Using telehealth for people at the end of life with chronic illness in Australia

Margaret O'Connor, Tim Moore and Yaping Zhong

Abstract

Background: Traditional models of palliative care have been tested by the challenges of caring for increasing numbers of people at the end stages of a chronic non-malignant illness. The COVID-19 pandemic and consequent reliance on telehealth services, has enabled the development of creative models of care. Aims: To improve home-based palliative care for people with chronic illness using telehealth, and this was demonstrated using quality-of-life measures. Methods: A total of 35 non-cancer referrals to a community palliative care service were recommended for the pilot project, with one specialist palliative care nurse as their contact. All were offered a telehealth service with a specially designed app to self-monitor their symptoms, a session on advance care directives, and self-rated quality-of-life measures using the RAND 36-Item Health Survey (Version 1.0), consisting of 36 items that cover nine domains. Statistical analysis was performed using SPSS software. Findings: Over the 21 months of the pilot study, 13 people chose to participate in the pilot. For participants, telehealth meant more control over their symptoms, fewer emergency presentations and appointment travel time was alleviated. Quality-of-life surveys highlighted physical impairments, which did not change over time. Conclusion: This pilot programme demonstrated an innovative approach to addressing the demands of people dying of chronic illness, with further work required to explore the place of telehealth consultations in the overall healthcare system.

Key words: • chronic illness • palliative care• quality of life • telehealth • community palliative care service

ost palliative care services have traditionally cared for people dying of cancer (Connor and Gomez, 2017). Over recent years, however, there has been a developing focus on the end-of-life needs of people dying from chronic non-malignant illnesses, with the Victorian State government recommending that palliative care services need to be more responsive to the unmet needs of this population (Victorian Auditor-General's Report on Palliative Care, 2015). However, perhaps because of an unpredictable illness trajectory at the end of life, and that people are living longer with the disabilities of chronic illnesses, the use of palliative care services by people dying with chronic illnesses has been slow. Thus, it may be difficult to demonstrate the link between the use of palliative care, and lower use of medical resources like hospitalisations (Maddocks et al, 2017).

Chronic illnesses, specifically heart and lung diseases, are among the five leading causes of death in Australia (ABS Causes of Death, Australia, 2020). Healthcare systems are often ill-equipped to meet the needs of those people with chronic illness, meaning that people risk either falling through the cracks, or they receive inappropriate and/or ineffective care (Victorian Auditor-General's Report on Palliative Care, 2015). Numerous studies have queried the appropriate use of diagnostic testing and acute hospitalisations in the last few weeks/ months of life (de Schreye, 2018), indicating an emphasis on life-prolonging care, instead of promoting comfort when death is expected in the foreseeable future (Scherens, 2018).

People with chronic illness prefer care at home to have more control over their care (Scherens, 2018), and to receive home-based palliative care (Swiersson and Duckett, 2014). Supporting care at home, may provide a more consistent alignment between the use of medical resources and an individual's care wishes (O'Connor and Moore, 2022). A 2016 US-based study described the benefits of home-based palliative care on healthcare use for individuals with chronic obstructive airways disease, reported fewer hospital admissions and lower costs (Cassell et

Margaret O'Connor Emeritus Professor of Nursing, Monash University, Australia

Tim Moore Palliative care Clinical Nurse Consultant, Melbourne City Mission, Palliative Care, Australia

Yaping Zhong Research Fellow, Nursing and Midwifery, Monash University, Australia

Correspondence to: margaret.oconnor@ monash.edu al, 2016). Home-based palliative care may reduce hospital deaths, improve individuals' quality-oflife and enable greater control over the symptoms experienced at the end of life (O'Connor and Moore, 2022).

Telehealth has become an acceptable way of connecting clinicians with those in need, spurred on by the COVID-19 pandemic which severely limited face-to-face contact (O'Connor and Moore, 2022). While vast distances inhibit access to healthcare services in regional and rural Australia, and telehealth has been seen as a way to equalise access, some argue that the wider use of telehealth was a rapid response, forced upon healthcare professionals as a consequence of COVID-19 (Adams et al, 2021). Telehealth has proven useful in terms of easing access, especially when distance is a difficulty (O'Connor and Moore, 2022), and studies have demonstrated the equivalent satisfaction compared to in-person interactions (Sirintrapun and Lopez, 2018). Adams et al (2021) suggested that telehealth may be of most benefit when monitoring chronic conditions, not for diagnosis or treatment.

In Australia, case conferencing using telehealth comprised 14% of specialist palliative care consultations in 2020/21 (www.AIHW.gov.au/ palliative-care-services).There have been calls for telehealth to become a permanent feature of Medicare, Australia's universal healthcare coverage system, and to make telehealth a normal offering among other modes of care (Cloyd and Thompson, 2020; Wosik et al, 2020). There are many documented benefits of telehealth, including reduced adverse events, improved healthcare outcomes and ease of access for those living in rural areas (Wade et al, 2012).

The use of telehealth may serve to shift some healthcare from institutions to people's homes (Dorsey and Topol, 2020). An essential aspect of communication using technology is building rapport, which while contested, is also seen as possible (Henry et al, 2018; English 2021).

This paper describes a pilot project which aimed to improve home-based palliative care management for people with chronic illness; reduce emergency department presentations; and to improve self-rated quality-of-life (QoL). An app was offered to participants to assist in developing both telehealth capability and increase service capacity in the palliative care of people with chronic illness.

Method

The aims of the pilot project were to:
Increase interactions with general practitioners and medical specialists

- Improve home-based management of infective exacerbations, and therefore reduce emergency department presentations
- Increase completion of advance care directives (which include refusal of treatment)
- Improve self-rated quality of life (QOL)
- Increase engagement with counselling.

From June 2021—March 2023, all referrals of those with a non-cancer diagnosis to a community-based palliative care service, were recommended the pilot project, whereby one specialist palliative care registered nurse (the clinical lead) became their main contact. Individuals were admitted into the project if deemed to not be at or near the end of their life at admission.

Data collection

All participants were offered the opportunity to develop an exacerbation of symptoms plan, using a specifically-developed app—PalcareGo, which enabled the self-monitoring of symptoms and aimed to prevent a return to hospital when experiencing an exacerbation of their condition.

Responsiveness to the Edmonton Symptom Assessment Scale (ESAS) self-reported via the app, was measured, as were the numbers of an individual's interactions with their general practitioner, and/or their hospital specialist team. The app was monitored by the clinical lead, who used the results to plan responses to individuals, with particular attention to those reporting higher symptom scores.

Additionally, self-rated quality-of-life measures were undertaken using RAND SF-36 Item Health Survey (Version 1.0) (Hays et al, 1993) at three time-points, on admission at 3 months and 6 months. An additional short qualitative survey was mailed to carers to provide additional feedback. Ethical approval was received from Monash University (no:30476).

Content of the programme

As noted, all participants were offered the Palcare Go app. The clinical lead provided initial education on the app's use, then ongoing support throughout the period. Those who chose to use the app were able to self-monitor their symptoms using the ESAS, which were then visible to the clinical lead. Scores above three activated a contact from a clinician, either by phone or in person. Participants were additionally offered an educational session on advance care directives.

Instruments:

The widely-used RAND 36-Item Health Survey (Version 1.0), a validated instrument that

measures health-related quality-of-life (Hays et al, 1993), was administered at baseline and at months 3 and 6. The Survey demonstrated good to high levels of reliability across its scales, with alpha values ranging from 0.78 to 0.93 (RAND Health Care, 2023). This is based on data from the Medical Outcomes Study (n=2471), which involved participants in an observational study examining variations in the practice styles of physicians and patient outcomes across different healthcare delivery systems (Ware and Sherbourne, 1992; RAND Health Care, 2023).

The instrument consisted of 36 items that covered nine domains: physical functioning (10 items), role limitations due to physical health (4 items), role limitations due to emotional problems (3 items), energy/fatigue (4 items), emotional wellbeing (5 items), social functioning (2 items), pain (2 items), general health (5 items), and health change perception (1 item). All scores were transformed to a 0 to 100 scale based on a standardised scoring system. Lower transformed scores indicate poorer health-related quality of life (Hays et al, 1993).

Statistical analysis:

The normality of the variables was checked using the Shapiro-Wilk test. Normally distributed variables were reported as mean ± standard deviation, while non-normally distributed variables were reported as median \pm interguartile range. Changes in participant responses before, 3 months, and 6 months after the telehealth programme were evaluated using repeated measures ANOVA for normally distributed variables, and the Friedman and Wilcoxon signed-rank tests for non-normally distributed variables. In all analyses, a two-sided p < 0.05was considered statistically significant. Any missing values were excluded from the domain score calculations according to the instrument's scoring instructions (Hays et al, 1993). Statistical analysis was performed using SPSS software (IBM SPSS Statistics for Windows, version 28.0. Armonk, NY: IBM Corp.).

This study had a statistical power of 18%, with a sample size of 10, an alpha level of 0.05 (2 tails), and an effect size of 0.39 (Faul et al, 2007). According to Cohen (1988), effect sizes below 0.50 are generally considered to be small, those between 0.50 and 0.80 are moderate, and those above 0.80 are large.

Results

Of those admitted to the palliative care service over the 21 months of the pilot study, there were 35 people with chronic terminal illness; of them, 13 chose to participate in the pilot study using the app, and to respond to the quality-of-life surveys. Referrals to the pilot programme came from a variety of sources—general practitioners, hospital-based palliative care staff, and other external sources.

Participants' demographics:

Of the 35 participants (22 female, 13 male), most had a primary diagnosis of lung disease and were aged 54–95 years old (mean 72.9, median 73). Of those who responded to the quality-of-life surveys (n=13), ten completed all three surveys, with three participants dying before they were able to complete all surveys.

The average length of time on the pilot programme was 159 days (median 95 days), with 16 deaths during the trial period. In the first year there were 107 individual telehealth sessions, 157 in the 9-month period of the second year.

A total of 13 participants received formal counselling, and while there were 25 conversations about advance care planning, only ten participants wrote an advance care directive.

Across all clients on PalCare, there were 194 instances of direct liaison regarding clients between the clinical lead and treating specialists and/or case managers. The number of specialist contacts for each client fell within a range of 0–38 instances, with an average of 5.5 (median four) contacts per client. The clinical lead also completed regular meetings and liased with internal and external stakeholders during the trial.

Across the duration of the study, there were 32 instances of individuals commencing their plan for managing an exacerbation of their illness, with 22 of these following instruction from the clinical lead. This included commencing antibiotics, corticosteroids or diuretics. Of these, 10 courses of treatment were commenced either by themselves, or following consultation with their general practitioner, following the earlier education from the clinical lead. This demonstrates up to 32 instances of potential emergency admissions avoided in part due to the support provided by the project. Additionally, the participants who used the resources of the project for longer than 6 months attended the emergency department an average of 1.08 times compared to the baseline average of 1.25 times in the 12 months prior to admission.

Health-related quality-of-life

Table 1 displays the RAND domain scores at baseline, 3 and 6 months after the telehealth programme. The only significant change was observed in the emotional wellbeing domain, which decreased significantly 6 months after the programme compared to the baseline (mean changed from 62.5 to 47.6; F(2, 18)=5.746; p < 0.05). The other eight domains did not show any significant difference between baseline and follow-up scores.

Participants reported very low levels of physical functioning, role limitations due to physical health and health change perception at baseline, which either did not improve or worsened in the subsequent 3 and 6 months (median changed from 5.0 to 0.0, $\chi 2$ (2)=0.636, p > 0.05; median remained at 0.0, $\chi 2$ (2)=2.667, p > 0.05; median remained at 25.0, $\chi 2$ (2)=0.333, p > 0.05).

The scores of the role limitations due to emotional problems, social functioning and pain domains increased slightly at 3 months and decreased at 6 months, but these changes were not statistically significant.

The energy/fatigue domain had a mild drop at 3 months, followed by a slight increase at 6 months, with no statistical significance (F (2, 18)=0.213, p > 0.05).

Lastly, the general health domain displayed a slight increase at 3 months, and a further increase at 6 months, but this was also statistically insignificant (F (2, 18)=0.372, p > 0.05).

Participants were able to write comments at the end of each survey, and all reflected limitations resulting from their illness. While there were few qualitative comments from family carers, those who responded were overwhelmingly positive about the support provided by the pilot programme. One carer described being:

'Very comforted by the understanding and care received.'

As well as appreciating:

'The honesty and advice given to Dad in dealing with his terminal condition, and in a way, relieved to discuss how he was declining'.

Even though participants were very debilitated, the programme provided 'new ways to help

Table 1. Comparisons of health-related quality-of-life prior to, 3 months after, and 6 months after the
telehealth program (n=13)

Domain	M (SD) / Mdn (IQR)			Two-group comparison (Pairwise comparisonsa / Wilcoxon)		Three-group comparison (ANOVA / Friedman
	B aseline ^b	At 3 months ^b	At 6 months ^c	M difference ^c / Zb (1st vs. 2nd survey)	M difference ^c / Zc (2nd vs. 3rd survey)	F (df) ^c / χ2 (df) ^c
Physical functioning	Mdn (IQR)=5.0 (18.0)	Mdn (IQR)=5.0 (15.0)	Mdn (IQR)=0.0 (14.0)	Z=-0.172	Z=-0.378	χ2 (df)=0.636 (2)
Role limitations due to physical health	Mdn (IQR)=0.0 (0.0)	Mdn (IQR)=0.0 (0.0)	Mdn (IQR)=0.0 (6.0)	Z=0.000	Z=-1.342	χ2 (df)=2.667 (2)
Role limitations due to emotional problems	Mdn (IQR)=0.0 (100.0)	Mdn (IQR)=33.3 (100.0)	Mdn (IQR)=0.0 (41.7)	Z=-0.577	Z=-1.105	χ2 (df)=0.875 (2)
Energy/fatigue	M (SD)=26.5 (19.8)	M (SD)=24.2 (20.1)	M (SD)=28.5 (20.6)	M difference=2.000	M difference=-5.000	F (df)=0.213 (2, 18)
Emotional wellbeing	M (SD)= 62.5 (20.0)	M (SD)=59.7 (14.0)	M (SD)=47.6 (17.0)	M difference=3.600	M difference=12.400*	F (df)=5.746 (2, 18)*
Social functioning	M (SD)=30.8 (26.3)	M (SD)=33.7 (24.1)	M (SD)=28.8 (19.6)	M difference=5.000	M difference=0.000	F (df)=0.431 (2, 18)
Pain	M (SD)=45.0 (32.0)	M (SD)=47.5 (29.2)	M (SD)=40.2 (23.2)	M difference=0.250	M difference=9.250	F (df)=0.863 (2, 18)
General health	M (SD)=14.6 (10.3)	M (SD)=17.3 (14.8)	M (SD)=18.5 (12.7)	M difference=-2.000	M difference=-2.000	F (df)=0.372 (2, 18)
Health change	Mdn (IQR)=25.0 (50.0)	Mdn (IQR)=25.0 (25.0)	Mdn (IQR)=25.0 (12.5)	Z=-0.513	Z=-0.816	χ2 (df)=0.333 (2)

Note: Mean (M); Standard deviation (SD); Median (Mdn); Interquartile range (IQR); a. Adjustment for multiple comparisons: Bonferroni. b. n=13.c. n=10. *p < 0.05.

deal with his condition'. Acceptance of one's diminished state meant that one participant was 'more relaxed', and it was 'alright to feel scared, unmotivated and at times depressed'. There were no comments about the mode of delivery not being face to face.

Discussion

The telehealth programme commenced during the COVID-19 pandemic, and was offered to people with chronic illness admitted to a palliative care service, who were experiencing significant symptom burden. In this environment, there still emerged benefits to both the palliative care service and recipients of care (Dykgraaf et al, 2021, Adams et al, 2021).

Those who used the resources provided by the project said they felt more supported, but the reason why some eligible people did not participate is unknown. It is difficult to postulate about why less than half chose to participate in the additional support provided by the app, nor about the low uptake of advance care directives (Adams et al, 2021). However, there is some evidence of a correlation between older age and reluctance to use new technologies (O'Connor and Moore, 2022), noting that the cohort for this pilot study had a mean age of almost 73 years.

For the service, telehealth enabled better responsiveness to the increased demand for homecare, especially in alleviating travel time and potential exposure to the pandemic (O'Connor and Moore, 2022). For participants access to telehealth meant more control over their symptoms, also alleviating travel time to appointments (Tieman et al, 2016).

Those who participated in the pilot project were eligible because of their reduced health status due to chronic illness; it is thus no surprise that limitations due to physical impairments were evident in the quality-of-life surveys and did not change across the 6 months of reporting. Most quality-of-life measures changed little, or not at all, and were statistically insignificant. The only significant change was the emotional wellbeing domain, which saw a significant decrease across the 6 months of the surveys. This indicates increased anxiety over time, which given participants' circumstances, is not surprising.

Responsiveness and ready access to support may also have resulted in fewer hospital admissions, akin to Scheerens et al (2020). Having an exacerbation management plan to follow, with the support of the clinical lead, in most cases seems to have been sufficient for most participants to not need additional medical support (Taylor et al, 2021). That some participants availed themselves of multidisciplinary care in the form of counselling, may also have been a factor in their confidence to self-manage and in reducing anxiety (Dunleavy et al, 2021).

While the uptake of advance care directives was low, it does not negate the importance of having conversations about one's end-of-life care wishes, including refusing treatment; the impact of such conversations is unknown, and may not have been captured in a formal advance care directives document (White et al, 2019).

Qualitative feedback from participants reflected the survey measures, with many describing their physical limitations, and the impact of COVID-19 limitations on their ability to function. Carers, however, were perhaps more objective than those receiving care, with comments reflecting the importance of the programme in supporting the ill person and providing ready access to a trusted relationship.

Limitations

This pilot study sought the views of the recipients of the service. The views of the healthcare professionals involved in service delivery of the project were not included, and further research could consider this aspect. Of the numbers who enrolled in the pilot study, less than half chose to participate in the quality-of-life surveys, thus limiting the results of these surveys.

The pilot study was conducted mostly during the pandemic, which directly impacted the ability of the clinical lead to visit the referral sources to network with hospitals, consultants and others, resulting in fewer referrals to the project. COVID-19 also saw many clinicians with usual end-of-life care roles, seconded to roles relating to managing the pandemic, which meant their original roles may have been vacant.

Conclusion

With increasing demands on palliative care services, and a growing ageing population, the demands of people with advanced chronic disease will require innovative methods towards the best use of healthcare resources. This pilot program has demonstrated one such approach, in arming people with self-help tools and close clinical support for when crises occur. Further work is required to demonstrate the impact of demand for telehealth consultations on the overall healthcare system. *IJPN*

Statement of interest: None

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CPD reflective questions

- Is telehealth a way to increase GP involvement in palliative care, especially in their care of people dying from chronic illness?
- How can people, especially older people, be encouraged and supported to overcome their reticence to use technology for their healthcare?
- Is telehealth a satisfactory means of interaction for health professionals?

Key points

- Creative models of palliative care will assist in responding to increasing demand for care
- Telehealth is a way of supporting people dying from chronic illness
- Telehealth has many benefits, including keeping people at home and alleviating the need for emergency admission
- Self-help tools enable people to have some control over their illness.