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Enhancing palliative care for advanced cancer patients: evaluating implementation and impact of a virtual nurse-led symptom monitoring and telehealth initiative

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Abstract

Background As a result of the COVID-19 pandemic, we implemented a novel nurse-led symptom monitoring and virtual telehealth program for patients with advanced cancer on palliative care.

Aims To evaluate the **reach, effectiveness, adoption, implementation, maintenance** and acceptability of our program.

Methods This was a prospective study carried out in a cohort of patients with advanced cancer over the period of 3rd June 2020 to 22nd October 2021. Demographic characteristics, cancer diagnosis, and functional status of patients were collected upon recruitment. Patients were asked to complete a patient-reported outcome measure (the Integrated Palliative Care Outcome Scale, IPOS) prior to the first palliative care consult and subsequently every week for the duration of their participation in the program (12 weeks). The IPOS measures the severity of physical symptoms, emotional concerns, information, and financial needs. Participants' utilization of healthcare services by participants 3 months before, during and 3 months after the telemedicine program was reviewed. At the end of the program, a client satisfaction questionnaire (CSQ-4) to survey participants' experience with the telehealth program and their willingness to pay for this program was administered.

Results Reach: The recruitment to adoption ratio of the program was 0.71. Acceptability: Participants expressed satisfactory experience. Effectiveness: We noted that the severity of patients' symptoms and number of emergency department visits decreased over time with nurse support. Adoption: we received referrals from 23 oncologists, yielding an adoption rate of 70%. Implementation: Of the 99 patients recruited for the program, 88.9% of them managed to complete their initial video consults as planned. 16% of them failed to complete the program due to factors such as patient demising. Maintenance: The declining rate of IPOS completion throughout the study period (98.9% at week 1 to 60.8% at week 12) demonstrated the difficulties in sustaining regular administration of self-reported patient outcome measures.

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Conclusion The telemedicine program was effective and acceptable. We noted challenges in sustaining the administration of patient reported outcome measures over time. Further studies on how we can improve the sustainability of symptom monitoring in a telehealth program for patients with advanced illnesses, under palliative care, should be conducted.

Keywords Telehealth, Nurse-led, Reach, Adoption, Implementation, Effectiveness, Maintenance

Contributions to the literature

- A virtual, nurse-led telehealth symptom monitoring service for patients with advanced cancer under palliative care, has acceptable reach, adoption from oncologists, is effective and could be implemented satisfactorily in the Asian population.
- However, there are challenges in sustaining the regular reporting of patient reported outcome measures over time.
- The use of the REAIM framework in this study has helped guide the evaluation of programs and helped generate areas for future studies.

Introduction

Palliative care has been proven to improve the quality of life of patients with serious illnesses [1, 2]. On 23 January 2020, the first case of COVID-19 in Singapore was confirmed [3]. Due to the restrictive measures imposed during the pandemic, providing comprehensive face-to-face palliative care for patients at the outpatient clinics of our tertiary cancer centre was not feasible.

Therefore, efforts to provide palliative care virtually were pushed to the forefront. This necessitated the study team to develop a novel nurse-led telehealth program to facilitate regular monitoring and management of cancer patients who needed palliative care support in the outpatient setting [4].

In a systematic review published prior to the COVID pandemic in 2016, telemedicine was shown to be a feasible method to deliver palliative care [5]. However, the designs of the reviewed studies were not robust enough to conclude the effectiveness of providing palliative care via telemedicine. Similarly, a Cochrane review in 2020 concluded that whilst there was evidence supporting the use of telephone-delivered symptom management for adults with cancer, the studies were limited by methodological issues such as the short length of patient follow-ups [6]. Another systematic review published in 2019 described the various facilitators and barriers of video consultations which include user perception, technological, privacy and economic concerns [7]. Two qualitative studies published in 2019 have also described challenges with regards to the optimal time in the patient's illness journey to initiate video consultations [8] as well as the additional logistics required to facilitate multidisciplinary participation and cooperation [9]. Despite these challenges described in earlier published papers, the use of telehealth as a strategy to improve access to palliative

care has been more successful in recent years [10–12], especially in rural communities. [13]

Thus far, no studies have specifically reviewed the effectiveness of virtual nurse-led symptom support and its impact on patients' healthcare utilization in the local setting. Furthermore, as the digital literacy in Singapore is lower than that of other countries [14], it is unclear if more large-scale systemic efforts for telehealth in patients with advanced cancer would be acceptable and feasible in Singapore.

Objectives

Therefore, the study team aimed to systematically evaluate the acceptability and effectiveness of our novel nurse-led symptom monitoring and telehealth support program in Singapore, to understand if it would be suitable for widespread implementation. This evaluation would be based on elements of the RE-AIM framework [15].

Methods

Study setting

This was a pragmatic study carried out in the National Cancer Centre Singapore (NCCS), a national and regional referral centre for cancer that sees more than 150,000 specialist outpatient attendances annually. During the study period, NCCS also started a new medication delivery service for patients, which was utilized by our study patients as well.

Inclusion criteria and exclusion criteria

The study recruited patients who had advanced (Stage 3 and Stage 4) solid tumours in the gastrointestinal, respiratory, genitourinary, or head and neck regions as there were no existing palliative care telehealth support programs for these groups of patients. Participants had to

have an oncologist estimated prognosis of 2 years or less. The study team did not recruit patients with gynaecological, breast or haematological cancers in significant numbers as they were mostly known to existing supportive care programs in the National Cancer Centre Singapore.

Participants who were unable to access the videoconferencing application, had psychological issue(s) which impeded them from providing informed consent, had a bedbound (Eastern Co-operative Oncology Group) status 4 [16] or who were already known to existing palliative care services were excluded from the study. Bedbound patients were excluded as the team felt it would be better for them to be referred to existing palliative home care services.

Recruitment

Oncologists who were primarily responsible for the care of patients with the tumour types listed in the inclusion criteria were encouraged to refer their patients for telemedicine support from the study team when necessary. A research coordinator also pre-screened the patients of the respective oncologists and engaged them to determine if patients were suitable to be recruited for the study and receive telemedicine service.

Intervention description

All patients would have an initial consult with a specialist palliative care physician and nurse via tele-videoconferencing. The initial tele-consults were done via the “Zoom” [17] videoconferencing so that the team was able to visually assess the patient and their caregiver as well as to understand their concerns.

Prior to the initial consult, participants would submit the “Integrated PC Outcome Scale” (IPOS) [18–20] to share their main symptoms and concerns. The IPOS is a brief survey that assesses a patient’s concerns globally. The survey includes questions on symptoms, practical problems, and psycho-emotional issues. Items are scored on a 5-item Likert scale (Not at all, Slightly, Moderately, Severely, Overwhelmingly) to assess the severity of the problem. Both the English and translated Chinese IPOS have been validated locally [19, 20].

Regarding survey administration, the patient would receive in his or her mobile phone, a text message, containing a link to the IPOS survey. This text message would be sent via an institutional IT approved secure platform, by the study research coordinator. Results of the IPOS survey would be stored on our institutional IT platform after survey completion. Participants’ responses on the IPOS survey would then be downloaded from the IT platform by the palliative care nurse. Participants did not receive any regular reminders to complete the IPOS.

Throughout their 12 weeks of participation in the program, patients would complete the IPOS survey on a

weekly basis. The nurse would then triage the patients based on a prior established triage guide derived from literature [21]. If the patient reported concerns of at least mild severity on their IPOS, the nurse would contact the patient first via the telephone to re-assess the severity of the issue. If the concern could not be evaluated satisfactorily over the phone, the nurse would utilize videoconferencing software to get a visual of the patient’s concern. Depending on the nature of the problem(s), the nurse would proceed to institute treatment of the problem including coordination of care resources, in accordance with established treatment guidelines and with the support of the patient’s treating medical oncologist or a palliative care physician, a pharmacist and a social worker. Should pharmacological treatment be needed, medications would be delivered to the participants. Participants would also be given a (a) brief psycho-education guide on common issues whilst living with advanced cancer (b) a help-line number to call during office hours on weekdays, if new problems arise prior to the next self-administration of the IPOS. Participants were still allowed to have active contact with their oncologist during the study period. The program ran for 12 weeks due to resource constraints for longer-term follow-up beyond 12 weeks. At the end of 12 weeks, participants were referred to existing community services for follow-up on an as needed basis.

Data collection

At baseline, demographic characteristics, medical condition (including type of cancer), and functional status (ECOG score) were collected. The IPOS survey was also administered prior to initial consult, and weekly for 12 weeks as described above. Data regarding the healthcare utilization of participants (including the number of emergency department visits, intensive care unit visits) 3 months before, during and 3 months after the telemedicine service was also collected. The number and type of community palliative care services received after recruitment into the study was also tracked by the study team.

At the end of the study, a client satisfaction questionnaire (CSQ-4) [22] which asked participants about their experience with the telemedicine program as well as how this program enhanced their ability to cope with their health condition. To evaluate the need for financial subsidies for future iterations of this program, participants were also asked about their willingness to pay for this program.

Preanalytical definition of study measures

The specific aspects of the RE-AIM (*Reach, Effectiveness, Adoption, Implementation/Fidelity, Maintenance*) framework through which the team evaluated the study, were defined as follows prior to commencing the study. **Reach:**

Table 1 Demographics of recruited participants (N = 99)

Variable	Mean (SD)/N (%)
Age	63.4 (11.3)
Gender	
Female	34 (34.3)
Male	65 (65.7)
Race	
Chinese	82 (82.8)
Indian	3 (3.0)
Malay	11 (11.1)
Other races	3 (3.0)
Marital Status	
Divorced	3 (3.0)
Married	84 (84.9)
Single	8 (8.1)
Widowed	4 (4.0)
Payment class	
Private	18 (18.2)
Subsidized	81 (81.8)

Recruitment to consent ratio; **Acceptability:** This would be related to participants’ experience and satisfaction with the program. **Effectiveness:** Changes in participants’ IPOS scores over time and changes in participants’ health care utilization before and after participation in the program; **Adoption:** Percentage of oncologists, out of all that we engaged, who referred patients to the telemedicine program; **Implementation/Fidelity:** Percentage of recruited patients who managed to successfully complete the initial video consult and IPOS on baseline; **Maintenance:** Percentage of participants who completed the entire program and did not drop-out.

Data analysis

We analysed and summarized the data that was collected using descriptive statistics. We did not conduct formal sample size calculation as it was a pragmatic study.

Ethics and informed consent

All participants signed informed consent prior to participating in the program. Participants were also required to give additional consent for participation in telemedicine services. This project was approved by the SingHealth Centralized institutional review board (CIRB), IRB number: 2020/2384.

Results

The study team recruited participants from 3rd June 2020 to 22nd October 2021. We completed follow-up of the last participant by 11th January 2022.

Reach

A total of 140 patients were approached to participate in the program. Out of these 140 patients, 31 rejected

Table 2 Reasons that staff withdrew patients or patients withdrew participation

Reason	Total number of rejections (N = 41)
Patient related:	
Not interested; could not commit to study period; did not think telemedicine service was necessary; preferred face-to-face consultations.	28
Cost	2
IT related issues	1
Staff related	
Referred to other palliative care services instead	4
Referred to other non-palliative care services instead	2
Patient not literate	2
Not physically able to comply with video consult	1
Not able to comply with IT	1

to participate, 10 patients were deemed unsuitable for participation by the study team. Eventually, 99 patients agreed to participate in the program and were recruited, yielding an approach to recruitment ratio of 0.71. Demographics of the 99 participants are described in Table 1. Reasons for rejecting to participate are described in Table 2. Comparing the demographics of patients who accepted as compared to rejected participation, we noted that patients who were recruited into the program were generally younger (mean age 63 years) than patients who rejected participation in the program (mean age 66 years). We also noted there were higher rates of recruitment for married patients (77.8%) as compared to widowed (36.4%), single (53.3%) or divorced (50%) patients.

Acceptability

To get feedback on the telemedicine program, the study team sent the CSQ-4 to all patient participants, as well as 4 caregivers who were still in contact with the telemedicine nurse. Generally, patients and caregivers were satisfied with the nurse-led telemedicine program, and this is shown in Table 3. 46% of participants were willing to pay for the telemedicine consult and the amount they were willing to pay as compared to a normal face-to-face consult is described in Table 3.

Effectiveness

Among the main problems (1021 listed by participants) described on the IPOS survey, physical symptoms were most common (450 instances, 44.0%), followed by overall well-being (361 instances, 35.3%), practical problems (186, 18.2%) and information needs (24, 2.35%). The severity of problems listed by participants on the IPOS survey was noted to decrease over time, as described in Table 4. At week 1, the mean IPOS score was 19. At week 12, the mean IPOS score was 13. In addition, although

Table 3 Scores on the client satisfaction Questionnaire-4

Item	Response	Score (% of agreement)
To what extent has our program met your needs	Almost all of my needs have been met	39
	Most of my needs have been met	49
	Only a few of my needs have been met	12
Have the services helped you to deal more effectively with your problem	Yes, they helped a great deal	54
	Yes, they helped somewhat	40
	No, they didn't really help	4
	No they seemed to make things worse	2
If you were to seek help again, would you come back to our program	Yes, definitely	54
	Yes, I think so	42
	No, I don't think so	4
In an overall general sense, how satisfied are you with the service you received	Very satisfied	49
	Mostly Satisfied	46
	Indifferent or mildly satisfied	5
Do you think patients should be charged for telemedicine consultations	Yes	46
	-76-100% of normal consult	16
	- 51-75% of normal consult	19
	- 26-50% of normal consult	32
	- 1-25% of normal consult	26
	- missing	7
	No	54

Table 4 Changes in IPOS severity scores over time

Week	Count of IPOS completed	Mean	Median	Inter-quartile range
1	87	19	18	(13.0,26.5)
2	65	17	15	(11.0,21.0)
3	61	14	14	(9.0,20.0)
4	60	16	15	(10.0,20.0)
5	56	14	14	(8.8,16.8)
6	49	14	13	(8.0,17.0)
7	47	13	13	(8.0, 17.5)
8	52	13	12	(7.0, 16.3)
9	45	12	12	(7.0,16.0)
10	48	13	12	(7.0, 16.3)
11	43	13	12	(6.0,18.0)
12	45	13	12	(6.0,18.0)

physical problems were most common, emotional problems had the highest severity scores as rated by participants. By the end of week 12, the greatest decrease in severity of problems was also noted in the emotional problems category. We have described the changes in the IPOS problem categories over time in Table 5.

In terms of hospital utilization, 3 months prior to recruitment into the telemedicine program, 87 patients had a total of 32 emergency department (ED) visits (0.37 visit per patient) and 61 inpatient admissions (0.70

Table 5 Changes in scores of IPOS problem categories over time

Week	Physical	Emotional	Practical/communication
1	0.93	1.56	1.32
2	0.81	1.27	1.15
3	0.68	1.17	1.02
4	0.74	1.30	1.09
5	0.68	1.11	0.96
6	0.61	1.15	0.95
7	0.59	1.10	0.93
8	0.58	1.14	0.97
9	0.54	1.04	0.96
10	0.55	1.06	0.99
11	0.56	1.15	1.00
12	0.55	1.14	0.97
Change from week 12 to week 1	-0.38	-0.42	-0.35

admission per patient). During the study period, 88 patients had a total of 27 ED visits (0.31 visit per patient) and 53 inpatient admissions (0.60 admission per patient). Within the period of 3 months after completing the telemedicine program, 69 patients had a total of 18 ED visits (0.26 visits per patient) and 49 inpatient admissions (0.71 per patient). We note that the ED and inpatient admission numbers dropped during the telemedicine program period and did not increase after completing the telemedicine program.

Over the course of the study period, 53 patients (53.5%) received at least one referral to a community service. Of these 53 patients, 37 (69.8%) of them received referrals to only one type of community service; 14 (26.4%) of them received referrals to 2 types of community services and 2 (3.77%) of them received referrals to 3 types of community services. With regards to the types of service they were referred to, 2 of them were referred to day rehabilitation services, 2 of them were referred to home nursing, 51 of them were referred to hospice home care, 1 of them was referred to an interim caregiver service for support for physical caregiving, 8 of them were referred to inpatient hospice palliative care service.

Adoption

The study team approached 33 oncologists to refer their patients for participation in the program. Eventually we received referrals from 23 oncologists, yielding an adoption percentage of 70%.

Implementation

Out of 99 recruited patients, 88 participants (88.9%) managed to have an initial video consult. Reasons for not being able to actualize the consult included patient related and staff related factors. Patient related factors were patient changed their mind about telemedicine

service (3 patients), could not manage the IT system (1 patient), cost concerns over video consult (1 patient), miscommunication about video consult logistics (1 patient). For staff related factors, for all 5 patients, the telemedicine nurse was informed by patient regarding changes to their condition, thus a decision was made not for video consult.

Maintenance

Of the 88 patient participants who completed their initial video consults, 74 (84.1%) of them completed the program. For the 14 participants who did not complete the program, 9 passed away in the midst of the study, whilst the other 5 were referred to other palliative care services such as an inpatient hospice, due to deterioration in their condition. The IPOS completion rate was also noted to drop across the weeks, from 98.9% of participants completing it during the first week, to 60.8% of patients completing it at week 12. This is shown in Table 6. In all, we received 658 completed IPOS questionnaires and our nurse was required to do 643 phone calls in all.

Discussion

Main findings

This was a novel study of a nurse-led telehealth program in the palliative care setting, which was conducted during the COVID-19 pandemic. Our findings showed that despite being in pandemic conditions, the reach of the program was still satisfactory (recruitment to adoption ratio of 0.71). Adoption of the program by oncologists was good (70% of oncologist had recommended at least one patient to receive the telemedicine service). Implementation of protocol was satisfactory, with 88.9% of patients managing to have an initial video consult as planned. The nurse led program was also effective, as demonstrated by symptoms decreasing in severity over

time. Patients were also generally satisfied. Healthcare utilization was not increased during the period and showed a decreasing trend in terms of ED visits. Even though there was drop out in the program due to natural progression of disease leading to patient death, 84.1% of patients managed to complete the program. Compared to the traditional no show rate of about 25-30% in hospital clinics [23, 24], we hypothesize that the presence of the nurse helped to keep the patient engaged in our telehealth program. However, the rate of IPOS completion did drop across the program, demonstrating difficulties in sustaining regular administration of self-reported outcome measures by patients.

In terms of acceptability of telemedicine, the findings of our study are like previous studies – which showed that despite palliative medicine traditionally being a high-touch speciality, telemedicine as a mode of palliative care consult was still acceptable [8, 9].

Not unexpectedly, factors such as whether patients have access to social support and their level of technological literacy was correlated to the reach of the telemedicine service. This has highlighted the potential lack of equity in the access to palliative care services, which is an issue that is acknowledged in current palliative care literature [25]. Further work on how to make healthcare services equitably available to all populations [26] as well as how to improve health and technological literacy in those socially disadvantaged populations should be considered. Further work should also be done on to evaluate how we could leverage on systemic factors that facilitate the uptake and eliminate the barriers to patient reported outcome measure administration [27].

Strengths

The strengths of this study were that first, we relied on a robust framework to evaluate the implementation of the program and offered a pragmatic, real-world view of the feasibility of providing nurse-led telemedicine service in an Asian context. Second, we have demonstrated impact of the telemedicine program on patients’ healthcare utilization, as well as the challenges in maintaining and sustaining a program over time. Third, this program was also conducted in an Asian population, which is a population that is traditionally rarely studied in western literature.

Limitations

One of the limitations of this study was that it focused mainly on an advanced cancer population, who had mainly gastrointestinal cancers. This may potentially limit the generalisability of our findings, though we do not expect there to be significant difference regarding effectiveness of palliative care support because of differences in underlying disease type. Second, as it was a pragmatic study, we did not have a comparison group.

Table 6 IPOS completion rate over time

IPOS week	Number of IPOS scheduled	Number of IPOS completed
1	88	87 (98.9%)
2	85	65 (76.5%)
3	84	61 (72.6%)
4	83	60 (72.3%)
5	83	56 (67.5%)
6	81	49 (60.5%)
7	79	47 (59.5%)
8	77	52 (67.5%)
9	77	45 (58.4%)
10	75	48 (64.0%)
11	74	43 (58.1%)
12	74	45 (60.8%)
	Total number of scheduled IPOS over time:	Total number of completed IPOS over time:
	960	658

Therefore, we are not able to fully state, that the differences in outcomes from our program, are not due to natural changes in patient's condition over time, though it should be stated that without effective palliative care support, patient symptoms have been noted to worsen over time [28], rather than improve as per what was shown in our study.

Implications for current practice and future research

Future studies should consider further evaluating the impact of telehealth through a randomized controlled trial, as well as recruiting participants from other disease types. An optimal frequency of patient reported outcome measures should also be explored.

Conclusions

The telehealth program was effective and acceptable. We noted challenges in sustaining the administration of patient reported outcome measures over time.

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Author contributions

SHN was the primary investigator of the grant, and was responsible for conceptualising, conducting, and analysing the study. NM was responsible for running the study, and data collection and analysis. XZ and XHN were involved in the running of the study. All authors contributed to critical review of the paper.

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Data availability

Not applicable.

Declarations

Ethics approval and consent to participate

All participants gave informed consent. All methods were carried out in accordance with current and relevant guidelines and regulations. This project was approved by the SingHealth Centralized institutional review board (CIRB), IRB number: 2020/2384.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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