

A Qualitative Evaluation of the Gold Line Telehealth and video-linking to support people at home in the last year of life: Patient and carer perspectives

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Executive Summary

The use of telehealth to support people at home is a key focus within current healthcare literature and for some clinical conditions there is a large and growing evidence base as to its acceptability and effectiveness. However little is known about how telehealth is viewed by people in the last year of life and their families and carers.

The Gold Line is a dedicated service for people who have been identified as potentially being in the last year of life. All patients registered on the End of Life Care Register on the Electronic Palliative Care Coordination System (the local version of the Gold Standards Framework register) are eligible to access the service, which provides 24-hour access to a registered nurse either via telephone, or via an app on an iPad enabling video contact. Calls are triaged and may result in (1) direct advice (2) referral to another professional, or (3) admission to hospital or hospice. This report relates to a qualitative service evaluation carried out between July 2014 and January 2015. The aims of the evaluation were to identify examples of the range of situations leading to accessing the Gold Line, evaluate the attitudes and perspectives of patients and carers, and describe different ways in which the service is utilised.

In total, 13 participants (service users and carers) were interviewed; 6 participants were visited again three months later to ascertain whether the use of the service changed as their condition and individual needs change. Interviews were transcribed verbatim and analysed using constant comparison methodology to identify emerging themes.

Themes included expectations and knowledge of the service, integration with other services, purpose of the service, support and reassurance, practical advice, using the technology, and smoothing the journey. For those using the iPad, the technology was considered easy to use. Staff were seen as supportive in a disparate range of circumstances. Issues were identified with connectivity, continuity with other services and perceptions of the purpose of the service.

A key aim of current policy in palliative and end-of-life care is to increase the proportion of people who are able to die in their preferred place of death. Telemedicine, as a complement to direct care, can ease the anxieties and strain that might precipitate an unwanted admission. It is essential that new technologies are developed in collaboration with the people who will be using them.

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19 June 2014

Mrs Laura I Middleton-Green
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Dear Mrs Middleton-Green

Study title: **Qualitative evaluation of patient and carer perceptions on the implementation of the "Gold Line" telephone support service for patients identified as being in the last year of life and living at home**

REC reference: **14/YH/0166**

IRAS project ID: **149772**

Thank you for your submission of 18 June 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair together with Professor Kenneth Brodlie.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Sarah Grimshaw, nrescommittee.yorkandhumber-leedseast@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations

A Research Ethics Committee established by the Health Research Authority

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Background

For many people in the United Kingdom living with life-limiting conditions, the last year of life is frequently characterised by rapidly changing needs requiring intervention from a variety of professionals across primary and secondary care. For the majority, the last year of life is spent at home, although the place of death is most likely to be hospital. This is in spite of the majority of people stating a preferred place of care other than hospital (Gomes et al., 2012, Murtagh et al., 2012). The gap between preferred and actual place of death is a key indicator of quality in current end of life care policy (NEoLCIN, 2011). This is only one indicator of quality in end of life care. It is possible for a death at home to be poorly managed or against the wishes of the patient. Furthermore, a person may change their preferred place of death to hospital because of unanticipated factors, but this change of mind is not always clearly documented. Locally, there is emphasis on discussing and documenting preferred and actual place of death (Sinclair, 2007) in order that the reasons for the high proportion of hospital deaths are known rather than assumed. Actual place of death gives no indication as to the extent to which the person's death was comfortable or dignified, although some indication of this is provided from the findings of the "VOICES" questionnaire sent to bereaved relatives and carers. Analysis of this data provides a picture of the quality of different aspects of care at the end of life, including dignity, comfort and communication. For people who died at home, one of the areas where care was rated less highly than in other settings was in coordination of care; 42% of carers felt that care had been coordinated "to some extent" (as compared with "completely" or "most of the time") (ONS, 2012)

For some, death in hospital, hospice or care home is unavoidable due to sudden unpredicted deterioration, acute events or other changes in home circumstances. Home may not be a realistic option for end-of-life care for social, psychological or financial reasons. Sometimes spending the end of life in hospital is a positive choice, made because of perceptions of better care, avoiding burdening carers, and preventing distressing associations of home with death. However the reasons behind people dying in hospitals may also relate to carer strain, poor coordination of services, inadequate information and support, and difficulty achieving adequate symptom control (Gomes and Higginson, 2008). A key aim of current policy in palliative and end-of-life care is to increase the proportion of people who are able to die in their preferred place (DOH, 2008) which for many people is their own home.

The use of telehealth initiatives to support people at home is receiving widespread attention in the research literature (Akesson et al., 2007), using a range of research

methodologies from both quantitative and qualitative traditions (Ekeland et al., 2010). This report relates to a funded evaluation of patient and carer views about the use of both the Gold Line telephone and video telehealth services in Bradford and Airedale.

Telehealth is a rapidly growing field of healthcare that has been implemented in various clinical areas as a complement to direct care (for an overview, see Wootton (2012)). Increasing the adoption of telehealth is a key priority in the Department of Health's "TEC" policy (DoH, 2014), although robust trials of effectiveness are not yet widespread. The uptake of telehealth in some clinical areas has not been as fast as had originally been anticipated (Davies and Newman, 2011). Greenhalgh and colleagues undertook a discourse analysis of 68 publications relating to telehealth technologies, and found competing perspectives that may impact on working towards shared visions and understanding of the benefits and challenges in the uptake of telehealth (Greenhalgh et al., 2012). One perspective was viewing telehealth as a utopian, futuristic development for meeting the needs of older people through the creation of a "smart" home environment that delivers safety and efficiency. A competing perspective was that telehealth could simultaneously meet human needs, providing person-centred care for some, whilst potentially alienating others. A political viewpoint was that there are powerful vested interests driving the widespread commodification of healthcare and supporting private telehealth businesses. One argument that has still not been satisfactorily resolved is that a similar level of face-to-face contact could be achieved through significantly cheaper software or apps such as Skype or FaceTime. Concerns about potential breaches in information security have not yet been proven. Finally, Greenhalgh's analysis identified the viewpoint that change management is a key consideration in implementation of telehealth programmes, requiring coordinated processes and clear project management with inclusion of all current and potential stakeholders. The latter has been emphasised in a report by the Commonwealth Fund which profiled lessons learned from early adopters (Broderick and Lindeman, 2013). Potential reasons for limited uptake of telehealth include the view from healthcare professionals that telehealth is not favoured by patients and carers, concerns around the privacy of patient information, the impact of distance in terms of lacking the "human" touch, and anxieties about the medicalization of the home environment (Hughes, 2003, Demiris et al., 2006). Recommendations included the need to engage in dialogue in order to avoid "talking past" one another from the standpoint of one of these four competing discourses. It is important to find out whether these professional perceptions are shared by the patients and carers who are service users.

The idea of telehealth in palliative care is not new; many hospices have provided dedicated support lines for patients who are known to them. However, these initiatives exclude the

majority of people who are thought to be at the end of life because they have not been referred to specialist palliative care such as hospices. Their needs are thought to be able to be met by the generalist services. Telehealth offers face-to-face contact when direct access is difficult, whether due to geographical isolation, difficulty attending clinics due to poor health, or time delays in receiving a home visit. People with life-limiting illness are often burdened with fatigue and mobility issues and new or unexpected symptoms can arise at any time. Many complaints relating to end of life care arise as a result of events that occur outside GP surgery hours (DEMOS/Sue.Ryder, 2014). Many unplanned hospital admissions occur at night or over the weekend. At these times, patients encounter new health professionals they do not know and who have varying levels of palliative care expertise. Out of hours, patients and carers often do not know who to contact, as many of the services that they have faith in are unavailable.

The Gold Line

In Bradford & Airedale, an Electronic Palliative Care Coordination System (EPaCCS) has been developed to record all patients in the district identified as being in the last year of life. A number of these patients have been provided with 24-hour access to a Telehealth hub known as the Gold Line. This is staffed by registered nurses who have had additional training in communication skills and general palliative care principles. Access to the Gold Line is either via a single point of access telephone number, or via an app on an iPad, the latter enabling face-to-face contact. The service is envisaged as a single point of contact, for a group of patients who often have a disparate and extensive list of professionals involved in their care. Calls to Gold Line are triaged and may result in (1) direct advice (2) referral to another professional, or (3) admission to hospital or hospice. The Gold Line is novel in terms of its remit of offering support to all people identified as being potentially in their last year of life. Another novel feature is that a proportion of these patients who are assessed as being suitable are provided with an iPad that enables them to access the Hub using video, rather than just via a voice telephone connection (as yet there is no clear guidance as to whether a patient is provided solely with the telephone number, or whether they are also given the iPad. This decision is left up to the person who refers them to the Gold Line).

Literature Review

A systematic review of the evidence has been reported by Kidd et al (2010). They identified 111 papers relating to the use of telehealth in palliative care settings. 21 of these were included in their review, undertaken as part of a scoping exercise looking at uptake of

telehealth across Scotland. They explored a broad range of telehealth initiatives, including mobile phone apps for symptom management, and video-conferencing between hospice and oncology. Of the innovations reviewed the most similar service to the Gold Line appeared to be “Palcall”, a service providing 24-hour telephone advice for patients registered with a hospice service. It differed in terms of the nurses providing the advice; in Palcall these appeared to all be nurses with specialist palliative care training. This was reported by Campbell *et al* (2005) but although the service was described in detail, it was not evaluated from the perspectives of service users.

Johnston *et al* (2012) conducted an evaluation of the use of Telehealth in palliative care settings in Scotland, derived from focus groups with patients, carers and professionals. Their study explored a range of types of telehealth, such as video-conferencing, e-learning and support groups. Many of the initiatives they reviewed related to the provision of palliative care advice to professionals. For those services offering a similar intervention to Gold Line, the main benefits identified were as follows:

- It compared favourably with existing automated telephone services
- Services were valued very highly by those unable to leave their homes
- It can reduce confusion regarding knowing who to contact, particularly in crises

The main drawbacks were considered to be:

- Variation in broadband signal strength (the study covered remote areas of Scotland, whereas the areas covered by the Gold Line have reasonably good coverage according to a recent OfCom UK coverage report (Ofcom, 2013))
- Some people may perceive themselves as being less familiar or comfortable with the technology and therefore resist using it
- Varying understanding of the purpose of the service from both patients and staff
- Lack of continuity between out-of-hours services and telehealth providers

The service in Johnston *et al*'s review which was most similar to the Gold Line in structure was that studied by McCall & Keen (2008). Positive feedback was received about the use of a “virtual hospice” which included remote symptom monitoring and assessment as well as creative therapeutic support. However, this service was only available to patients who were already receiving hospice care, and it may be that their positive feedback related to the provision of hospice care as a whole. Often where patients are receiving input from multiple services, their level of satisfaction relates to their perception of their care as a

whole, and it may not be possible to extrapolate these views to the specific benefits of the virtual hospice. Campbell *et al* (2005) reported on a service to support patients and carers directly; however, their study was predominantly descriptive. It outlined the profiles of people using the service, but did not explore the views and perspectives of service users. In their study, 64% of calls came from carers. They concluded that patients and carers considered telehealth to be an adjunct to, rather than a replacement of, existing services, and that implementation needed to take into consideration the perspectives of a range of potential service users in order to maximise equity and acceptability. A further conclusion was that little was known about how telehealth initiatives relate to existing systems of care. The authors also note the importance of linking telehealth to regulatory bodies during implementation and development.

Because there were two existing reviews, a further literature search for this study was undertaken to identify and appraise existing evaluations of telehealth initiatives to support people at the end of life. This was limited to 2010-2015 in order not to replicate work already done in this area. However, it was not restricted to the United Kingdom as in the case of Kidd's review (Kidd *et al* 2010), as it was felt that there may be relevant research in other countries. . The databases CINAHL and MedLine were searched, as well as Google Scholar, using the combined search terms "telehealth", "telemedicine", "virtual hospice", "videolinking" with "palliative", "end of life" and "end-stage". References lists were also hand-searched. Inclusion criteria were papers that were primary research into the use of telehealth in end of life care. Papers focused on chronic disease management were excluded, as were papers that explored the views and perspectives of nursing and medical staff. The search terms used were as follows:

Box 1: Keywords used in search
Telehealth OR telemedicine OR information technology OR
Palliative care OR end of life care OR terminal disease OR hospice OR terminal illness
Year: 2010-2015

21 papers were identified, which were then hand searched. Of these, only 3 were available as full text, so the abstracts of the remaining papers were scrutinised. Included papers were those that reported on the views of patients and/or carers. Papers were excluded if they only explored the views of health professionals, referred to specific support after a treatment such as radiotherapy, or related to educational interventions supported by video information technology, or referred to paediatric palliative care. A paper reporting on organisational aspects of implementing telehealth was not included in the review. The majority of studies were undertaken in countries other than the United Kingdom so there may be limited transferability to the demographic of the population served by the Gold

Line. However, two international studies raised pertinent issues so they were included in the review.

A Canadian mixed-methods study on patients receiving palliative care was undertaken. They interviewed patients and family caregivers to find out their views of telehealth support, and identified the following three key benefits: increased access to care, family and caregiver reassurance, and pain management. Barriers to the use of the service included lack of integration of services, inappropriate timing of the service, and technical problems such as connectivity (Stern et al., 2012).

A Brazilian study reported on the use of the Edmonton Symptom Assessment Tool for evaluating the impact of telehealth on the symptom burden of patients (Hennemann-Krause et al., 2014). They followed 12 cancer patients through a range of consultations, some of whom received telehealth support as well as a range of other palliative interventions. They report that those receiving telehealth scored lower on distress scales than did those without this additional input, concluding that telehealth offers a useful adjunct to a package of care. However, this study did not report on any qualitative findings such as interviews or free text questionnaires, and bases its evaluation on a perceived improvement of symptoms in a relatively small sample.

Cox *et al* (2011) report on the use of e-technology to monitor patients' symptoms following palliative radiotherapy for lung cancer. They found a general reluctance on the part of physicians to permit the researchers access to their patients to assess the potential of this new technology. Clinicians perceived that their patients were generally too unwell, and rapidly deteriorating, and would not be suitable to participate in the study. The researchers were thus unable to report on any potential benefit of the service from the patients' perspectives.

A response to the Cox *et al* study by Abernethy *et al* (2011) suggests that despite the lack of findings, research involving very unwell patients is of importance in the evolution of healthcare. They suggested that patients in poor physical condition may prefer remote monitoring of symptoms, because of the privacy this offers. Their paper refers to the use of telehealth for monitoring symptom burden rather than the provision of support, which is clinician-led rather than patient-led. Concerns suggested by the author included inequalities in the uptake of technology by different ages and genders, and an unacceptable burden on carers to provide information; however they did not provide evidence that this was the case.

Although not strictly within the inclusion criteria, a study by Edwards *et al* (2014) was reviewed as it reported a large survey of patients with chronic health conditions (n=1740)

about the use of telehealth. 60% of participants stated they would make use of a dedicated telephone support line, while 57% said they would consider internet-based support. The main factors associated with the uptake of telehealth provision were confidence in using phone technologies, and the perception that there were more advantages than disadvantages. The study found no great difference in views on telehealth by socio-demographic variables. In this approach, the study population comprised people with long-term chronic conditions, both mental and physical. Although this population are likely to have many similar issues facing them as those referred to the Gold Line, there are also key differences, such as the speed of change of symptoms, and the involvement of other services. These differences may limit the usefulness of the findings of this study.

A randomised controlled trial of telehealth currently underway in the Netherlands is using a range of questionnaires to evaluate the benefits of the service, including the Edmonton Symptom Assessment Scale (ESAS) and the Hospital Anxiety and Depression Scale (HADS). The trial will also report on secondary outcome measures such as hospital admissions, perceived continuity of care, and patient & caregiver satisfaction (Duursma et al., 2011). Results from this trial have not yet been reported.

In summary, the literature review has highlighted a range of telehealth interventions that may be useful in end-of-life care. There are no completed randomised trials and no qualitative evaluation of a dedicated palliative care service within the United Kingdom has been identified using the current search criteria. It may be that services exist and have been evaluated, but the findings are unpublished. The current study seeks to address the gap in qualitative evaluation, by speaking directly to a group of patients who have been identified as being in the last year of life, and to their carers. The findings will add to the small but growing evidence base around the benefits and challenges to the utilisation of telehealth in end of life care in the community.

Study aims.

- *Identify examples of the range of situations leading to accessing the Gold Line*
- *Evaluate the attitudes and perspectives of patients and carers on Gold Line*
- *Describe different ways in which Gold Line is utilized*

Methodology

8 patients and 5 carers who had been given access to the Gold Line service were approached by a nurse who coordinates the "Hub". The Hub is the nurse support line and includes the Gold Line service. It is based within Airedale Hospital.

Patients provided with the Gold Line number all have a life-limiting condition that has led to their having been identified as potentially in the last year of life. These patients are added to the “Gold Standards Register” within the GP practices, with a view to being better placed to coordinate care between services during what can be an unpredictable time. This includes people with a range of illnesses, including cancer, heart disease and chronic respiratory conditions. In order to be referred to the Gold Line service they will have had a conversation with a healthcare professional, usually a General Practitioner (GP), in which the reason for the referral has been explained. They will be aware of their diagnoses and will also be aware of their limited prognoses, although that awareness will vary. It was intended that the sample include patients living alone as well as with a carer, and with a range of medical conditions, in order to demonstrate the different ways in which the Gold Line meets peoples' needs.

Once identified, patients and carers were verbally asked by the Hub nurse whether they would be happy to be sent an information sheet and consent form and the project was described. Information sheets and consent forms were sent to the patients' home and followed up two days later with a telephone call from one of 2 researchers on this study.

Participants were informed that they could be interviewed in a place of their choice, as long as there was no risk of breaching confidentiality and the setting was quiet enough to audio-record data. Potential venues included the University of Bradford (a “quiet room” can be booked) or an interview room in a local community centre. Most participants elected to be interviewed in their homes, with the exception of Carer 7 (place of work) and Patient 4 (hospital - due to admission).

The day before each scheduled interview, the researcher contacted the “Hub” nurse to check on the patient's record to ensure that as far as they were aware there had been no recent events that would impact on their suitability for interview, for example hospital admission, acute deterioration, or loss of capacity. Once this was confirmed, the participant was telephoned on the morning of the interview to offer a further opportunity to voice concerns or ask questions, and to ensure that it was convenient to visit that day.

The interviews were digitally audio-recorded. During the interview participants were asked a series of questions related to their experiences of using the service. The interview was semi-structured (See Appendix 1 for interview schedule) which means that any additional topics raised by the participants would also be explored should these be relevant to the research question.

Participants were given the opportunity to ask questions about the project before interviews commenced, and to withdraw at any stage of the process, without impacting on their access to the Gold Line service. None withdrew following initial consent. After the interviews, participants were asked whether they wished to check the transcripts; however, none did. They were also asked whether they wished to see a summary of the final report. None requested this.

Initially it was hoped that 5 patients and carers would be recruited and seen for three visits, at 2-monthly intervals. However, due either to patient deterioration or admission, this was not possible. In addition, the Hub nurse identified to recruit potential participants went on prolonged sick leave, so there were some delays in recruitment of participants.

Interviews were transcribed verbatim, and the scripts were analysed for broad themes. Comparison of identified themes was carried out individually and then between the four members of the research team in order to minimise the risk of bias. For the interim report, the themes were pre-defined as the questions asked during the interview (appendix 1). For the final report, however, the transcripts were analysed using an approach described by Bernard and Ryan (Bernard et al., 2012). This entailed listening and then reading all scripts several times, making notes of prominent issues (either because of their frequency or intensity) that related directly to the research questions. Sections of the script were highlighted and allocated to the identified themes. As further themes emerged during this stage they were added to the list. Themes were then clustered and collapsed in order to give coherence to the structure. Overarching themes were used in the presented findings.

Ethical issues

Ethical approval to conduct this study 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) (Appendix 2). A final report is required by the NRES in June 2015. Two researchers with prior backgrounds in palliative care undertook the interviews to ensure sensitivity and appropriate responsiveness to the participants and their situations.

Findings

Four patients identified by the Hub were not approached for interview due to deterioration or admission to hospital or hospice. One patient who was unable to communicate verbally could not be consented due to practical barriers; she would have needed a home visit by the Hub nurse for consenting, or a major amendment to the Ethics Application would have had to be made. In the event it was decided not to approach this patient. One patient with learning disabilities was not interviewed because of difficulties contacting his next-of-kin, leading to delayed consent during which time the patient died.

The demographics of the participants who were interviewed were as follows:

	Diagnosis	Lived alone?	Revisited
Patient 1	Cancer, bipolar disorder	N	Y
Carer 1			Y
Patient 2	Mesothelioma	Y	N (died)
Patient /Carer 3	Patient on GSF (cirrhosis) also a carer for husband on GSF (lymphoma and dementia)	N	N (died)
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

The following main themes were identified:-

1. Expectations and knowledge about Gold Line
 - 1.1 Changing needs
 - 1.2 Clarity of purpose
 2. Integration with other services
 - 2.1 Varieties of experience
 - 2.2 Working together
 3. What the Gold Line is for
 - 3.1 Out of hours support
 - 3.2 Expediting appropriate admissions
 - 3.3 Preventing admissions
 4. A “friend in the corner”
 - 4.1 Competence
 - 4.2 Companionship and support
 - 4.3 Responsiveness and reliability
 5. Emotional support and practical advice: examples of the Gold Line in Practice
 6. Using the technology
 - 6.1 Connectivity
 - 6.2 Intimate but at a distance
 - 6.3 A personal link
 7. Smoothing the journey
 - 7.1 Getting things done
 - 7.2 Confidence in the service
 - 7.3 Emotional impact of prognosis
 8. An example of Gold Line at the end of life.
-

1. Expectations and knowledge about the Gold Line service

1.1 Changing needs.

Of the six interviewees who were interviewed twice, four had used the Gold Line before the first interview and of these, only one had used it again in the second interview. Those who had not used it again attributed this to not having had the need, either due to their condition, or because of the support they received from elsewhere.

Carer 7 had stated that at first keeping health professionals out of the family home and maintaining normality had been very important. But as his wife deteriorated and on the day before she died, he contacted the Gold Line:-

"I just said, "you know, I said, it's not enough, the things that we are doing are not helping any more." And rang again, the Gold Line, and I said "thank you for leaving us alone, but we need you now". And they came with the GP. And they, you know, I think they just had, they upped the levels of whatever pain relief she was having and helped her to be more comfortable for the last few hours"

The importance of the Gold Line service not intruding until called in by the carer or patient was an important aspect of the service, as was their availability when required. But there were problems if the carer was not clear what the service could reasonably be expected to do. One carer described a very difficult domestic situation where she was caring for her husband who had fluctuating cognitive problems and occasionally became verbally aggressive towards her. She did not speak English and it was not clear whether she had understood the purpose of Gold Line or whether she had elected not to use it.

One carer, who had expressed dissatisfaction with the service in the first interview, had reflected upon this and claimed her views had been influenced more recently by hearing about the experience of a friend.

Carer 6 (2nd interview): *"I think it was one of those of "well at least they could help ***", yeah. They didn't do much for my Nan, but to be honest, when you actually look back on it... what else could they have done other than phone an ambulance, really? Do you know? Because of what situation, she was in. Yeah, it's bought me round to them a little bit more, yeah."*

1.2 Clarity of purpose

Most of those interviewed linked being offered the Gold Line to being offered palliative care

services or stopping active treatment.

Carer 6: *“Because she’s palliative care now.”*

Carer 4: *“We were offered the Gold Line when the nurse popped in to see Mum, when my Mum... she decided against the chemo.”*

Patient 9: *“They said because of my illness, because I’m terminally ill.”*

Carer 7 appeared to have been well aware of his wife’s prognosis:

“we knew it was moving quickly and then it became very much just about her being comfortable as she went towards death, it wasn’t about keeping her comfortable while she lives, does that make any sense? If it had been three months, and you going to have days when you’re like this and days like that and maybe getting bedsores, then possibly that would have been a different thing, but it wasn’t like that, because we knew”

Exceptions who did not appear clear as to the purpose of the Gold Line included Patient 5 and Carer 5 who both expressed a belief that the Gold Line was a means of accessing a GP much faster than through normal processes. Carer 5 did explain that she had been given the number because her husband was always in hospital and had been very ill, but did not give any rationale that included an indication that her husband was in the last year of life. Some who saw the Gold Line as part of palliative care provision also expressed the view that they had been given it to speed up access to services, or to help avoid hospital admissions.

Patient 1: *“they thought it was a good thing for me to be able to get quick help, I think. To get more rapid attention.”*

Patient 8: *“Because I were in and out of hospital a lot, you know. I think. I think that’s why... They thought... you know, there’s no need for him to come in, only in emergencies. And because I were in and out all the time, because I were catching infections, they give me an iPad, which I don’t know if that is... Nobody give me a reason, they just said,... One of the nurses – what’s her name, at (hospital). She said, “I’ll put you down for an iPad, because... I think it were, because I were in and out a lot.”*

Some talked of how the Gold Line had been introduced to them as a service they could call anytime, day or night.

Carer 7: *“she (hospital doctor) came in and said “can I have a quiet word?” And handed me a piece of paper with a phone number written on it, and just said “you can ring this number any time, day or night, anything you*

need.” And so that’s how I first heard of the Gold Line.”

Amongst patients who explicitly linked the Gold Line to palliative care there were differences in how much they felt this was relevant to them at the present time. Patient 2 expressed frustration at the pessimistic nature of the literature he had been given about his condition. He explained that palliative care services and the Gold Line would take over when his chemotherapy finished sometime in the future, but also expressed the view that he had actually been given Gold Line to overcompensate for what he perceived was a clinical mistake made by a hospital doctor.

2. Integration with other services

2.1 Variety of experiences.

All participants identified at least two sources of support from health or social care professionals with one patient identifying seven sources. District nurses and the GP were most commonly included and most identified some form of specialist palliative care service, although the precise service used varied as did the terminology used to describe them. When asked about what support services they currently received, seven of the thirteen interviewees specifically identified the Gold Line.. The reported quality of support was variable for individual services as well as for the care package as a whole. Two carers reported an inadequacy of support, carer 5 saying: *“I don’t get no support”* However, most of those interviewed spoke highly of one or more of the professionals or services they could access.

Carer 1: *“We have a lot of help”*

Carer 4: *“her main doctor...she’s very good”*

Patient 9: on the district nurse:- *She’s just a wonderful lady, she’ll bend over backwards to help me, she really is nice”.*

Patient/Carer 3: on the hospice palliative care nurses:- *“I can ring them and they’ll come and support in any way... they are excellent”.*

Patient 1: *“very good service from my GP’s now” “At night-time I can speak to the cancer ward, I’ve never done so, but the problem with that is if I need to speak to a doctor or something, if they’re busy doing something else it could be several hours. Which is why the iPad is absolutely brilliant.”*

Sometimes experiences were mixed:

Patient 2: on the GP:- *“Complete waste of time”. On the Hospital Cancer Support Centre:- “she filled everything out... she got everything for me. And she did that, and that was a great weight lifted.”*

Patient 2: *“I won’t be ringing the chemo Ward, because they’ll be over and done with, because they seem to drop you like a lead balloon. They seem to pick you up like, the palliative services were in first. They were in... And then after that she came round and said “now you’re fixed up with chemo and all, you don’t really need us now, we’ll sign you off our list.”*

For some people there was a need to continue to work with other problems. A number of interviewees spoke of receiving support from other health care specialties in addition to palliative care. Interventions and support from cancer services were still ongoing for four patients. Two patients received support from members of the mental health team, one from a diabetic nurse, one from a respiratory nurse, and another from the drug and alcohol team.

Carer 2 (2nd interview): *“She got diagnosed with anxiety in 2000, I think. And then she’s had it on and off, and then she got prescribed by the doctor to the specialist...She couldn’t go into all the big stores, shops, you know, but gradually got better and better and she could control it more then, you know. But obviously with this now, it’s kind of brought it back on, I think a little bit, you know. Because it’ll be like, “what’s going to happen?”*

Carer 1 (2nd interview): *“We have a mental health nurse who comes in weekly at the moment, and we had a visit when he started on the pills from the psychiatric doctor...They’re brilliant, and she is quite happy to come once a week, which feels enough at the moment... I think we do need somebody to... I need somebody to share the monitoring with me.*

Carer 6 (2nd interview): *“I had a word with the diabetic nurse and she says there’s no, it’s not really going to plummet, so just check her finger maybe once every two weeks, twice a week.”*

Patient 9: *“while I were in there (hospital)... the breathing nurse said I’m going to get you in contact with *(hospice)”.*

2.2 Working together

Views on how well, or how smoothly, 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."*

Carer 1 did report some improvement in the situation in the second interview, but still had some concerns.

Carer 1 (2nd interview): *"They are sort of talking to each other at least now...Information is being copied. But because the iPad scheme is centred in Trust 1, it does mean that there isn't the link with the Trust 2 hospital"*

3. When the Gold Line is for

3.1 Out of hours support

In her first interview Carer 1, who at that stage had not used the Gold Line, expressed that she would use it if she needed to contact someone in the night, when her preferred contacts were not available. This sentiment was echoed by Carer 6. Carer 5 described how she used it at around 6 am, having been awake all night trying not to contact the out-of-hours doctors. Eventually her partner became worse and so she contacted the Gold Line for advice.

Carer 5: *It was very quick, very quick. The doctor was very quick, very good. Better than before, anyway...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"*

3.2 Expediting appropriate admissions

One patient reported the use of Accident & Emergency (A&E) via emergency ambulance. This patient also contacted the Gold Line who reassured her she had done the right thing. She reported that she appreciated knowing she had the Gold Line to contact if the ambulance did not turn up. In a similar situation prior to being given the Gold Line this

patient had used the out of hours service who had contacted an ambulance for her, which she says didn't arrive until several hours had passed. This patient had found the process of using the out of hours service tiresome.

Patient 3: *"because you ring them up and they ask you a long list of questions, whoever it is, I don't know who it is, just a receptionist or what. And they say "just a moment, I'll transfer you" and you get the next person who asks you the same questions."*

A carer reported calling 999 to get an ambulance to take her mother to A&E after feeling frustrated when the attempts of a district nurse to try and get her mother admitted to a ward without the need to go via A&E appeared to be failing. The carer had not contacted Gold Line as their intervention had not prevented an admission through A&E in the past. In both the above cases haemorrhage had been the reason for calling the ambulance.

In cases of uncertainty as to the best course of action, the Gold Line offered an opportunity to be certain about the necessity of an acute admission. This process was described by Carer 1 as making her feel better about allowing admission. She considered this to have been a calm and considered decision, rather than a reaction, and given that her husband had requested he avoid hospital admissions where possible, the additional time to consider this was perceived to have helped avoid conflict.

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."*

3.3 Preventing admissions

Many of the participants viewed a hospital admission negatively, as a sign that something had gone wrong. Carer 6 described how dialing 999 had a massive impact on her mother:-

Carer 6: *"sends her into volumes of unbelievable madness, anxiety. It's like she takes her psyche out of her body and then becomes a totally different person.. she is extremely difficult to deal with when we eventually get her back from the hospital; the whole hospital experience for my mum is terrible".*

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, they got back to the Gold Line nurses on the teled and between them got a GP organised to come out and visit 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*

However, the carers of one patient reported a negative experience which occurred shortly after the Gold Line had been introduced. They had hoped that the Gold Line would help reduce the need for their relative to undergo an emergency ambulance admission to hospital via A&E. This type of admission was not avoided, which they reported led to great distress for the patient and frustration for themselves.

Carer 6: *"it took another two hours for the doctor to phone back just to turn around to me and say, "I'm sending an ambulance". I could have done that on the Friday, and this was on the Monday. I could have phoned 999 on the Friday, we've got people here that drive that could have taken her up... whether we misunderstood the Gold Line, making it easier to get ward access and less stressful treatment for different stages of it, or whether the Gold Line was just not getting down to the staff that it needs to, it just gets frustrating. I'm trying to say to her, "well, this is how it works." "But it shouldn't work like that", she's saying. So you're stuck in the middle, you're trying to understand the healthcare professionals and trying to appease your mum".*

The visual capability of using the iPad had value for one carer when negotiating with her husband, who wanted to avoid a hospital admission.

Carer 1 (2nd interview): *"By phone it would have been my interpretation of the situation, whereas with the iPad, they could actually see and interact directly with him, you know...Although there was *** saying "don't take me to hospital." Which might have made me hold back a bit from making that call (to the ward), just in case there were other options, and I think the iPad system clarified that for both of us."*

Gold Line was seen as a way of avoiding hospital admission but providing some support. Carer 2 considered that she knew the difference between needing a hospital admission and just "panicking a little bit", and said that she would use the Gold Line for the latter.

4 A “friend in the corner”

4.1 Competence

Several accounts described the ways in which the skills of the nurses working on Gold Line was conveyed through the competent manner in which they responded to requests:-

Carer 3: *“I rang one time, it was quite late and at that point in the middle of the night if someone had said “I’ve just got to go and find the notes” I would have thought “fair enough”, but they didn’t – they just, they just knew exactly who I was when I rang”*

Patient 3: *“she knew, she knew what to do. You can tell, you can tell when you’re talking on the phone, you don’t have to see the person to know that they know what they’re talking about. You know, you just pick it up straight away. And if they say “just hang on a minute, I’ll just go and see so and so” you’re thinking “oh hell, we’ve got the learner here”*

Carer 7: *“Everything they said they would do, they did. They were very reliable, I have confidence in it”*

Patient 8: *“I think things are getting better as they go along. You know, obviously there’s going to be teething problems, but you know, as it’s gone on it’s got better. You know, especially ones I know... who know me, they know I’m a bit down... So yes, them people who know me just... You know, are really helpful. The others are sort of... They don’t know me, you know. They don’t know me situation... They don’t know all the ins and outs but certain nurses do. And yes, it’s a very good thing.”*

Gold Line can be something that might help in the future :

Patient 1: *“I mean, the disease will come back again, because it always does. It’s not going to go away forever, so in the next few months, next year, whatever it will come back again, and it will come back into its use again, obviously. But at the moment I haven’t had any problems where I’ve had to use it.”*

4.2 Companionship and support

Carer 2: *“I think that initial help there, it does calm you down a bit because you know that somebody’s there.”*

Patient 3: *“And I’ve just sat there and cried to them, and you know, they just listen and offer any help, “do want us to get your GP out? Do you want*

us to get somebody to get you some medication?" And if not "just carry on talking, you're all right, carry on crying, you're all right."

4.3 Responsiveness and reliability

Most of those interviewed reported that they had not had any problems getting through to the Gold Line and that calls had been answered quickly.

Patient 1: *"Straight through instantly. Only once I think they didn't answer straight away but within half a minute they were there."*

Carer 7: *"And they also, if ever they couldn't do anything they said "you know, we'll ring you back in five minutes" and they always did. Never failed to do that."*

Patient 8: *"Oh, they answer straight away, you know.... No problems at all getting through."*

Speaking about the difference between ringing the Gold Line and NHS 111, Patient 2 observed

Patient 2: *"They answered the phone straight away. It wasn't a computer"*

The carers of one patient had a less positive experience and described a situation where it appeared the computer systems which enable the Gold Line nurses to access patient's records were not working.

Carer 6: *"That time that I actually called Gold Line as well, the first time I phoned the nurse on the other end of the phone were like, "well, I can't get on the system," so I've got to go through everything. Obviously, you put the name in and it will come up with what's wrong with Nanna, but she couldn't even get that, so I had to go through everything, the medications that she took, and everything. Just so she could write it down, just so she could speak to this doctor, which I found a bit, I found that a bit silly to be honest."*

5. Emotional support and practical advice: examples of Gold Line in practice

Some participants talked of 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 8: *"Day, night, whatever, yes. Even if I just feel a bit depressed and*

I just want somebody to talk to, you know, with living on me own. I'll ring them and I'll tell them "I'm tired" you know "it's getting me down, all this... All this... You know, breathing difficulties". You know, I'm a bit depressed about it sometimes. And it's just good to talk to them, you know. "

Patient 9: *"the iPad is invaluable for me...when there is an aspiration 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, it's not just on the phone hearing you, they can physically see ... if I go to bed I can just sit up and just chat and even if I feel breathless a bit I can just ring up and say "I'm a bit breathless today. Can we have a chat?" 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."*

One carer had received support from the Gold Line whilst planning his wife's discharge from hospital, at various points throughout her care, around her death at home and then after her death. This support came in the form of practical advice such as how to obtain or return equipment, provision of specific requested information and emotional support.

Carer 7: *"so I rang up and said, "look, would you just please describe to me what's going to happen, what are we going to see?" Because then, if it's not a shock to me. I mean I've never seen anybody die before, but if it's not a shock to me then we'll be able to react better for P "*
"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 maybe needed addressing in a different way."

"the next time that I rang them was just an hour or two later to say P's died. I don't know what to do." I mean, what do you do? Who do you ring? I have no idea. What do you do? And they were lovely, and they stayed on the phone for quite a while, just being kind, but then said, "right, we'll sort it out. This is what is going to happen. The GP will come at some point, and then you'll need to do this tomorrow and so on." So that was a very practical thing, you know, like, what do you do?"

When first interviewed Carer 1 had not used the Gold Line and felt it would not be her first point of contact, but that it was reassuring to know it was there. The carer valued that the service enabled her husband to get support in the night, thereby allowing her to catch up on sleep.

Carer 1: *“So I’ve benefited indirectly, although I’ve not used it directly myself.”*

When interviewed a second time this carer reported how they had contacted the Gold Line when she became concerned about her husband’s condition.

Carer 1 (2nd interview) *“Well, there was an event ... when he was actually quite ill... he slept in the chair most of the day, but his chest was quite wheezy. And eventually I realised he wasn’t, he hadn’t eaten, he hadn’t drunk. And we did use the iPad then. And that was really helpful, because I was quite anxious...And eventually, with discussion with them we decided I should take him into hospital and it was actually a pneumonia. So it was very serious and we nearly lost him... it was kind of as the day progressed. It just gradually dawned on me that things were wrong, you know. And then I needed that reassurance as to whether I should take action straightaway, and I was talked through that, which was good.”*

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.” Because I know it’s there. So it’s actually saved phone calls... It is like a crutch, basically. I know if I ring it, I sometimes sit down, have a cup of tea, ten minutes, and I’m ready to go back to bed again.”*

Carer 3: *“I rang one time, it was quite late and at that point in the middle of the night if someone had said “I’ve just got to go and find the notes” I would have thought “fair enough”, but they didn’t – they just, they just knew exactly who I was when I rang”*

Carer 3 also described in detail a situation where she was able to turn on the iPad and show the Gold Line operative, using the iPad, how her husband was behaving, and follow their advice to firstly administer some analgesia, and then when this was ineffective to try a “little blue thingy that you break in half and pop under your tongue” when her husband was becoming agitated and distressed. A visit was arranged to assess him, but crucially this incident enabled and empowered her to try some different things to try and make him feel calmer. Indeed, when the nurses did arrive...

Carer 3:*“he’d sort of settled down, and he sort of said to my daughter, “well, I think I’ll have some soup now, I’ll have some mushroom soup,” he said. And the nurses came and they had a look at everything and they took a water sample... the next morning he were 90% better. So to me, it keeps people out of hospital, it gives you security. I don’t use it*

an awful lot, but there's times when I fly for it, like then and that was a time when it just did the trick that, because it calmed him as well."

6. Using the technology

6.1 Wireless connectivity

One patient described the problems he had experienced when he took the iPad to a hotel and could not access the internet.

Patient 1: *"Because I didn't know what to do. I went on it, and you're on somebody else's Wi-Fi and that's the problem obviously, it didn't recognise anything. And in the end, it said do you want to, whatever, and I tried doing something on it, but it didn't work. So when I came back home, it still wasn't working so I rang up the helpline and they sorted it out."*

Another patient described how she had been supported by the Gold Line telephone line when she was unable to use the iPad.

Patient 9: *"Well I had a problem yesterday, because the iPad had something downloading to it, but I got them on the phone and they said, download it and I did and within fifteen twenty minutes, they were back up and running. And I were talking to them on the phone at the time when it was doing it."*

6.2 Intimate but at a distance

There were differences in attitudes towards having people visit at home. For some people, the iPad offered an alternative to a visit, managing to sustain a personal touch without actually attending. Over time, patients and carers got to know the Gold Line nurses, and developed rapport. This continuity was positively perceived.

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. "*

Those who used the iPad reported satisfaction with the face-to-face aspect of the service. One of the participants (who had the telephone line only) said that he would consider the iPad to be an invasion of privacy and stated a preference for the telephone line due to the

rapid decline of his wife's condition and wanting some level of control over their circumstances. He acknowledged, however, that if their situation had been different then he could imagine using the iPad.

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.*

A carer described how she had used the iPad to seek advice about how to deal with her confused husband without having to spend time describing his behaviour.

Patient/Carer 3: *"So I got on the iPad and I turned the iPad and I said, "look at that!" (laughs) and she could see that he was wandering about, distressed, disorientated, quite aggressive, quite agitated."*

7 Smoothing the journey

7.1 Getting things done

Participants all agreed that the Gold Line responded rapidly to their calls, particularly out of hours. Patient 9 spoke of the relief she felt knowing the Gold Line could contact an out of hours doctor for her if needed.

Patient 9: *"They said "you're okay, you don't want me to phone the doctor?" and they can ring my GP and get the out of hours to come and see me. If I do that, it's not going to happen, if I ring for an out of hours doctor it's just not going to happen... But they, they can push it forward, get them to come and see me. And that's amazing. And that makes me a lot less anxious about the whole situation."*

7.2 Confidence in service

Patient 9 had visited A&E due to an increase in pain. He was not satisfied with his treatment. The Gold Line was quite new to him at the time and he indicated that if he were in the same situation again he would contact it, rather than go to A&E.

When asked if they would use the Gold Line again, most participants said that they would, but the reasons varied:

Patient 1: *"Oh yes, I'd ring them first. Because there's no point going onto the hospital I can't speak to anybody."*

Patient 2: *“Yes, I’d use it again, no qualms” (although he later admitted that he considered “it’s too early to tell.”)*

7.3 Emotional impact of prognosis

Several participants described feeling dazed when they first heard their prognosis. They were unable to retain any information that was given:

Carer 7: *“she was sat there, I was sat here, we were just looking at each other and we didn’t know what to do. We didn’t know what to do”*

Patient 2: *“It was unbelievable. I don’t think you can imagine what it’s like, unless you go through it. It’s unbelievable. I filled out an insurance form for work, for a claim, and I totally forgot about one place I had worked. I mean, how do you forget where you’ve worked? It’s like everybody in life has a goal, and you just imagine, all your goals have just been taken away, and that’s what it feels like. You’re just desolate. We were just going through the motions of life.”*

In this emotional state, there was some relief at the simplicity of having a single contact number for Gold Line. Carer 7 said:-

Carer 7: *“I did have a pile of stuff from the palliative care team, and we had things from the hospital, and drugs and things, and I did briefly think “Gold Line what? What is the Gold Line?” But then the name is quite handy, in that it does sort of stick in your head, and it instantly. Kind of makes you think...I got piles of information from all over the place, but that one phone number was fantastic.”*

8. 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: *“there was no need to tell her that “you’re feeling restless because this is your body closing down”, because she wasn’t... she never had more than maybe a minute or two lucid, being properly awake. And that would have been cruel, because I had no idea what she would understand or remember from what I said to her, but other than just feeling kind of restless, you know, we had a few laughs and jokes that night as well. And she was sad and I held her when I could. But she was just, that was difficult. 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. I could care for her, and I could react to the things she did and said what I saw, and not be - I wasn't panicking, or alarmed. I mean, I was sad and frightened, but not... It gave me sort of control over my feelings, which ultimately meant that she was looked after better than she would have been"

Later, he described the value of speaking to people openly about death and dying, and receiving a response that was at an appropriate level:

"And the fact that all of the people involved with it clearly know what they're talking about. And are not afraid to have conversations about death, is kind of nice"

"I got a really good explanation, appropriate explanation for me... I kind of appreciated that they judged my level of understanding and the fact that I really did want to know.. she was just very, I think very understanding.. I'm very grateful that those sorts of things happened, because it meant that, it means that now, those things that happened on that night meant that my children are coping much better now."

Discussion

The qualitative evaluation of the Gold line explored the experiences of patient and carers who had used both the telephone line and the Ipad app. The findings have highlighted a degree of concordance with previous studies.

Introducing a new service and understanding its purpose

From the available evidence the introduction of the Gold Line to patients and carers needs greater clarity about the reasons for providing the service and about what the service can be expected to achieve. Participant narratives indicate this initial information may at times be clouded by concurrent discussions around prognosis. There was some consensus by the participants that the Gold Line was offered in combination with receiving palliative care for those with cancer. However those with a non-malignant diagnosis appeared to have less clarity about why they had been offered the service. The point of referral to Gold Line can be a difficult time for patients and carers. It is important that the purpose of the service is communicated clearly. The simplicity of the Gold Line “card” was appreciated. However, the range of views regarding the purpose of the service suggests that it may be helpful to provide additional information, perhaps in the form of a leaflet or website.

There was also some difference in understanding of the service between patients and carers. This was also seen in who used the ipad and who made the contact with the Gold Line staff. For patients who wanted to manage their own conditions, they were the main user of the service, however where the patient preferred their family to manage the contact or when there were too unwell or confused the control over contact was with the family members/carers.

New technologies and maintaining connectivity

Reflecting the findings by Johnson et al (2012) issues with wireless connectivity and downloads affecting the operation of the Ipad were mentioned. However, the use of the telephone helpline enabled these issues to be resolved. This highlighted the need to account for mobility of patients taking their Ipads into different locations where knowing how to access new wireless settings was essential. Whilst the numbers are small in this study, the developing reliance on the accessibility offered by the Ipad to the Gold line nurses when patients are not at home does need considering in the advice and information provided. It appears that a high priority for this group of patients and family members/carers is the ease of use, combined with the reliability and connectivity of the service. However, it was very clear from the story told by one family member/carer that

tolerance for mistakes or misjudgements is rightfully low at this vulnerable time of someone's life.

Given that participants highlighted both positive and negative aspects of the telephone and the video line, investment in one technology rather than the other would need careful consideration. Indeed, echoing the findings of Johnston et al (2010), technology to support people at home tends to expand in relation both to local demographic conditions, and the acceptability of the service to health care workers

Providing personalised care through technology

The Gold Line overall was perceived to enable a personalised approach to the contact and care offered over the telephone and over the Ipad. Both patients and family members/carers commented on the friendliness and responsiveness of the Gold Line staff. The instantly available information on each patient was most valued thus preventing the need to repeat information at a stressful time with unknown or untrusted telephone operators.

The face to face nature of the Ipad was found to be very helpful in that the patient or family member/carer could show the Gold Line staff what was happening to themselves or their relative. Users of the Gold Line liked being able to see the staff and felt reassured by this. This finding supports, in part, the work by Johnson et al (2012) and Stern et al (2012). However, this evaluation did also highlight that not all wanted the face to face contact offered by the Ipad, views about the relative "privacy" offered by the two options differed with a wish to control visual access to the home for some and has been raised by Broderick and Lindeman (2013). This also supports the competing discourses found by Greenhalgh et al (2012) between personalised care and potential alienation.

Out of Hours support

The Gold Line was perceived to provide practical advice, symptom advice, reassurance and emotional support to patients and family member out of hours. The competence of the nurses to provide advice about managing symptoms and guiding families through the use of particular medications was valued. Patients also valued the direct advice offered to them in the middle of the night when sleep was challenging. The ability to call in when breathless and on the verge of a panic attack enabled one patient to be able to manage these episodes more effectively. It is often the crisis in the middle of the night that can lead to an admission to hospital.

Practical advice about what to expect in the last hours of life was also offered and valued by one family member/carer, enabling him to prepare himself and his family and manage his wife's death at home in a manner that most palliative care services would identify as a good death.

The Gold Line was also perceived to be the main service to cover out of hours for these participants. It provided a personalised, responsive, safe and efficient service to enable a situation to be assessed and services to be coordinated. The Gold Line was perceived to provide a process that accesses emergency services and GPs by evading the standard processes which participants felt were depersonalised and time consuming. However, the clarity in understanding the role of the service in facilitating appropriate admission as well as preventing inappropriate admissions was missing for at least one family where an emergency admission was arranged, causing distress to the patient and family. This links directly to issues related to setting up a new service, already discussed

What cannot be underestimated is the reassurance that the Gold Line offered across a variety of contacts and issues out of hours where families often feel most alone (NCPC & Macmillan Cancer Support 2011).

Seamlessness and coordination of services

The Gold Line has coordinated and provided access to services and is seen as complementary to the hospice, district nursing and GP services for some participants. However, what is apparent, is that for some patients and their family members/carers who actually coordinates and facilitates the intervention of different services is not always apparent. Having one number to call is valued when some people have a number of services involved in their care. Often the Hospice is seen in this role, but there are some examples from the interviews of how the Gold Line team have responded and started a sequence of services and interventions to meet a patient need.

Is the Gold Line meeting the needs of patients and their family members/carers? From this small qualitative evaluative study, the Gold Line is providing a service that people trust and feel a sense of security and reassurance having. Issues that have arisen appear to be related to ensuring people understand the service aims and what it can and cannot achieve. Early introduction and lack of information did affect some perceptions of the service. It is key to responding to individual need and choice where having either an iPad or telephone line is possible.

Filling a Gap

The Gold Line can be seen to be filling the gap between standard services in an effort to provide ever increasing support for people facing the end of life with limited community and out of hours service provision. It 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. The Gold Line is not a Specialist Palliative Care service, but it is supported by the local Specialist Palliative Care team. Gold Line nurses have identified some learning needs around end of life care which have been provided by the team.

Limitations of the Study

This evaluation represents a small sample of the full range of service users who are currently accessing support from Gold Line. Due to funding and time constraints, it was not possible to follow participants for more than two subsequent visits, so 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. This is something that can sadly occur in end of life care research.

Although one of the couples visited were Italian, the remainder of the sample were White British. This sample is not representative of the local demography, but it appeared from discussions with the Hub nurse that the service is somewhat underutilised by black and minority ethnic groups. Her perception of this was that often people have wider family networks, and it is known that it is rarer for some ethnicities to live alone, particularly South-East Asian families (ONS, 2011). This is the sort of assumption that needs to be tested empirically to minimise the risk that some groups are disadvantaged. Purposive sampling of potential or current service users from minority groups would be a useful further step and may indicate potential barriers to uptake that have not been identified within the current study.

The knowledge and competence of the nurses was generally positively viewed. This evaluation has not sought the perspectives of the nurses, but given the clearly emotive content of some of the calls that have been described above, it would be prudent to undertake an evaluation of both the supportive and educative needs of the workforce.

Conclusion and Recommendations

Most people in the UK with terminal illnesses express a wish to die at home, which is achieved by a minority. Reasons for high hospital admissions in the last year of life include out of hours crises, uncontrolled symptoms and lack of support

The Gold Line is viewed as a valuable adjunct (and sometimes replacement for) mainstream services in both the acute and community settings. It provides a personalised service at a time of need and potential crisis. It appears that overnight is a time when patients and family members reach out to the Gold Line to provide practical advice, support and calm reassurance. It is this personalised support that can prevent or reduce a crisis, facilitate intervention, manage symptoms or prepare family members for an expected death.

The support provided by the Gold Line does not necessarily prevent hospital admissions; sometimes admission is the appropriate course of action, as shown by some of the other stories in this report. In some cases, however, it can prevent a patient being admitted in a crisis by providing an alternative source of support. However, as we can see from at least one patient, just calming an episode of breathlessness can prevent panic and what might under less supportive circumstances lead to a crisis admission.

The Gold Line has great potential to fill the gap in out of hours service provision for patients and their families over the last year of life. Palliative care services have a long held tradition of identifying and filling gaps in patient care often found in the space between statutory services and the independent and voluntary sectors. However, the future development of the Gold Line needs to carefully consider how the service is rolled out, how patients and family members have the service explained to them and what expectations they can have of the service.

There was a difference in perception and understanding of the reasoning behind being offered the Gold Line by patients with a non-malignant diagnosis and their family and this is one area that needs further exploration and discussion. Importantly the Gold Line needs to consider if they are adequately engaging in an effective way with people from the diverse cultural and educational backgrounds across Bradford, Airedale and Craven in order that the needs of all client groups are served.

The success of novel technologies such as the Ipad and telephone helpline rely on perceptions of patients, carers and staff of its ability to support and enhance the provision of care.

Moving Forwards

There are opportunities to continue to extend and explore the work of telemedicine in supporting people at home in the last year of life. Some potential avenues of work might be to:

- Wider roll out of the Gold Line with improved patient and family preparation
- Use of Gold Line to improve outreach care into care homes
- Use of the Gold Line Ipad to enable patients and families to participate in multidisciplinary case discussions
- Use of the Gold Line Ipad to support Carer education in the home eg. Medicines management and giving prn doses of medication
- Use of the Gold Line Ipad to assist in bedside ethical decision-making with palliative care team eg withdrawal of treatment

- Explore the perceptions of the Gold Line Hub staff and their educational needs and the potential changing roles of specialist palliative care staff in relation to telemedicine
- Explore and develop the use of the Gold Line with patients who have a non-malignant diagnosis, as they have a less clear understanding of why they were receiving the service
- Explore and develop the use of the Gold with patients who are from a range of different cultural, linguistic and educational backgrounds

Appendix 1 – Semi-Structured Interview Schedule

1. Who are the healthcare professionals and services who support you, and what is it that they do?
2. What is the reason that you have been give the GoldLine number?
3. Have you used the service? If so, can you tell us about what happened and why?
4. If you haven't used it, why is that? Do you think you would use it? and is it helpful knowing it's there?
5. What situations might you use the Gold Line for? (If you haven't already)
6. Were there any problems getting through? If you left a message did it take long for them to get back to you?
7. Have you accessed any other out of hours services? Eg A&E, 111, walk-in service, pharmacy
8. What was the result of contacting the GoldLine service?
9. How did they respond to your problem? Did you feel the nurse helped you, and how?
10. Would you use it again?

Appendix 2 – Letter of confirmation of ethical approval



Health Research Authority

NRES Committee Yorkshire & The Humber - Leeds East

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19 June 2014

Mrs Laura I Middleton-Green
Lecturer in palliative and end-of-life care
University of Bradford
Richmond Road
Bradford
BD7 1DP

Dear Mrs Middleton-Green

Study title: **Qualitative evaluation of patient and carer perceptions on the implementation of the "Gold Line" telephone support service for patients identified as being in the last year of life and living at home**

REC reference: **14/YH/0166**

IRAS project ID: **149772**

Thank you for your submission of 18 June 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair together with Professor Kenneth Brodlie.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Sarah Grimshaw, nrescommittee.yorkandhumber-leedseast@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations

A Research Ethics Committee established by the Health Research Authority

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