit in terms of face-to-face contact, one expressed a preference for the telephone line only as they felt it was less intrusive.

**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.

#### 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, and participants were keen that they received consistent messages. Carer 7 (below) describes seamless coordination of multiple and complex services needed by his wife as she was dying:

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.

In contrast, Carer 1 felt there was some inconsistency in the messages she was receiving from physical and mental health professionals, and considered that this reflected a lack of integration of services:

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 nurses, and developed rapport and trust. Some of the reasons for their calls (reassurance, company) were highly valued, yet would not have been available through any other service in the absence of the Gold Line.

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.

### 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. 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. Patients and carers valued the direct advice and support offered during times of crisis, and it was clear that the relationships with the staff were an important contributory factor to their feeling empowered to use the service. The Gold Line provided access to emergency services and GPs by avoiding the standard processes which participants felt were depersonalised and time consuming, a perception upheld in other studies.<sup>3 10</sup> 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.

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 accident and emergency departments because a ‘specialist’ service has enabled it.

A priority for those using the iPad 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 Johnston *et al.*<sup>16</sup> This has implications for development and expansion of such services in areas in the UK and abroad where broadband coverage is patchy, although current plans in the UK are to ensure ongoing broadband expansion to include remote and rural areas as part of the Government's ‘digital inclusion’ strategy.<sup>21</sup>

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 Johnston *et al.*<sup>16</sup> and Stern *et al.*<sup>17</sup>. 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<sup>18</sup>).

## Research

Retaining a range of modes of support would enable patient choice.

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<sup>22 23</sup> and less than 20% of older patients<sup>19</sup> are appropriately identified for palliative care.

#### Limitations of the study

This evaluation includes interviews with a small sample of service users who were accessing support from Gold Line. Owing 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. Quantitative data were collected retrospectively and limited by current reporting systems. During the study period there was some inconsistency in record keeping.

#### CONCLUSIONS

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.

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.

**Twitter** Follow Laura Middleton-Green at @heblau and Linda Wilson at @doclgw

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**Contributors** LW, SN, AS and LM-G were involved in the study plan and design; LW and HL were involved in the quantitative data collection; LM-G and BN were involved in the qualitative data collection; SN, AS, BN and LM-G were involved in the data analysis (qualitative); AG and SN were involved in the data analysis (quantitative). SN, LM-G, AG, AS, BN, SN, HL and LW were involved in the paper authorship.

**Competing interests** None declared.

**Ethics approval** NRES Yorkshire and the Humber (Leeds East) —(REC Reference 14/YH/0166 IRAS ID: 149772).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** Additional anonymised data is available for the purposes of further research. Data relating to service can be obtained from Dr Linda Wilson. Email for details.

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