

Telehospice: A Bistate Proposal to Improve End-of-Life Care

Evaluation Report

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Introduction

In 1999, researchers from Michigan State University and the University of Kansas Medical Center joined forces to submit a telehospice research grant to the NTIA. The overall purpose of the project was to launch separate telehospice projects in two Midwestern states and compare results and experiences across the two programs. Within each state, videophone equipment was to be placed in rural and urban hospice patients' homes and traditional hospice services were to be augmented with this equipment. Funding was awarded in the fall of 1999 and development efforts were launched in both states.

On the Michigan side of the project, Hospice of Michigan rural offices (Gaylord, Alpena, and Milford) and urban offices (Detroit and Wayne Suburban) were selected to participate in the project. Eventually, Milford (a small, satellite office) was dropped from the project due to significant intra-office staffing and logistical problems. In Kansas, Hospice, Inc. rural (Phillipsburg) and urban (Wichita) offices and SE Kansas rural (Phillipsburg) and Hays Hospice rural (Hays) offices were selected to participate in the project. By 2001, it was clear that the Wichita office was not willing to fully participate and was dropped from the project. Hospice of Kansas City urban office in Kansas City joined the project in 2001, but was eventually dropped in 2002 due to lack of participation. Thus, the Kansas project was almost exclusively comprised of rural office-based activities.

The original research plan proposed five research themes, namely:

1. Access/Utilization
2. Patient and Provider Perceptions
3. Delivery of Services
4. Outcomes (Pain Efficacy, Cost, Types of Services Delivered via telehospice)
5. Educational Programming

Significant efforts were made to collect and evaluate data. Multiple data collection strategies were employed, including: utilization logs, decline surveys, telehospice nursing notes, cost frame data collection, patient interviews, provider interviews and surveys, caregiver interviews and focus groups, and videotaped telehospice visits. In most cases, the evaluators were successful. In several cases, additional research questions and data collection strategies were employed (e.g., post provider surveys, caregiver interviews and focus groups). In two cases, however, evaluation is not complete. For the cost evaluation, the evaluator responsible for this component has not completed the cost analysis. For the pain efficacy component, the evaluator in charge of this component was unable to collect data due to sampling and logistical constraints.

Overall, the evaluators collected significant data, particularly from the Michigan patients, that provide valuable lessons regarding the use of mediating communication technologies for the delivery of end-of-life services. As data from the project will demonstrate in this report, evaluators discovered that patients and caregivers readily accept telehospice services, often expressing the wish that it was utilized more. Evaluators learned that not all patients are appropriate for telehospice services (e.g., those in the final stages of dying), but that there are exceptions to these criteria. Anecdotal evidence indicates there are numerous heart wrenching

examples where telehospice played a significant role in the final days of someone's life. Telehospice services are typically initiated by the nurse, rather than the patient or caregiver, and are most often employed for physical assessments and teaching. Important to note is that providers remain a significant barrier to the deployment of telehospice services, with only a handful of nurses and social workers fully embracing this technology.

All data in this report were collected between Winter 2000 and Fall 2002. This report is presented in ten sections, including utilization, decline surveys, telehealth consult notes, anecdotal evidence, patient perceptions, patient encounter videotape analysis, caregiver perceptions, provider pre and post surveys, provider educational activities, and archival and support documents. We conclude with an overview of the most significant lessons derived from the project.

A) Utilization

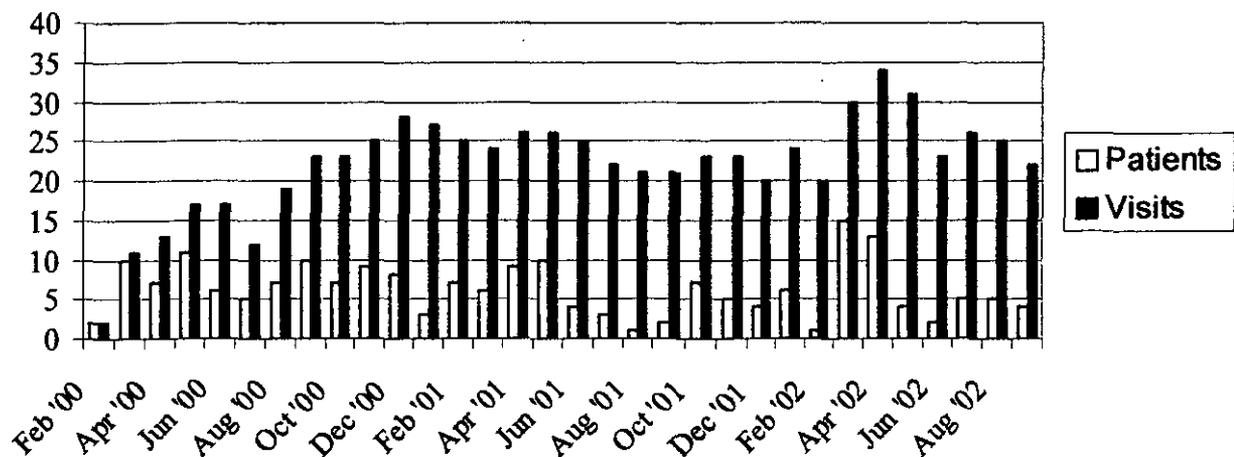
The potential for telehospice

In order to determine what proportion of home hospice visits could be performed using videophone technology, a retrospective chart review analysis was conducted. Clinical notes were obtained from Hospice of Michigan and Hospice, Inc. Records were randomly sampled for those patients that received hospice nursing visits during the month of January, 2000. The charts were reviewed for patient demographic information, patient clinical assessments, teaching activities, and interventions. Five hundred ninety-three hospice nursing visit notes were analyzed using an 85-item coding instrument. Our study documented that traditional services performed for hospice patients during home visits included physical assessment, teaching and various interventions. Activities related to the physical examination (vital signs, visual inspection, stethoscopy, mental status check) were routinely performed. As one would expect, teaching was also common, including discussions pertaining to psycho spiritual support, hospice services, and disease processes. After careful record review, the observers also made a subjective observation regarding the suitability of each visit for telemedicine. For 65% of these visits, telemedicine could reasonably have replaced the on-site visit. Thus, telehospice has the potential to replace or supplement a significant proportion of hospice care. The remainder of this section reports telehospice utilization activities for Michigan and Kansas.

Michigan

In Michigan, a total of 189 patients participated in the project and 749 visits were recorded. Figure A1 shows the rate of usage throughout the telehospice project, both in terms of patients on the project each month and number of visits each month.

Figure A1
Telehospice Usage By Month



Of the total patients who received telehospice services in Michigan, 51% were female and 49% were male. Patients ranged in age from 26 to 98, with the mean age being 71 years old. The average length of stay for rural telehospice patients was 136 days and for urban telehospice patients 100 days. Of the patients who participated in the telehospice project, 61% had cancer as a primary diagnosis and 39% had another disease as the primary diagnosis. Finally, 77% of the telehospice patients had medical coverage through Medicare, 5% through Medicaid, and 18% through other payment schema. This study was not purported to be a random trial; instead a convenience sample was employed. However, evaluators in Michigan wanted to determine if the patients in this study were representative of the patients as a whole for Hospice of Michigan. Chi square analyses were conducted for the demographic variables and found that in most cases, the demographics from the telehospice patient sample were representative of the overall agency population. The exceptions (at a .05 level) included age for the urban sites and the incidence of cancer/non-cancer as a diagnosis for the Alpena/Detroit/Wayne offices.

Of the 189 total patients, 45% came from the rural sites (Gaylord/Alpena) and 55% came from an urban site (Detroit/Wayne Suburban). Given the difference in provider acceptance and enthusiasm between the rural and urban sites, evaluators were initially surprised to see such an even utilization split between the rural and urban offices. Yet, it is important to document that the urban offices are significantly larger than the rural offices, so the rural offices actually had a higher percentage of patients employ telehospice. Table A1 provides data regarding the percentage of telehospice patients per office.

Table A1: Percentage of telehospice patients per office.

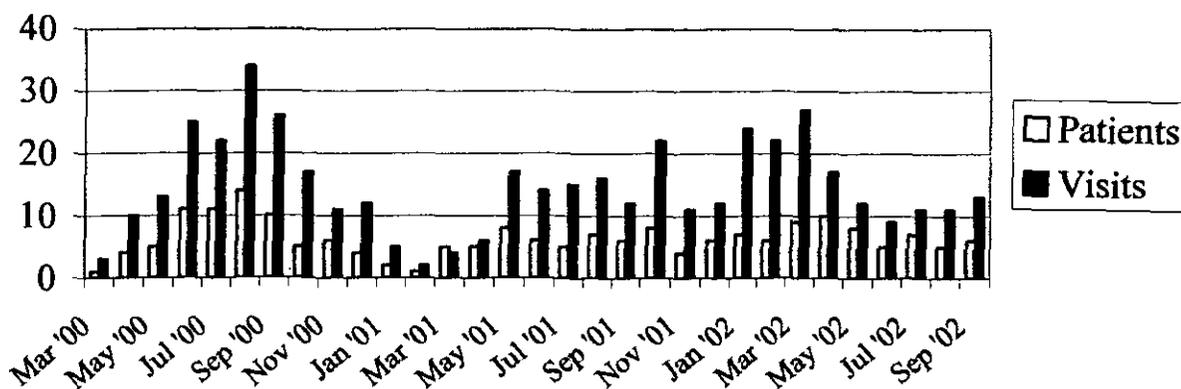
	Telehospice Patients	Non-telehospice Patients	Telehospice Patients as Percentage of All Patients
Alpena	58	443	11.58%
Gaylord	27	328	7.61%
Detroit	57	1246	4.37%
Wayne Suburban	47	1565	2.92%

It is worth noting that even though 45% of the total patients in the project came from a rural location and 55% came from an urban location, utilization statistics for teleconsultation demonstrate that rural offices actually employed the telehospice system more frequently than their urban counterparts. In Michigan, 55% of all the televisits were conducted with rural patients and 45% of the total televisits were conducted with urban patients.

Kansas

In Kansas, a total of 88 patients participated in the project and 455 visits were recorded. Figure A2 shows the rate of usage throughout the telehospice project, both in terms of patients on the project each month and number of visits each month.

**Figure A2
Telehospice Usage By Month**



Of the 88 patients, 22% came from an urban area and 78% came from a rural office. Seventy-two percent had cancer as a primary diagnosis. Table A2 provides a breakdown of patients by location in Kansas.

A2: Percentage of telehospice patients per office

	Telehospice Patients	Percentage of Telehospice Patients from Each Office
Phillipsburg	14	15.9%
Coffeyville/Pittsburg	46	52.3%
Hays Home Health	9	10.2%
Kansas City	12	13.6%
Urban Wichita	7	8%

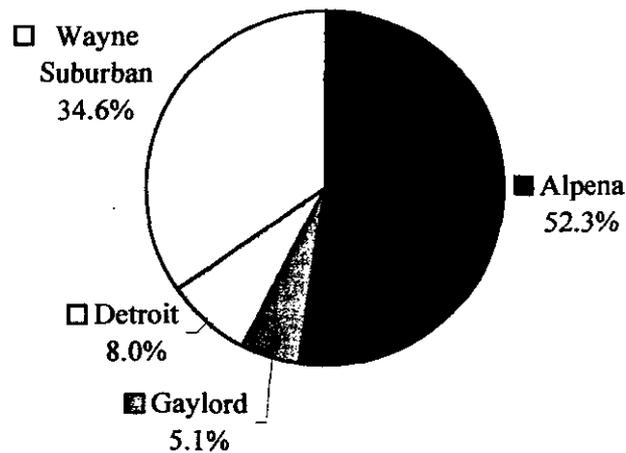
B) Decline Surveys

Michigan

As telehospice equipment was available at each office, nurses were instructed to invite newly enrolled patients to participate in the study. Most telemedicine projects neglect to record the reasons patients decline to receive telemedicine services. In this project, patients or nurses were asked to complete a decline survey (See Appendix A for instrument). Data about the 751 patients who opted not to take part in the telehospice project in Michigan are presented in this section.

Figure B1 displays the percentage of the 751 declinations by site. Alpena, which also had the most telehospice patients enrolled in the project, had more declines than the other three sites combined. A big part of the success of the telehospice project in Alpena was the Alpena team's consistency in offering telehospice service to all patients. This also led to an increased number of declines.

Figure B1
Telehospice Decline By Site



The decline forms were filled out by patients if they were invited to participate in the project and refused. They were also completed by the nurse if a patient was ineligible for the project or the nurse felt outstanding circumstances made it inappropriate to invite the patient (e.g., roach-infested home; stressed caregivers). As Figure B2 illustrates, more than 70% of the decline forms were actually completed by a nurse, meaning these patients were never given the opportunity to accept or decline the telehospice service.

Figure B2
Who Declines Service?

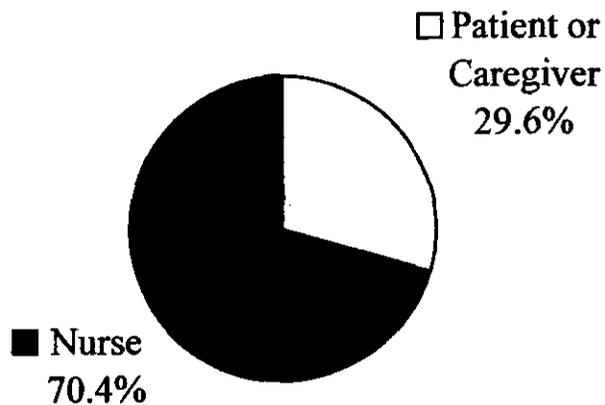
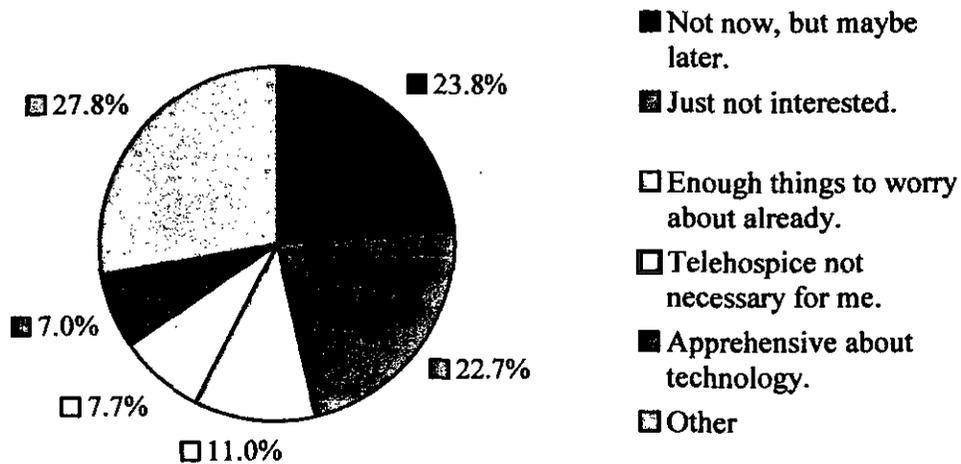


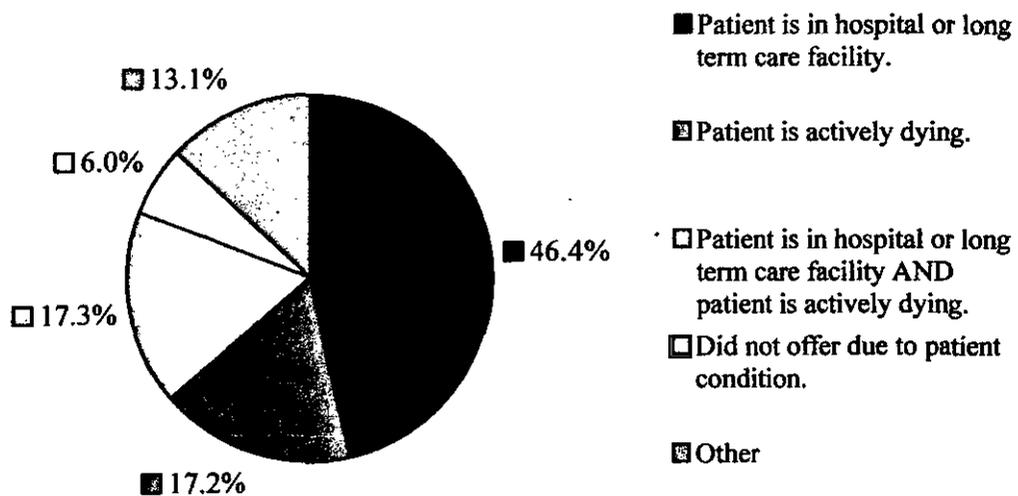
Figure B3 displays the five most common reasons that patients declined telehospice service. Almost half of the patients who declined service were either not interested in telehospice or wanted to think about it more. Because Hospice of Michigan is looking to expand and grow telehospice services beyond the research project, current discussions are underway to determine the optimal time to offer the service. Perhaps it is best to wait until a patient has been enrolled for 48 hours or more as initial hospice enrollment is a high-stress event for both patients and their caregivers. In addition, hospice nurses offering the telehospice service need to be highly educated and experienced to ensure that they are able to fully educate patients. Improving the patients' understanding of telehospice might reduce the number of patients uninterested in the service. Other reasons for patients not accepting telehospice service included a handful who thought the research side of the project was too invasive, those who felt they did not have room in their home for the equipment, or those who stated that they do not like talking on the phone.

Figure B3
Reasons Patients Refuse



Nurses completed almost 530 of the 751 decline forms. Figure B4 illustrates the most common reasons that patients were deemed ineligible or inappropriate for telehospice service. The vast majority of patients were either in a long term care facility, actively dying, or both. When patients were not offered the service due to patient condition, this was typically because the patient either had poor eyesight or poor hearing. Some patients did not qualify for the telehospice project due to lack of access to appropriate phone service.

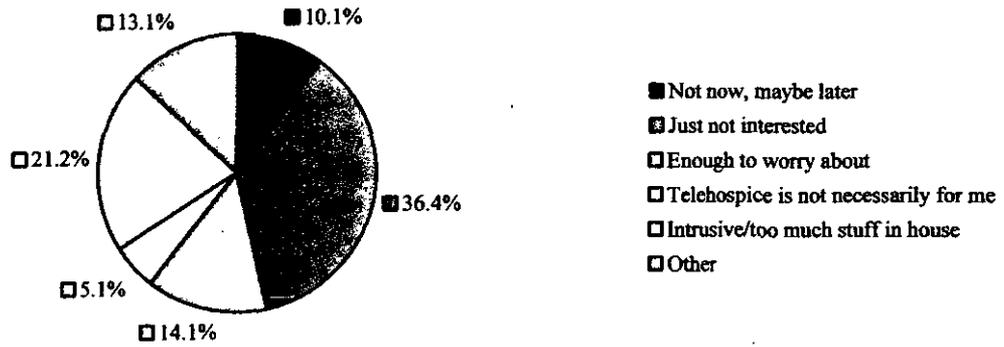
Figure B4
Reasons Patients Are Ineligible



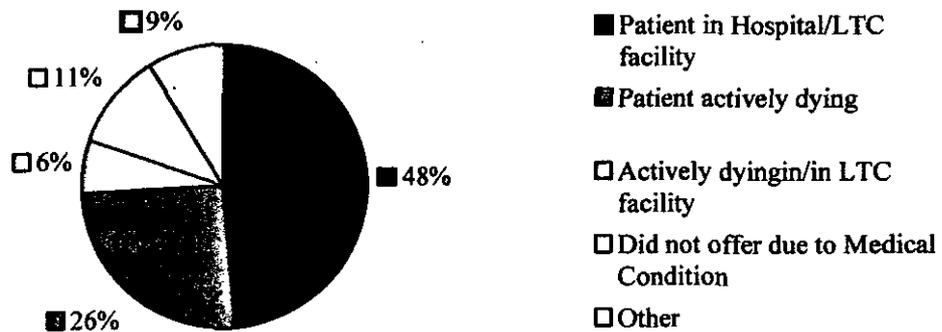
Kansas

In Kansas, 247 decline forms were collected. Forty percent of the decline forms came from patients with 60% being initiated by the nurses. Figures B5 and B6 represent the patient and nurse reasons for decline respectively.

**Figure B5
Patient Reasons for Decline**



**Figure B6
Nurses Declines**



C) Nurse Telehealth Notes

Michigan

Every time a call was made using the telehospice system, a “Nurse’s Note” was filled out to gather data regarding the telehospice visit. (See Appendix B for copy of Telehealth Nurse Note.) This section includes information gathered from these 825 Michigan Nurse’s Notes. (Note: There are more nurses’ notes than actual counted telehealth visits as in some cases, the nurse would complete a nurses’ note for a visit that was never completed due to patient unavailability.)

Figure C1 shows a breakdown of who initiated the telehospice calls throughout the course of this project. Clearly nurses initiated the vast majority of calls. The “Other” category includes social workers, project coordinators, and spiritual care providers. The few patient-initiated calls tended to be emergency calls to after-hours Hospice of Michigan support staff.

Figure C1
Who Initiates Telehospice Calls?

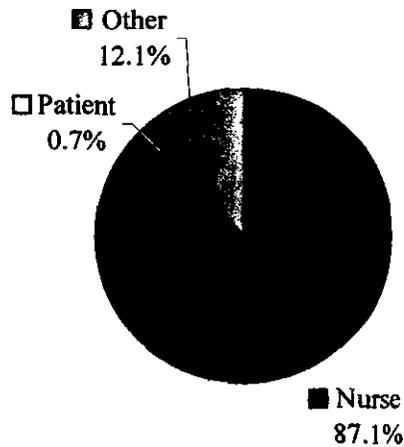


Figure C2, displays information about who participated in telehospice visits. The graph shows that nurses participated in almost all calls over the telehospice system. Patients, not surprisingly, are the second most common participants in telehospice calls. Occasionally, a nurse would conduct a telehospice call with a family caregiver rather than the patient. The strong use of the system by caregivers is clear, as they are involved in nearly half of all calls. The “overlap” in percentages between nurses and social workers, and patients and caregivers, shows that there are often more than two people involved in a telehospice call. In fact, data from the Michigan visits shows that almost 30% of visits over the telehospice system included more than two people.

Figure C2
Who Participates In Calls?

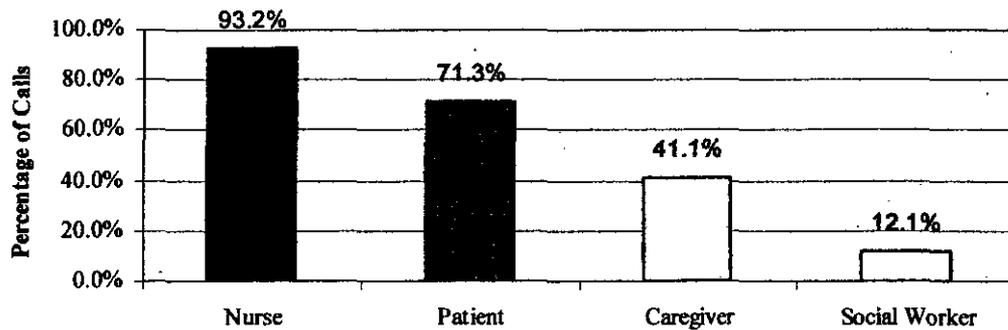
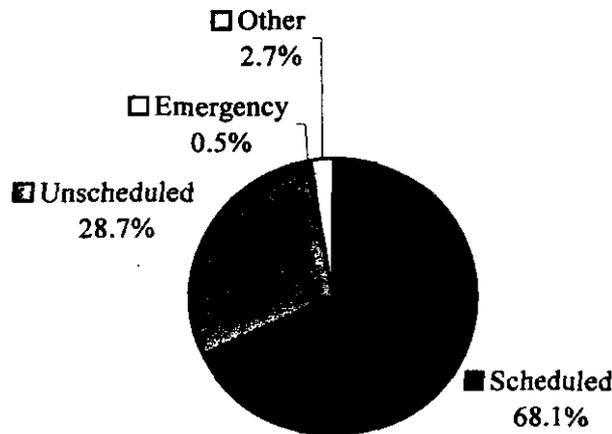


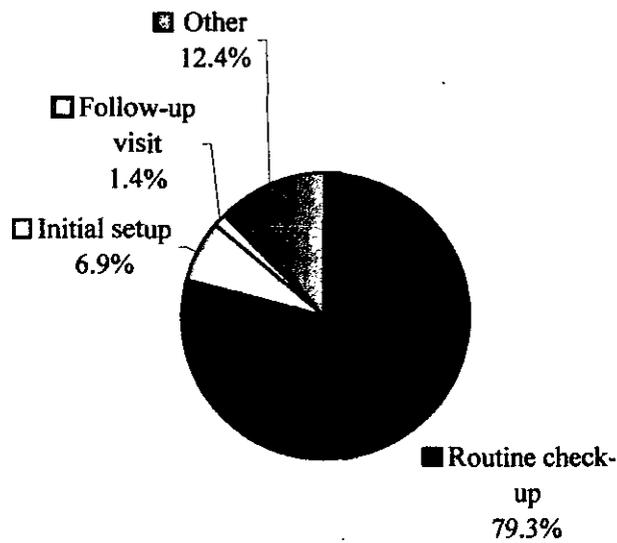
Figure C3 provides a breakdown of the purpose of the telehospice visits. From the graph, it is clear that a majority of calls were scheduled between Hospice of Michigan staff and telehospice patients for a routine follow-up or assessment visit. Still, 28.7% of calls were unscheduled in nature. These unscheduled calls were typically made to check up on patients through routine checks. The small percentage (.5%) of emergency calls shown in this graph supports data from Figure C1 which showed that patients initiated a small number of calls (.7%).

Figure C3
Nature of Telehospice Calls



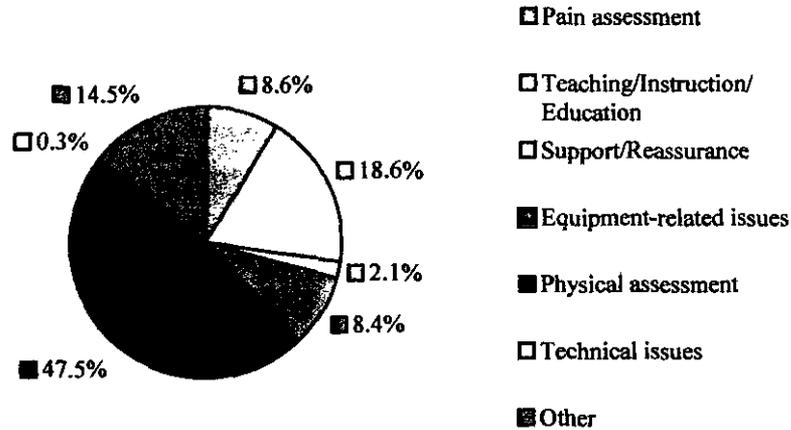
The specific nature of the telehospice visits are illustrated in Figure C4. The vast majority of calls were conducted to go through a routine check-up of telehospice patients. Calls to ensure the system was functioning and to get patients comfortable with use accounted for almost 7% of calls as new patients were brought onto the project.

Figure C4
Reason Behind Telehospice Calls



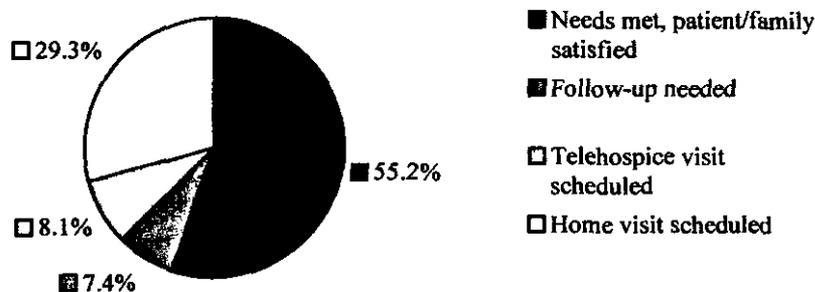
Specific activities conducted over the telehospice system are illustrated in Figure C5. Physical assessments accounted for nearly half of telehospice use, with teaching, support, and pain assessments each accounting for a significant percentage of telehospice utilization. Equipment-related issues represented more than 8% of telehospice activities; equipment-related issues included the initial setup of telehospice systems in patients' homes and the troubleshooting of telehospice equipment.

Figure C5
Nurse Use of Telehospice



Finally, as is the case with traditional nurses' notes, the telehealth note also required nurses to document the outcome of a telehospice visit. Figure C6 offers information about the outcomes obtained via telehospice visits. It is certainly encouraging that a majority of calls resulted in the patients' and families' needs being met through a telehospice visit. Yet, it is important to note that in almost 30% of the notes, a traditional home health visit was scheduled. In many cases, these in-person visits would have been scheduled anyway and did not result from an unsatisfactory telehospice experience.

Figure C6
Telehospice Outcomes



D) Anecdotal Evidence

Throughout the course of this project, it became clear to evaluators and hospice providers that telehospice was significantly impacting the quality of care for patients and caregivers. This section contains a sampling of this anecdotal evidence.

Michigan

- The caregiver of a patient at one of the rural sites called Hospice of Michigan's extended coverage (extended hours) support team at approximately 3:00AM to report that the patient was in extreme abdominal pain. The nurse who was on call was approximately sixty miles away from the patient having this trouble. The extended coverage nurse asked the caregiver to pan the telehospice unit over the patient's body, so she could see what was going on. She was able to see that the patient's catheter tube was kinked and the flow of urine was obstructed. The nurse instructed the caregiver how to fix the catheter tube. This use of the telehospice system saved the on call nurse two hours in the car, saved Hospice of Michigan the cost of her hourly wages, and – most importantly – saved the patient from unnecessary pain as the on call nurse was on her way to the patient's home.
- The caregiver of a patient in an urban setting called Hospice of Michigan extremely anxious because her husband was bleeding from the neck, and she did not know what to do. A nurse instructed her to get the telehospice unit, and that nurse instructed the caregiver about what she should be doing while another nurse was en route to the patient's home. The caregiver's anxiety level decreased upon seeing the nurse's face, and the caregiver was on the phone while waiting for the nurse to arrive at their home. Additionally, the nurses involved were able to communicate findings with one another via the telehospice units.
- A golfer on the PGA Senior Tour, Allen Doyle, was touring a Hospice of Michigan building in Detroit. A telehospice patient near Alpena lived in a golf course community and had been an avid golfer his entire life, before his illness prevented him from playing. Allen made a telehospice call to this patient, and it meant the world for the patient to talk with Doyle face to face using the telehospice equipment. The patient talked about that call many times before his death.
- A nurse was on the telehospice unit with a patient when the patient began to talk about thoughts of suicide. The nurse was able to pull a social worker into the conversation immediately to talk to the patient about this. The social worker could see the patient and the patient could see her. This helped the patient express his thoughts, it decreased his anxiety, and eliminated his thoughts of suicide.
- A nurse received a call from her patient that was complaining of upper chest, neck, and arm pain. The patient had a cardiac history and could have been having spinal cord compression due to his terminal illness. The nurse got on the telehospice unit while

another nurse was sent to his home. Using the telehospice equipment, the nurse could see the patient and that he was not appropriately following her instructions to relieve his pain. She then instructed him on what he was doing wrong, and how he could correctly work to relieve his pain. She stayed on the telehospice call with the patient until a nurse arrived at the patient's home, and the two nurses used the telehospice units to consult about the patient's care.

- A telehospice unit was put into the home of an actively dying patient, something not usually done due to the high levels of anxiety in the home at that time. The caregiver and a social worker both felt this could benefit the patient and caregiver and decrease the level of anxiety in this case. At one point, the caregiver called the extended coverage staff stating that her husband was having difficulty breathing and that he was very congested. A nursing visit was offered but declined by the caregiver, as the caregiver wanted to be alone with her husband in his final hours. Still, the nurse was able to offer instructions on how to properly inject the patient correctly to help decrease secretions. The patient died a few hours later. The caregiver was thankful for telehospice and the support of the staff. She was also thankful that the staff respected her wishes to be alone with her husband. She was appreciative that through telehospice, someone was able to see what she was doing and help her do it correctly.
- One of the most innovative uses of telehospice has been to connect patients to distant relatives. Telehospice units have been sent to Alaska, Hawaii, Florida, New Mexico, Arizona, North Carolina, and throughout Michigan to connect Michigan hospice patients to their family members. Telehospice has helped Hospice of Michigan improve quality end of life care to dying patients by bringing them together with distant relatives who otherwise could not be with them throughout the dying process.
- Perhaps the most touching story of the telehospice project was when a unit was installed in a nursing home for a forty-year-old patient who had a five-year-old daughter that lived seventy-five miles away. The patient was only able to see her daughter every two weeks, until a telehospice unit was installed in her daughter's home. The day the patient was being instructed how to use the unit happened to be the daughter's sixth birthday, and her daughter brought all her presents to the camera and was able to share the day with her mother. The patient was crying, saying, "You have no idea what you've given me. For me to be able to see my daughter every day is something no words could ever express." For two weeks the patient was able to see her daughter at least every day through telehospice, helping her with homework and sharing stories. The patient improved emotionally in her final weeks as she was satisfied and fulfilled. She died two weeks later. Telehospice presented a unique opportunity to provide this patient with true quality end of life care.

Kansas

- Hospice nurses from southeast Kansas received a call from a caregiver reporting her husband had become quite agitated in the preceding two hours. While he had been confused for over a week, he was noted to be much more agitated, even combative. They

connected using the telehospice equipment, and the caregiver was asked to 'scan' the camera over the patient. The hospice nurse conducting the visit was able to see a kink in the Foley catheter. When the catheter was repositioned by the client's wife, the obstructed urinary flow was corrected, and the patient rested comfortably. This saved the nurse 1 ½ hours driving time to and from the patient's home.

E) Patient Interviews

Michigan

During the course of the project, 35 patients were interviewed in Michigan via telephone. The purpose of these interviews was to gauge patient perceptions of telehospice and its role in delivering end-of-life services. (See Appendix C for patient interview guide.)

When asked to describe hospice services in general, almost all of the patients feel that hospice is primarily to provide supportive services so that patients can die in comfort at home. Yet, when asked to explain the purpose of telehospice, 26% of the patients described it simply as a piece of equipment, and 63% defined telehospice as a communication tool. For example, one patient said, *it's "another way of checking up on me...call me once in awhile, check me over. I can see them and they can see me."*

When asked if receiving care via telehospice was different than care delivered in person, 77% responded that it was. Some explained that this was due to the missing physical proximity. *"Yes, because the person is right there, you know, right there to actually be close to the problem versus telehospice."* Yet others described the difference in advantageous form. One patient stated, *"Yes, because you can see them (providers) whenever you want."* Some patients did list services best delivered in person such as checking blood pressure and vitals or providing personal care. Some patients also described services best delivered via telehospice such as emergency care or a simple call to just check on a patient.

When asked what the best thing about telehospice care is, 60% stated the immediate access they had to their providers. Many described the comfort this affords, particularly for those in rural areas. One patient stated, *"...it's helpful since we live in a rural area around Alpena...we can call if we need anything or anything answered."* Another patient said, *"They're there. You can always reach them."* Almost 15% of the respondents listed the equipment-related issues as the best part of telehospice. One patient explained that she really liked *"using the phone to see people."*

Patients expressed great satisfaction with telehospice. When asked what they would change about telehospice services, more than 70% responded that they would change nothing about telehospice. Twenty-five percent stated that they would change some aspect of the equipment, with most saying they would like the phone to be bigger.

Almost 60% of the patients felt that telehospice had positively influenced their overall end-of-life care. One patient stated, *"Well, just having it there is peace of mind, that if we need it, it is there, we can use it."* In another case, a patient's caregiver told researchers, *"I don't think it has influenced my mother's care, but it helps me if I have any problems."* When asked if they would utilize telehospice again if given the choice, more than 70% said yes, 11% said no, and 17% said that it depends or that they couldn't think of a reason that they wouldn't. Evaluators were often told that patients or caregivers would benefit even more if the system would be used more frequently by the providers.

Finally, 60% of the patients told researchers that they valued and enjoyed their telehospice visits. One patient explained, *"I can see somebody before I go cuckoo."* Another stated that it was fun, *"even with bad hair days."* An additional 20% stated that sometimes they enjoyed visits. For example, one patient explained that she liked telehospice visits *"when I am well enough to use it."* An older gentleman told evaluators that he never was *"a telephone man, so I can't say I really enjoy talking on the telephone, but it does leave me the option if something's going wrong here, I can find someone to talk to and ask for help. And I think that's very important for a guy that's 88 years old."*

F) Patient Encounter Video Tape Analyses

Michigan

In order to better understand the dynamics occurring during a telehospice visit, fifteen random telehospice visits were video and audio recorded one year into the project. The purpose of gathering this qualitative data was to provide an initial description of what is actually happening during these mediated visits.

In 100% of the teleconsults, a health issue was addressed. In more than 70% of the visits, however, the providers also discussed personal and/or social matters with the patients. What is most interesting about this statistic is that in 30% of the teleconsults, the provider and patient stuck solely to the business at hand. Though traditional visit comparison data are unavailable, it is likely that this would be a smaller number in face-to-face visits due to perfunctory small talk that accompanies face-to-face communication.

Most of the topics covered during the recorded teleconsults concerned a specific outstanding health issue. Table F1 provides a breakdown of activities during the teleconsults. Please note that many teleconsults had multiple activities.

Table F1: Activities During Telehealth Consults

Activity	Frequency
Medications	80%
Pain Management	67%
Scheduling/Coordination of Care Issues	67%
Physical Assessment	67%
Equipment-related issues	13%
Teaching/Instruction	6%

Worth noting is the incidence of multiple parties participating in the teleconsult. In many cases, patients and their caregivers would visit with the nurse. In other cases, multiple providers (e.g., a nurse and a social worker) would participate in the visit. Overall, almost 50% of the visits included more than the nurse and patient. This indicates that telehospice is a convenient way to coordinate multiple appropriate parties within the same visit, something that is almost impossible when coordinating schedules to travel to a patient's home.

Finally, in more than 50% of the recorded teleconsults, the provider provided emotional support to the patient and/or caregiver. For example, in one case the nurse offered sympathetic comments to a patient because his wife was also ill. In another case, a nurse provided sympathy for a patient who had recently lost a family member. This has interesting implications for those arguing that the telemedicine medium is insufficient for more sensitive applications such as social or emotional support.

G) Caregiver Data

Michigan

Though not part of the formal telehospice research project, it became clear to evaluators during the course of the study that there was enormous potential benefit for patients' caregivers. As a result, a doctoral student was invited to conduct a dissertation to collect preliminary data on this issue. Telecommunications doctoral student Jennifer Gregg of Michigan State University performed a dissertation under the guidance of co-principal investigator Pamela Whitten, Ph.D. Gregg studied how telehospice could potentially affect caregivers in the hospice setting¹. Dr. Gregg was particularly interested in how telehospice services might support caregivers in their role taking care of a dying loved one, as well as what kind of policy changes might be necessary to help telehospice fulfill its potential in this regard.

Gregg's dissertation employed case study methodology which used social support as a guide to investigate how currently receive help from their support network. Specifically, data were gathered through semi-structured interviews with 51 hospice caregivers. The case also used policy analysis techniques to prescribe legislative and regulatory changes necessary to make telemedicine successful in providing support to hospice caregivers. Data were gathered through analysis of documents and interviews with pertinent people involved in hospice governance.

Gregg's research made clear that when hospice caregivers talk about the support they receive from others, it tends to be physical work – mowing the lawn, helping with cooking, etc. Yet, many of her subjects were overwhelmed by stress and loss of their social lives. It was clear that most caregivers do not have enough emotional support. This was particularly the case for caregivers without an extended family in the immediate geographical area to help provide support. Caregivers rarely sought help from Hospice of Michigan for their emotional support. This despite the fact that Hospice of Michigan holds supporting caregivers as part of its mission, and that Hospice of Michigan does make social workers available for caregiver support. Even though caregivers go through great strain, they are seemingly unaware of resources they can tap into for support. When asked about using telehospice as a convenient medium to obtain support, very few caregivers could imagine specific uses that would benefit them. This is line with their overall ignorance regarding the range and scope of support services available to them as caregivers.

Gregg proposed that *improving education of caregivers is the first step in facilitating their use of this technology*. Telehospice is a rich and convenient method of communication, far superior to a traditional phone – though not as rich as actual person-to-person communication. Still, telehospice could help in providing a great deal of support for caregivers, particularly those in rural areas. One example would be the use of telehospice to connect rural caregivers to distant family members, so that they might better provide emotional support to the caregiver. Another example would be connecting the caregiver to certain services – social workers, mental health professionals – that might not be available in their area. Hospice of Michigan (and hospices in general) may be able to improve the accessibility and quality of support services through the use

¹ Gregg, J. (2002). Telehospice: Changing health care policy to enhance social support for caregivers in rural areas. Unpublished doctoral dissertation, Michigan State University.

of telehospice. However, one significant obstacle that stands in the way to improving education about telehospice is a general shortage in nursing labor. Someone needs to do the educating, and nurses are already stretched thin in their efforts to serve existing patients.

Gregg also noted that many government agencies do not understand telehospice and do not always reimburse for its use. Certain changes must be made at the federal and state levels to make the use of telehospice for caregiver support the cost-saving alternative for hospice companies that it could be. Despite the obstacles mentioned, telehospice has great potential in aiding caregivers – both in terms of helping them with *their actual role as a caregiver*, and aiding them emotionally.

H) Provider Survey

Michigan

In order to gage provider pre-perceptions of telehospice, a survey was administered two weeks after the project launch. (See Appendix D for pre-perception provider survey.) Respondents were asked to rank their agreement with 11 statements on a one to five Likert scale with one representing strong disagreement and five representing strong agreement. Table H1 provides survey items and means.

Table H1: Provider Pre-Perception Survey (MI n=51)

Question	Mean	Standard Deviation
The telehospice equipment is easy to use.	3.55	.90
Telehospice is a good way to deliver hospice care.	3.00	0.94
The hospice patient is easy to hear when utilizing telehospice.	3.31	0.90
The hospice patient is easy to see when utilizing telehospice.	3.04	0.88
I enjoy the telehospice visits.	2.86	1.07
Telehospice increases my access to hospice patients.	2.98	1.10
Care via telehospice is comparable to the care I provide in-person.	2.06	0.84
I would rather visit with the patient in-person as opposed to telehospice.	4.31	0.86
I feel comfortable using the telehospice equipment.	3.57	1.02
Telehospice will improve the quality of hospice care given to patients.	3.42	0.84
My office has clear procedures for enrolling telehospice patients.	3.76	0.96

When the pre-perception surveys were completed early in the project, 25 respondents had participated in 1-5 teleconsults, 15 respondents had participated in 6-10 consults and 11 had participate in 11 or more.

At the conclusion of the project, a post-provider survey was administered for Michigan providers. (See Appendix E for post-provider survey.)The survey included the original questions, and was expanded to address issues that came to light during the course of the project. Respondents were asked to rank their agreement with statements on a one to five Likert scale with one representing strong disagreement and five representing strong agreement. In addition, they were asked to respond to demographic and utilization questions. Table H2 provides frequency statistics for the post-provider survey.

Table H2: Provider Post-Perception Survey (MI n=46)

Question	Mean	Standard Deviation
I have had adequate training in using the telehospice system.	3.89	0.92
I use the telehospice system effectively at work.	3.22	1.08
The use of the telehospice system enhances patient care.	3.70	0.74

I am developing expertise in the use of telehospice.	2.98	1.08
I would like to have telehospice equipment available for use in my home.	2.24	0.97
I would like every patient to have access to telehospice.	3.18	1.11
I feel tense when people start talking about telehospice.	2.33	0.95
I feel pressure from others to integrate telehospice into patient service.	2.84	1.08
I would like my patients to be able to use telehospice more.	3.12	0.91
Telehospice is dehumanizing.	2.05	0.94
I avoid telehospice whenever possible.	2.37	1.00
Telehospice is just another fad.	2.07	0.86
More training would increase my use of telehospice.	2.89	1.17
Telehospice diminishes my role as a provider.	2.11	0.81
Telehospice makes my job easier.	2.88	0.91
Telehospice skills will help me as a professional.	2.95	0.86
Learning telehospice makes high demands on my professional time.	2.84	0.97
Telehospice changes my role as a provider.	2.42	0.88
I can help others solve telehospice problems.	2.80	1.11
I am aware of successful telehospice applications within HOM.	4.02	0.72
Telehospice enhances patient care.	3.73	0.78
My telehospice patients provide positive feedback about the service.	3.39	0.73
I have had adequate time to learn the telehospice system.	3.64	1.01
I have sufficient access to telehospice equipment at work.	3.96	0.80
My office supports telehospice related training.	3.89	0.65
My office actively encourages the use of telehospice.	3.93	0.67
The system my office has in place for deploying and returning telehospice equipment is easy to use.	3.69	0.85
My team actively discusses potential patients for telehospice at team meetings or weekly IDG meetings.	3.35	0.99
I have seen my clinical supervisor use telehospice to support patient care delivery.	3.28	1.10
Team members in multiple disciplines take advantage of the telehospice equipment to maximize continuity of care for patients in our office.	3.39	0.95
The telehospice project coordinator responds to my needs in a timely manner.	3.79	0.77
The telehospice equipment is easy to use.	3.80	0.94
Telehospice is a good way to deliver hospice care.	3.46	0.81
The hospice patient is easy to hear when utilizing telehospice.	3.64	0.81
The hospice patient is easy to see when utilizing telehospice.	3.16	0.98
I enjoy the telehospice visits.	3.07	0.90
I feel making telehospice calls requires too much of my time.	3.15	1.08
telehospice increases my access to hospice patients.	3.31	0.89
Care via telehospice is comparable to the care I provide in-person.	2.10	0.94

I would rather visit with the patient in-person as opposed to telehospice.	4.22	0.77
I feel comfortable using the telehospice equipment.	3.68	1.05
Telehospice will improve the quality of hospice care given to patients.	3.51	0.91
My office has clear procedures for enrolling telehospice patients.	3.90	0.79
HOM technical support adequately assists me in problem solving and troubleshooting.	3.75	0.74
HOM technical support is dedicated to helping providers.	3.76	0.66
I have to contact our technical support several times before I get assistance.	2.26	0.79
I know who to call when I have a technical problem.	3.40	1.08
I am familiar with computer training available from HOM.	3.48	1.02
I use my computer for multimedia functions. (e.g., music, video)	1.88	1.23
I go online for fun/entertainment related activities	2.32	1.29
I use my computer as a communication tool. (e.g., e-mail)	3.66	1.46
I use my computer as a productivity tool. (e.g., to manage or have access to patient data)	3.14	1.77
I use my computer to search the Internet.	3.10	1.39
Gender Male:4 Female:39		
Race/Ethnicity Native American/American Indian:0 African American:9 White/non-Hispanic:32 Asian/Pacific Islander:0 Hispanic:0 Other:1		
Highest degree earned Bachelors:14 Masters:10 Specialist:0 Doctorate:1 Other:14		
Years at Hospice of Michigan	3.61	2.67
Years Experience in Field	11.72	9.11

When the post-perception surveys were conducted at the completion of the project, seven respondents had never conducted a teleconsult, 18 respondents had participated in 1-5 teleconsults, five respondents had participated in 6-10 consults and 15 had participate in 11 or more. Though there was normal turnover during the years of this project, these numbers are not radically different from utilization activity during the pre-perception surveys. This has important implications regarding provider interest and utilization of the telehospice system, namely those that are interested will employ the system early on and keep using and those that are not interested will not adopt this innovation.

Data from the post provider survey items indicates several interesting trends. First, providers feel that they received adequate training and organizational support for telehospice. Second, providers feel that telehospice can be helpful for patients and are aware of success stories at Hospice of Michigan. Yet, they also would still prefer to see patients in person rather than via telehospice. Finally, they feel that telehospice care is not comparable to care they provide in person.

Several preliminary statistical analyses were conducted on the pre- and post-survey data. First, t-tests were run to determine if responses to the original survey items were significantly different from the post-provider surveys. Even though there was some variation in respondents, surprisingly there were no significant differences in the mean responses for the pre- and post-perception surveys. This indicates that through the course of the project, providers perceptions did not grow (or decrease) in favorability. Again, this has interesting implications regarding provider acceptance and utilization of this technology. It would appear that providers approach a telemedicine project with specific perceptions regarding comfort, ease of use, and value. Furthermore, these perceptions do not change significantly as they participate in orientation, use or see others using telehospice.

Evaluators also ran a series of cross tabulations. First, evaluators were interested if there was any relationship between actual experience with telehospice (eleven or more visits) and agreement with statements regarding personal experience with the telehospice system. Contrary to evaluator expectations, preliminary analyses indicates that there was little impact on responses based on experience. The only responses linked by actual experience were items related to comfort with the technology. There were no significant relationships between level of education (coded as highest degree earned), years at Hospice of Michigan, years experience in position, and position and provider perceptions. See Table H3 for results. Due to small sample size, which impacts values in the cross tabs contingency table, this data should be carefully interpreted. The evaluators plan to collapse some of the scale items in future analyses to obtain a contingency table with smaller dimensions.

Table H3: Relationship between Actual Experience and Perceptions (significance reported at the .05 level)

Item	Experience (11 or more visits)	Degree Earned	Years at Hospice of Michigan	Years experience in health field	Position
The telehospice equipment is easy to use.	*				
Telehospice is a good way to deliver care.				*	
I enjoy the telehospice visits.					
Telehospice increases my access to telehospice patients.					
Care via telehospice is comparable to the care I provide in person.					
I would rather visit with the patient in person as opposed to telehospice.					
I feel comfortable using the telehospice equipment.	*				
Telehospice will improve the quality of					

hospice care given to patients.					
My office has clear procedures for enrolling telehospice patients.					

D) Provider Educational Activities

Michigan

The original intent of the grant included a goal to employ interactive video for statewide EPEC (Educating Physicians in the End of Life Care) in Kansas, and development of such a network in Michigan. Development activities were conducted in Michigan and several EPEC educational events were held in Kansas. However, half way through the project, evaluators obtained permission to move away from this goal and shift funding to focus primarily on patient care. In Michigan, however, two significant provider educational activities were evaluated. On October 24, 2001, in partnership with the Michigan State Medical Society, an interactive video, statewide educational session was conducted. The session entitled, "Hospice Medical Director's Training" included participants from sixteen sites around the state of Michigan. This event represented the largest multi-site event hosted by the Michigan State Medical Society to date. This interdisciplinary event included 16 physicians, 67 nurses, 7 students and 28 others (office managers, etc.) General impressions were extremely positive (see table II)

Table II General telehospice Conference Results

Item	Yes	No
1. Conference objectives were defined adequately.	113	5
2. Presentations carried out the stated objectives.	115	1
3. The material will be useful in my practice.	113	2
4. My expectations for this conference were met adequately.	114	3
5. The meeting facilities were satisfactory.	115	6

Participants provided dozens of additional comments. Sample comments are provided in Table I2.

Table I2 Sample Comments

Excellent section on self-care.	I really appreciated the awesome presentation on self preservation and especially the spiritual element...
Excellent presentation...answered many questions that I had related to hospice and palliative care.	Interesting self reflection...helpful info on compliance policy.
A shorter session for MDs would help with physician attendance.	Excellent conference...would like to see more opportunities for learning about hospice care.
Video conferencing worked very well.	The video hook-up was very poor.
Excellent conference; great handouts.	I am new to the hospice setting and feel the information you've shared will help me be a better nurse to my patients.

On February 19, 2002, a videoconferencing telehospice educational event was provided for Hospice of Michigan employees at the offices providing telehospice services. A total of 39 participants attended the event, entitled “ Telehospice: Connecting Patients, Providers, and Caregivers.” The purpose of this event was twofold: to educate providers about telehospice and study results to date, and to provide a forum for idea sharing to foster additional use of the equipment. This event was participatory by design so that active users from each office were invited to make recommendations to providers less active in telehospice use. This event was well received with 30 participants stating that they would recommend this presentation to another hospice provider. Table I3 provides results concerning participant perceptions of the event, and Table I4 provides a sampling of participant comments.

I3: Participant Perceptions

Item	Excellent	Good	Average	Satisfactory	Unsatisfactory
1. Overall goal met to satisfaction.	6	16	10	2	0
2. Enhanced understanding of study data.	9	16	9	2	0
3. Presented effectively.	8	16	11	2	0
4. Overall understanding increased.	11	16	11	2	0

Table I4 Sampling of Comments

Very informative regarding teams and sites	Answered a lot of questions for me
Great interactive approach	Should have had a unit demonstration for hands on demonstration
Great to hear other uses, gave new ideas.	Nice orientation, very rewarding
Appreciate the effort to improve the program	Need to encourage triage to use more
Inspired us to discuss opportunities to use telehospice	Need to have all disciplines using telehospice

Kansas

In Kansas, four different EPEC educational events were conducted during the period of the grant. Each spring, a two day educational seminar promoting excellence in end-of-life care was delivered (April 13, 14, 2000; May 17, 18, 2001; May 2, 3, 2002). Over 70 providers participated in these training programs. In addition, in the fall of 2002, 18 providers from three different Kansas communities (Pittsburg, Phillipsburg and Oakley) received EPEC certification after participating in the course via ITV. This educational program has been well-received by physicians, nurses and social workers involved in end-of-life care. Due to popular demand, these educational events are slated to continue beyond the grant on a semi-annual basis.

J) Archival/Collateral Materials

During the course of the project, several collateral materials were developed. Prior to the project launch, a Telehospice User's Guide was created and employed in training sessions (Appendix F). Various forms were created and employed within Hospice of Michigan to address research and logistical requirements. Appendix G provides the Patient Consent Form. Appendix H provides Presenting Telehospice to Patients and Family: Cheat Sheet. Finally, Appendix I provides Frequently Asked Questions.

K) Conclusions

The telehospice project will prove to be an important telemedicine study through its documentation of a number of key issues related to utilization, acceptance, and effectiveness. This paper concludes with an outline of the most significant lessons learned from this research project.

- **Telehospice was adopted more readily and demonstrated a more significant contribution for rural patients as compared to urban patients.** Providers in rural hospice offices in both states identified applications and benefits more readily than their urban counterparts. Even though there are delivery challenges in urban areas, the sheer distance to reach rural patients dominates as the most important benefit of telehospice.
- **It is important to carefully time when a patient is offered telehospice.** A great number of patient refusals for telehospice are directly attributable to feelings of being overwhelmed when patient is first being enrolled into hospice care. This is an extremely sensitive event, often when patients and caregivers are accepting the inevitability of death. Many patients are better prepared to consider telehospice a week or two into their hospice enrollment.
- **Though a wide range of end-of-life services can potentially be delivered via telehospice, nursing services dominate.** Even though this technology was made available to multiple specialties (e.g., spiritual care, social work), nurses most readily adopted this technology over other disciplines.
- **A wide array of physical assessments can be conducted over the telehospice system.** Many propose that home telehealth will predominately be used for teaching or instruction. Even though this was an important telehospice activity, almost half of the activities occurring during teleconsults were related to physical assessments of patients.
- **Activity during telehospice visits mirrors activity during traditional consults.** With the possible exception of equal levels of emotional/social support, nurses delivered the same services via telehospice as in person (e.g., medication-related, pain management, physical assessments.) One added advantage that emerged with telehospice was the ability to easily include third and fourth parties during the televisit (e.g., family members, other health providers on the patient's team).
- **Patients are comfortable receiving services via telehospice.** Data indicated that not only are patients content to receive a wide range of services via telehospice, but many wish their providers would employ the telehospice system more frequently. Patients quickly become comfortable with the technology and feel that they have received acceptable care via televisits.
- **Caregivers are an untapped recipient of telehospice services.** Though this project did not formally seek to evaluate end-of-life services provided to family members and friends taking care of hospice patients, these caregivers emerged as serendipitous beneficiaries. *More research is needed to evaluate the impacts on caregivers.*
- **Hospice providers make or break the successful use of telehospice.** Nurses, social workers, and other providers are the primary gatekeepers to the use of telehospice services for patients. We know that patients are comfortable receiving services via telehospice, yet this can only happen if their provider will use this innovation. Pre and post survey data informed us that experience does not have the impact we had hoped to

see. Providers have pre-conceived notions about whether they want to use this technology or not, and watching others successfully employ this technology does not appear to sway those with little enthusiasm for telehospice. This has significant implications for how hospice organizations should launch and employ telehospice services in the future.

L) Project Publications/Presentations to Date

Now that the project is completed, evaluators are drafting research articles for submission to peer-reviewed journals. During the course of the project, the following preliminary, peer-reviewed publications and presentations were accepted:

Whitten, P., & Doolittle, G. (2003). Telehospice in Michigan and Kansas: Final Study Results Abstract submitted for presentation at the American Telemedicine Association, April, 2003, Orlando, FL.

Whitten, P., Doolittle, G., Mackert, M., & Rush, T. (in submission). Telehospice: Using Videophones to Enhance End-of-Life Care. Submitted to *Nursing Management*.

Whitten, P., & Doolittle, G. (2002). Telehospice in Michigan and Kansas: Year Two Study Results. Paper presented at the American Telemedicine Association Annual Conference, Los Angeles, June.

Whitten, P., Mackert, M., & Rush, T. (2002). Telehospice in Michigan. Poster presentation at Michigan Hospice & Palliative Care Organization, Novi, MI, November.

Whitten, P. (2002). "Telehospice: Connecting Patients, Provider and Care" presented at Building Bridges of Excellence in Supportive Palliative Care International Conference, Windsor, Ontario, Canada, June.

Whitten, P. (2002). Telehospice: Accessing Rural and Urban Communities. Abstract accepted for publication at Preparing for Value Added Leadership conference sponsored by Michigan Hospice & Palliative Care Organization, East Lansing, MI, April.

Whitten, P., Doolittle, G. & Hellmich, S.A. (2001) Telehospice: Using telecommunication technology for terminally ill patients. *Journal of Computer Mediated Communication*, 6(4) <http://www.ascusc.org/jcmc/vol6/issue4/whitten2.html>.

Cook, D.J., Doolittle, G.C., & Whitten, P.S. (2001). Administrator and provider perceptions of the factors relating to programme effectiveness in implementing telemedicine to provide end-of-life care. *Journal of Telemedicine and Telecare*, 7(2), 17-20.

Whitten, P. (2001) An Overview of Telehospice Research. Paper presented at the National Hospice Work Group, San Diego, CA.

Whitten, P. (2001). "Telehospice in Michigan" presented at 14th Annual Continuing Education Program on Issues in Aging, Troy, MI, May.

Whitten, P., Doolittle, G., & Hellmich S.A. (2000). Telehospice: A bi-state project to improve end-of-life care. Paper presented at Healthcare Information and Management Systems Society, Los Angeles, November.

Whitten, P., Doolittle, G., & Hellmich, S.A. (2000). Telehospice: Using technology to virtually link nurses and patients. Paper presented at National Communication Association, Seattle, November.

Doolittle, GC, Whitten, PS, & Cook, DJ. (2000). TelehospiceSM: A bi-state initiative to utilize telemedicine to improve patient care at the end-of-life, Telemedicine Journal, 6(1), 157.

APPENDICES

Appendix A
Decline Survey
(©Michigan State University)

Name:

Pt ID#:

Date:

Telehospice Survey (Patient declines service)

Instructions: If the patient/family declines Telehospice service, obtain verbal permission to ask the following questions:

1. Would you mind telling me why you chose not to participate?

(If an individual cannot offer an explanation, try prompting with the following questions.)

- a. How are you feeling at this time?
- b. How do you feel about the technology used in the study?
- c. How do you feel about becoming involved in a research project?
- d. Would it have been different if we had explained this at a later time?

2. Have you had any past experience with a computer?

Do you have e-mail?

Yes No

Telehospice Survey (Patient is not eligible)

Patient was not offered Telehospice because:

- Not able to set up within 48 hours of offering.
- Patient is actively dying.
- Patient is in long-term care facility or hospital (circle).
- There is no touch-tone phone service in the home.
- Other reason: _____

Appendix B
Telehospice Nurse Note
 (©Michigan State University)

Call initiated by:
 Nurse
 Pt/Family
 Other:

HOSPICE OF MICHIGAN
Interdisciplinary Contact Note – Telehospice

PT ID# _____ Date _____  Time in _____  Time out _____ PT Name _____

All persons present during visit:

Main interaction with: Pt PCG Other

HOM disciplines present during visit: Nurse SW SpCare Physician Other

(Circle the number of present intensity as reported by patient)	Pain Scale: 0 1 2 3 4 5
Caregiver report:	
Given your current goals, are you satisfied with pain control?	Pt: <input type="checkbox"/> yes <input type="checkbox"/> no CG: <input type="checkbox"/> yes <input type="checkbox"/> no
Could you use more instruction on medications?	Pt: <input type="checkbox"/> yes <input type="checkbox"/> no CG: <input type="checkbox"/> yes <input type="checkbox"/> no
Do you have all of the equipment and supplies you need?	Pt: <input type="checkbox"/> yes <input type="checkbox"/> no CG: <input type="checkbox"/> yes <input type="checkbox"/> no
Do you know how to use the equipment you currently have?	Pt: <input type="checkbox"/> yes <input type="checkbox"/> no CG: <input type="checkbox"/> yes <input type="checkbox"/> no
Would you like a visit?	Pt: <input type="checkbox"/> yes <input type="checkbox"/> no CG: <input type="checkbox"/> yes <input type="checkbox"/> no

Mileage from team office to patient's home: _____

Expected travel time: _____

NATURE OF THE TELEHOSPICE VISIT: Scheduled Unscheduled Emergency Other: _____

REASON FOR THE CALL:

ACTION/RESPONSE:

Technical difficulties: Pt phone Pt monitor HOM equipment Describe:

OUTCOME/DISPOSITIO NEEDS MET; PT/FAMILY SATISFIED (refer to evidence of satisfaction documented above)
N:

FOLLOW-UP NEEDED:

TELEHOSPICE VISIT SCHEDULED:

HOME VISIT SCHEDULED:

SIGNATURE/TITLE: _____

XXXX Feb 00

ORIGINAL - Patient Record

COPY - Telehospice Liaison

Appendix C
Patient Interview Guide
(©Michigan State University)

1. What do you think hospice care is?
2. What are examples of services you receive in person from a hospice provider?
3. What do you think telehospice is?
4. What are examples of services you receive over the Telehospice system from a hospice provider?
5. Is receiving care over the Telehospice system any different from receiving care in person? If yes, how so?
6. Are there any services that you feel are best delivered in person?
7. Are there any services you feel are best if delivered over the Telehospice equipment?
8. What is the best thing about telehospice?
9. What would you change about the telehospice service?
10. Do you think being part of the Telehospice project is influencing your care in any way? If so, how?
11. If you had the choice again, would you use Telehospice? Why or why not?
12. Do you enjoy the Telehospice visits? Why or why not?
13. Would you like to mention anything else about Telehospice?

Appendix D
Provider Pre-perception Survey
 (©Michigan State University)

Telehospice Provider Survey

We would like to ask you a few questions pertaining to the Telehospice project so that we can improve Telehospice services. Please complete the following questions by circling the appropriate number that follows each question. Please be as candid as possible, as all information will be strictly confidential. We thank you for your time and hard work on the Telehospice project.

Pamela Whiten, PhD & Gary Doolittle, MD (Principal Investigators)

	Strongly Disagree			Strongly Agree
1. The Telehospice equipment is easy to use.	1	2	3	4 5
	Strongly Disagree			Strongly Agree
2. Telehospice is a good way to deliver hospice care.	1	2	3	4 5
	Strongly Disagree			Strongly Agree
3. The hospice patient is easy to hear when utilizing Telehospice	1	2	3	4 5
	Strongly Disagree			Strongly Agree
4. The hospice patient is easy to see when utilizing Telehospice.	1	2	3	4 5
	Strongly Disagree			Strongly Agree
5. I enjoy the Telehospice visits.	1	2	3	4 5
	Strongly Disagree			Strongly Agree
6. Telehospice increased my access to the hospice patients.	1	2	3	4 5
	Strongly Disagree			Strongly Agree
7. The care I provide via Telehospice is comparable to the care I provide in-person.	1	2	3	4 5
	Strongly Disagree			Strongly Agree
8. I would rather visit with the patient in-person as opposed to Telehospice.	1	2	3	4 5
	Strongly Disagree			Strongly Agree

9. I feel comfortable using the Telehospice equipment.

1 2 3 4 5

Strongly Disagree

Strongly Agree

10. Telehospice will improve the quality of hospice care given to patients.

1 2 3 4 5

Strongly Disagree

Strongly Agree

11. My office has clear procedures for enrolling Telehospice patients.

1 2 3 4

5

How many visits have you conducted on the telehospice system?

1 to 5 visits

6 to 10 visits

11 or more visits

Please Check One:

Nurse _____ Social Worker _____ Spiritual Care _____ Other _____

Appendix E
 Provider Post-Perception Survey
 (©Michigan State University)

Dear Hospice Provider:

As our Telehospice research projects draws to a close, we would like to gather one last set of data from you, the hospice provider. We would like to ask you questions regarding your perceptions of Telehospice. Please be as candid as possible, as all information will be strictly confidential. We thank you for your time and contribution to the Telehospice project.

Part I: The following statements are intended to reflect your personal perception of Telehospice. Please read each statement and circle the number that best reflects your response. Please note that this is a one-to-five scale, with one meaning that you strongly disagree with the statement and five meaning that you strongly agree with the statement.

	1=strongly disagree	2=disagree	3=neutral	4=agree	5=strongly agree
I have had adequate training in using the Telehospice system.	1	2	3	4	5
I use the Telehospice system effectively at work.	1	2	3	4	5
The use of the Telehospice system enhances patient care.	1	2	3	4	5
I am developing expertise in the use of Telehospice.	1	2	3	4	5
I would like to have Telehospice equipment available for use in my home.	1	2	3	4	5
I would like every patient to have access to Telehospice.	1	2	3	4	5
I feel tense when people start talking about Telehospice.	1	2	3	4	5
I feel pressure from others to integrate Telehospice into patient service.	1	2	3	4	5
I would like my patients to be able to use Telehospice more.	1	2	3	4	5
Telehospice is dehumanizing.	1	2	3	4	5
I avoid Telehospice whenever possible.	1	2	3	4	5
Telehospice is just another fad.	1	2	3	4	5
More training would increase my use of Telehospice.	1	2	3	4	5
Telehospice diminishes my role as a provider.	1	2	3	4	5
Telehospice makes my job easier.	1	2	3	4	5
Telehospice skills will help me as a professional.	1	2	3	4	5
Learning Telehospice makes high demands on my professional time.	1	2	3	4	5
Telehospice changes my role as a provider.	1	2	3	4	5
I can help others solve Telehospice problems.	1	2	3	4	5
I am aware of successful Telehospice applications within HOM.	1	2	3	4	5
Telehospice enhances patient care.	1	2	3	4	5
My Telehospice patients provide positive feedback about the service.	1	2	3	4	5

Part II: The following questions are directed specifically to your experience at Alpena. Please read each statement and circle the number that best reflects your response. Please note that this is a one-to-five scale, with one meaning that you strongly disagree with the statement and five meaning that you strongly agree with the statement.

	1=strongly disagree	2=disagree	3=neutral	4=agree	5=strongly agree
I have had adequate time to learn the Telehospice system.	1	2	3	4	5
I have sufficient access to Telehospice equipment at work.	1	2	3	4	5
My office supports Telehospice related training.	1	2	3	4	5
My office actively encourages the use of Telehospice.	1	2	3	4	5
The system my office has in place for deploying and returning Telehospice equipment is easy to use.	1	2	3	4	5
My team actively discusses potential patients for Telehospice at team meetings or weekly IDG meetings.	1	2	3	4	5
I have seen my clinical supervisor use Telehospice to support patient care delivery.	1	2	3	4	5
Team members in multiple disciplines take advantage of the Telehospice equipment to maximize continuity of care for patients in our office.	1	2	3	4	5
The Telehospice project coordinator responds to my needs in a timely manner.	1	2	3	4	5

How many visits have you conducted on the Telehospice system?
 ___ 0 ___ 1-5 ___ 6-10 ___ 11 or more

If you checked 0 for the above question, please proceed directly to the questions in Part IV. If you checked any of the other responses, please continue the survey at Part III below.

Part III: The following questions relate to your personal experience with the Telehospice system. Please read each statement and circle the number that best reflects your response. Please note that this is a one-to-five scale, with one meaning that you strongly disagree with the statement and five meaning that you strongly agree with the statement.

	1=strongly disagree	2=disagree	3=neutral	4=agree	5=strongly agree
The Telehospice equipment is easy to use.	1	2	3	4	5
Telehospice is a good way to deliver hospice care.	1	2	3	4	5
The hospice patient is easy to hear when utilizing Telehospice.	1	2	3	4	5
The hospice patient is easy to see when utilizing Telehospice.	1	2	3	4	5
I enjoy the Telehospice visits.	1	2	3	4	5
I feel making Telehospice calls requires too much of my time.	1	2	3	4	5
Telehospice increases my access to hospice patients.	1	2	3	4	5
Care via Telehospice is comparable to the care I provide in-person.	1	2	3	4	5
I would rather visit with the patient in-person as opposed to Telehospice.	1	2	3	4	5
I feel comfortable using the Telehospice equipment.	1	2	3	4	5

Telehospice will improve the quality of hospice care given to patients.	1	2	3	4	5
My office has clear procedures for enrolling Telehospice patients.	1	2	3	4	5

Part IV: The following questions are intended to reflect your knowledge of the technical support at HOM. Please read each statement and circle the number that best reflects your response. Please note that this is a one-to-five scale, with one meaning that you strongly disagree with the statement and five meaning that you strongly agree with the statement.

	1=strongly disagree	2=disagree	3=neutral	4=agree	5=strongly agree
HOM technical support adequately assists me in problem solving and trouble-shooting.	1	2	3	4	5
HOM technical support is dedicated to helping providers.	1	2	3	4	5
I have to contact our technical support several times before I get assistance.	1	2	3	4	5
I know who to call when I have a technical problem.	1	2	3	4	5
I am familiar with computer training available from HOM.	1	2	3	4	5

Part V: The following questions are meant to reflect how often you use computers for various purposes either at home or at work. Please read each statement and circle the one that best reflects your response. Please note that this is a one-to-five scale, with one meaning that you don't do this at all and five meaning that you do this every day.

	1=not at all	2=once a month or less	3=once a week	4=several times a week	5=every day
I use my computer for multimedia functions (e.g., music, video).	1	2	3	4	5
I go online several times a week for fun/entertainment related activities.	1	2	3	4	5
I use my computer as a communication tool (e.g., e-mail).	1	2	3	4	5
I use my computer as a productivity tool (e.g., to manage or have access to patient data).	1	2	3	4	5
I use my computer to search the Internet.	1	2	3	4	5

Part VI: Please complete the following two questions to let us know about your perceptions regarding uses for Telehospice.

List any patient services that are best delivered via Telehospice rather than in person.

List any patient services that are not appropriate for delivery via Telehospice.

Part VII: Please complete the following demographic data about yourself.

Gender:

- Male
 Female

Race/Ethnicity:

- Native American/American Indian
 African American
 White/non-Hispanic
 Asian/Pacific Islander
 Hispanic
 Other, please specify _____

Highest degree earned:

- Bachelors
 Masters
 Specialist (Ed.S.)
 Doctorate
 Other, please specify _____

Years at Hospice of Michigan: _____

Years experience in field: _____

Position: _____

Any additional comments or input?

Thank you for completing this survey.

Appendix F

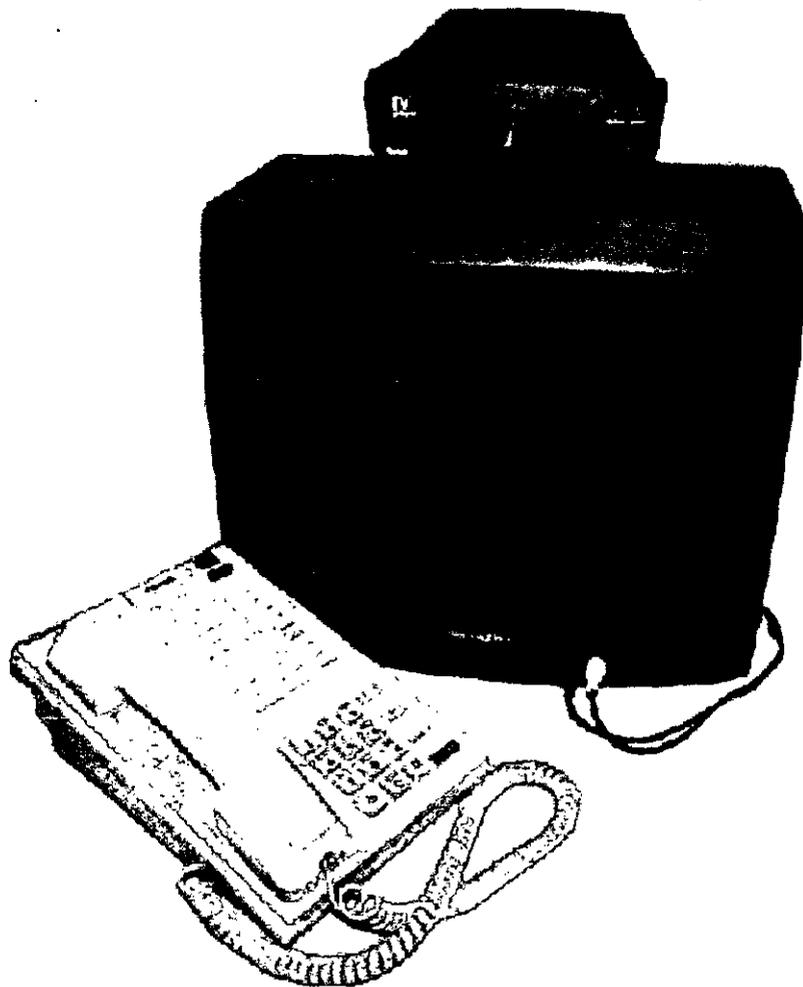
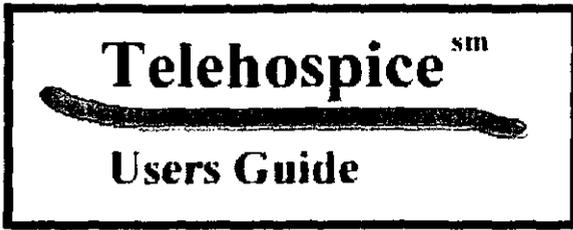


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Introduction



This manual is intended to help you, the health care provider, extend care to hospice patients and families by using a new technology we at Michigan State University call TelehospiceSM. It allows for visual and audio contact between two geographically separated parties. The use of such technology in the home health world is growing at a rapid rate and its use

in this setting is by no means intended to replace the hands-on care for which hospice is recognized. It is intended to augment what we consider excellent hospice care. The text to follow will teach you how to use the TelehospiceSM equipment, and how to present it to new hospice enrollees.

We sincerely thank you for taking the time to read and understand the enclosed materials. It is our firm belief that we can help comfort those with illness and disease by using TelehospiceSM technology, however, this conclusion cannot be supported without your help. Thank you for being a part of this project.

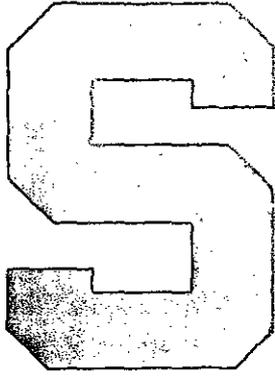
The Michigan State University Telemedicine Research Staff

Pamela Whitten, PhD
Primary Investigator

Seth Hellmich
Research Assistant

Hospice of Michigan Research Staff

Sylvia Bell, RN
Research Nurse



The History Of Telemedicine

Telemedicine, the use of Telecommunication technologies to deliver health care, has been under development during the past four decades. Wittson and colleagues are credited as the first to employ telemedicine for medical purposes in 1959 when they set up telepsychiatry consultations between the Nebraska Psychiatric Institute in Omaha and the state mental hospital 112 miles away. In the same year, Montreal, Quebec, was the site for pioneer teleradiology work being done by Jutra. In the 1970s, there was a flurry of telemedicine activity as several major projects developed in North America and Australia, including the Space Technology Applied to Rural Papago Advanced Health Care (STARPAHC) project of the National Aeronautics and Space Administration (NASA) in southern Arizona; a project at Logan Airport in Boston, Massachusetts, and programs in northern Canada. Grigsby and Kaehny (1993) reviewed telemedicine activities undertaken prior to 1993. With the exception of the 20-year-old telemedicine program at Memorial University Hospital of Newfoundland, none of the programs begun before 1986 has survived. Although data are limited, early reviews and evaluations of these programs suggest that the equipment was reasonably effective at transmitting the information needed for most clinical uses and that users were for the most part satisfied.

The decades of 1960, 1970, and 1980 exhibited a series of telemedicine pilot and demonstration projects. However, the 1990s have proven to be a period of rapid growth. In 1990, there were four active telemedicine programs. In 1994, there were 26 such programs, and by 1999, there are over 200 documented telemedicine programs



Traditionally, telemedicine applications have been developed around the provision of clinical services to people in remote areas. The top applications in telemedicine to date include Teleradiology, Telepsychiatry, Telecardiology, Teleophthalmology, Teleorthopedics and Teledermatology. Yet, there is a wealth of opportunity for telemedicine applications that are in the early stages of dissemination.

As we face the onset of a new century, the practice of medicine as we currently know it is poised to be recreated and redefined. Relationships between providers and patients are changing as a result of the changing methods of health care delivery. As perhaps the most innovative technology to be introduced in the health care arena, telemedicine has a potentially bright future.

Exciting projects in progress include Telemedicine to jails, Telemedicine to children in schools, and Telemedicine to chronically ill patients in the home. This project, Telehospice, represents a groundbreaking application in Telemedicine.

TeleMedicine In Michigan



UPPER PENINSULA TELEHEALTH NETWORK

The Upper Peninsula Telehealth Network (UPTN) was established with federal funds from the Office of Rural Health Policy and the Rural Utilities Services. These funds provided equipment to rural Upper Michigan hospitals and clinics for distance learning, teleradiology and other telehealth applications. Network organizations have provided significant match and in-kind funds to support the goals and objectives. The network establishes an electronic link between health care providers of Michigan's Upper Peninsula so that they may deliver the best health care possible.

Applications include distance learning, administrative meetings, and clinical telemedicine. Professional education provides an average of six physician continuing medical education events per month, and eleven nursing and allied health programs per month. Community education programs are varied and include monthly physician public lectures, childbirth classes, support groups, and general education. Administrative meetings average six per week. Medical applications are conducted between the hub and end sites, and between the hubs and quaternary care centers. Applications include psychiatric consultations, teleradiology, surgical follow ups, perinatology/fetal ultrasound consults, tumor board, pediatric discharge planning, multi disciplinary care conferences, and miscellaneous physician to physician consultations. Pre chemotherapy assessments and telepathology are anticipated in the near future.

A partnership with the Michigan State Department of Corrections provides telepsychiatry for prisoners in the region.

UNIVERSITY OF MICHIGAN

The Psychiatric Informatics Program at the University of Michigan has been working on the use and implications of Virtual Reality in psychiatry. Current work has been to compare how people respond to a virtual environment as opposed to a similar real environment. The study encompasses two experimental protocols examining virtual reality and acrophobia.

The main protocol measures fear of heights using a behavior approach test in the elevator area of the main hospital. Subjects go up one floor at a time, looking out through the window and giving subjective fear scores while we take physiologic measurements of heart rate and galvanic skin response. They stop at the floor where they feel unable to continue. The project then randomizes to one of three treatments: relaxation, in vivo exposure in the East Elevator area of the main hospital, or virtual exposure in a virtual environment that simulates the real elevator area as closely as possible. After ninety minutes of treatment, the study is repeated to see if there has been any change.

RURAL EMERGENCY MEDICAL EDUCATION CONSORTIUM

Twelve REMEC TeleHealth Network hospital sites are linked via videoconferencing technology in thirty counties throughout Michigan to provide Continuing Medical Education, Telemedicine Consultations, and Teleradiology services for health care professionals.

MICHIGAN DEPARTMENT OF CORRECTIONS

The Department of Corrections, or the state prison system in Michigan, began looking at telemedicine as a solution to its ever expanding transportation and health care costs during the first half of the 1990s, and actually launched its telemedicine program in 1995, a year when there were just under 40 telemedicine programs in the world. In 1994, the average annual health care cost (excluding mental health costs) was \$2015 per prisoner. The average cost for transportation was \$108 per prisoner per transport. During this same time period, there was a 9% increase in prisoner populations – the second largest in history. A pilot telemedicine project was launched in 1995 by the Department of Corrections to help address these issues in Michigan.

The Michigan Department of Corrections provides health care to over 40,000 prisoners at 40 institutions. Each of these 40 institutions provides outpatient clinical services. Four facilities also provide secondary level care. Project designers initially selected three remote sites to link up with Duane Waters tertiary hospital located at the prison in Jackson, MI. The first three remote sites were located in the prisons in Adrian, Plymouth and Muskegon, and were selected based on the accessibility to communication lines at reasonable costs and high number of off-site transfers resulting in costly transportation costs.

The DOC secured state funding and developed stringent planning, implementation, and maintenance protocols for the project. Between March 1996 through December 1998, more than 1100 consults were conducted. This averaged out to be 35 consults/month for the project. Many telemedicine projects with many more remote sites conducted the same number of consults per month.

However, the pilot is long over and the DOC is expanding its telemedicine project. During 1999, 10 new sites are being added to this network. The new telemedicine network will be composed of three hub sites which will deliver consultations and 13 spoke sites which will receive consultations. The entire network is operating on V-Tel videoconferencing equipment. Each spoke site also contains a Cardionics stethoscope, a Welch Allyn otoscope, an AMD general exam camera, and a Canon Document camera. Total estimated cost to fully equip each remote site is approximately \$ 60,000. The consults are conducted over a primary rate interface ISDN line, with consult speeds ranging from ½ to a full T1, depending on the nature of the

consult. If current utilization patterns continue, the Michigan Department of Corrections will conduct more than 2000 consults next year, making it one of the busier telemedicine programs around.

TeleMedicine Technologies

DELIVERY OF TELEMEDICINE: EQUIPMENT OPTIONS

Due to the nature of hospice care and the special needs of the client, equipment selection was carefully examined before introducing telemedicine into the home health context. The POTS (Plain Old Telephone System) system was selected for use at Hospice of Michigan. We selected the POTS based systems because they are portable, easy to set up; work universally in homes with telephone lines, and are user friendly. Further, they provide a relatively inexpensive way to gain immediate contact between a hospice care professional and a patient. The providers will utilize the set-top units that encompass a 13" television with a mounted camera affixed above the screen. The patients will employ a smaller desktop unit, located in their home, which combines the monitor and the camera into one unit.



EQUIPMENT AND SETUP

The set-top TelehospiceSM Unit (Provider's Unit)

The equipment being used includes:

- The camera unit
- A 13" TV w/ video inputs
- A speaker phone or standard telephone
- Two standard telephone cables
- One power supply



To set up the set-top unit:

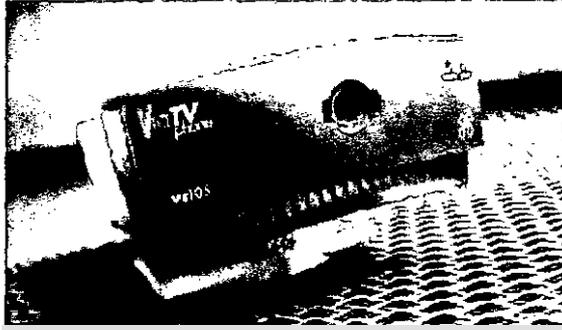
- Set up the TV and plug in its power cable.
- Place the camera unit on top of the TV. Then plug in its power supply.
- Insert the RCA a/v plugs into the audio/video inputs on the front of the TV. Insert the corresponding audio/video cables into the RCA jacks on the rear of the camera unit labeled "Video Out" and "Audio Out".
- Insert the shorter telephone cable into the "Phone" jack on the back of the camera unit. Then connect the other end to your telephone.
- Now, connect the longer telephone cord to the "LINE" connection on the camera unit. If the location does not have an unused telephone jack, unplug the telephone cable connected to the jack on the wall. Insert it into one jack of the telephone line splitting adapter and the telephone cable for the camera unit into the other. Then insert the adapter into the wall jack.
- To check if the TelehospiceSM unit has been properly installed, pick up the handset and check for a dial tone from the receiver.



To set up the all-in-one desktop unit:

(Patient's Unit)

- Set the desktop unit on top of a counter or desk with the screen in front. Units should be placed within 2-3 feet of the subject. For best results, the main light source should be positioned behind the camera unit and illuminate the subject.
- Unplug the cable connected to the telephone from the telephone jack on the wall. Plug the cable into the jack labeled "PHONE" on the back of the camera unit.
- Select one of the supplied telephone cables and plug it into the jack labeled "LINE" on the camera unit. Plug the other end of the cable into the telephone wall jack.
- Plug the power supply into a wall outlet. Plug the power supply cable into the connection on the camera unit.
- To check if the TelehospiceSM unit has been properly installed, pick up the handset and check for a dial tone from the receiver.



Using the TelehospiceSM Units

In most situations with the TelehospiceSM equipment, all you will need to do is turn the TV on, enter the telephone number and place your call. Here are some further instructions for the set-top and desktop TelehospiceSM units that you may be asked to use or train your clients to use.

TO INITIATE A CALL:

1. Switch the unit on with the switch on the back panel. The power light on the front of the unit will illuminate to indicate that the power is on. For the set-top model, turn the TV on and verify that it is in "LINE" input mode. On most TV's you can do this by using the channel buttons or the "INPUT" button on the remote control.
2. Lift the telephone handset. The TV/Monitor will display what its camera sees on the screen. You can now aim the camera and adjust the room lighting. (Hint: If you see a red image more direct light on the subject is needed). After making adjustments check for a dial tone.
3. Holding the handset or using a speakerphone, place a call to another party.
4. When the other party answers, he or she is ready to start a video call. Press the "#" (pound) key to bring up the "Start Video" menu.
5. When the "Start Video" menu appears on the screen, press the "1" key on the telephone keypad to start the video call. At this point, you will see a message at the bottom of the screen informing you that a video call is being established. This process normally takes 15 to 45 seconds. During this time, you will not be able to converse with the other party.

TO ANSWER A CALL:

The process for receiving a video call is identical to that for placing a video call. Either end can establish the video connection by pressing "#" then "1," however a call cannot occur if both users try to establish a connection.

IN-CALL OPTIONS

The TelehospiceSM units have display and camera options, which allow you and your clients to change the picture size; choose local view, remote view, or both; adjust the quality, and more. To access options to change the display and or camera settings, simply press the "#" key on your telephone keypad. You will then be able to select and change options as needed. To return to previous menus simply press "8" on your telephone keypad. To end the video call simply hang up the telephone or disconnect via the on-screen menus.

Display Options: The "DISPLAY" options are presented in four categories: 1) View, 2) Size, 3) Quality, 4) Privacy. The "VIEW" menu allows you to choose which picture you see on your screen. You can choose between local, remote, or both. The local display allows the person in front of the camera to view what they are sending. The remote picture allows for a view of the other location, or remote party. Finally, you can view both local and remote by selecting both.

The "SIZE" menu allows you to choose the size of the picture (the larger size is recommended). The "QUALITY" menu allows you to vary the quality of the picture you receive from the remote party. It presents a scale ranging from 1 or "SHARP", and 7 "FAST". Sharp is closer to one and the view will present more detail, but motion will be poorly represented. On the fast end of the scale, motion is better represented. The setting of 4 is recommended, but feel free to experiment and see what works best for you.

The last menu allows a privacy option, where you can mute the video transmission so the remote party can only hear you and no longer see you. When privacy is on you will see "Privacy Mode Enabled" on the screen.

Camera Options: The "CAMERA" options are divided into three categories: 1) Zoom, 2) Pan/Tilt, 3) Snapshot. The "ZOOM" option lets you choose between wide, normal, and tele. Wide displays a broad view, normal a "standard" view, and the Tele setting displays a close-up view of the chosen location. The "PAN/TILT" menu allows you to move the camera using the following keys: "1" up, "2" left, "3" right, "4" down, and the "5" key stops the camera from moving. Finally, the "SNAPSHOT" menu lets you capture an image on the screen. The image remains on the screen until you press "1" to take another snapshot, "2" to return to motion, or "8" to return to the main menus.

Note: The options are simply options. Your unit will come pre-set, so you can use the units "as is." However, knowing that they exist allows you to experiment, helping you extend better care to your clients.

Troubleshooting

TESTING THE CONNECTION

To check that the Telehospice unit has been properly installed, first check the telephone connection. You should hear a dial tone when you pick up the handset. If there is no dial tone, recheck your connections to both the camera unit and telephone jack.

COMMON PROBLEMS

Problem: No dial tone

Solution: See "Testing the Connection". If your problem is not solved, connect the telephone directly to the wall jack. If there is still not a dial tone, then try another wall jack.

Problem: Static and noise on the TV

Solution: Check to see if the TV is in the Cable/Air Channel mode. Cycle through the channels below channel 2 or press the **INPUT** button on the TV's remote. This will engage the TV's line input. Then press the **MENU** button to bring up the *Resource Link* screen to confirm the selection.

Problem: Poor audio quality and strange noises.

Solution: The built in microphone is picking up the volume on the TV. Turn down the TV volume until the noises are reduced.

Problem: Poor quality or calls unexpectedly quitting

Solution: Because the unit is using a standard telephone line, it occasionally experiences noise on the line. This may occur due to the switching system for the line, poor weather, or numerous other factors. Typically, the system will try to buffer the memory again, however the system is very likely to crash if it cannot reestablish a better connection.

How to Present TelehospiceSM to Patients and Families

HOSPICE OF MICHIGAN PROJECT: YOUR INVOLVMENT

As hospice care providers, you render an invaluable service to enrollees and their families. It is the intent of this project to further enhance the services that Hospice of Michigan provides and the care each patient receives by implementing the use of telemedicine technologies. Half of all new patients enrolling in Hospice of Michigan will be randomly studied and invited to utilize telemedicine or Telehospice services.

The unit presentation process is not quite as specific, unlike that of the set up and operation. However, in order for us to gather information to further our research in telemedicine, and in particular TelehospiceSM, a few guidelines must be followed. We encourage each of you to present the TelehospiceSM service as if you were presenting any other service that Hospice of Michigan provides.

To help explain the system, its uses, and the services provided over it you will be asked to present TelehospiceSM at the initial hospice consult. In doing so, you will provide each patient with a TelehospiceSM brochure and you may give a short demonstration of the system and answer any questions they may have about the service. If they choose to accept the service, the equipment will be delivered and set up as soon as the next hospice care provider visits the home.

Upon delivery of the unit, you should then set up an initial test call and a regular scheduled time for meeting with the patient. A regular schedule for using the system will help both you and the patient become more comfortable with the technology. Becoming familiar with the technology will directly affect the quality of the care you provide via telemedicine. As much time as needed should be spent to assure that the patient understands the unit before leaving the home. Five additional minutes of instruction in the home may end up saving quite some time if the patient has trouble later.

Getting Good

Results

As a care provider you will be asked questions and should have a working knowledge of the TelehospiceSM units. Feel free to practice with the unit you are provided or the unit at your base office. Further questions can be addressed to a Michigan State University staff member (refer to contact information at the end of this manual). Here are some simple tips to enhance the performance of the TelehospiceSM unit.

- The unit should be located in a room that will be very quiet while the patient is in a consult. This prevents extra noise from being transmitted and received by the physician.
- Subjects should be within 2-3 feet of the unit. For example, if the patient is bed-ridden the unit should allow for easy viewing of the patient in the bedroom.
- The foreground of the room should be well lit, while keeping the background darker. This will prevent shadowing on the face and over exposure of the background.
- Remain relatively still during calls to avoid changes in resolution and jumpy pictures.

The Research **What are we asking?**

What have we found?

The National Telecommunication & Information Association (NTIA) afforded Michigan State University with a grant to study the effects of Telehospice on end-of-life care. Hospice of Michigan and Michigan State University are jointly conducting this research as part of a continuing home health telemedicine movement. The goals of this research are to evaluate the following:

Access Issues

1. What is the relative percentage of people receiving Telehospice care who are in underserved groups (rural, urban, minority) compared to those receiving traditional hospice care?
2. What was the utilization of hospice services before and during the Telehospice study, for those using the technology and those receiving traditional care?

Clinical Efficacy and Outcome

3. Can an accurate pain assessment be performed via telemedicine compared to in-person?
4. What is range of hospice services can be delivered via telemedicine? What hospice services must be rendered in person?

Cost Issues

5. What is the average cost to provide hospice services to the home using telemedicine compared to the average cost using more traditional delivery methods?
6. What potential savings are there (1) for the health care system and (2) for clients/caregivers?
7. What procedures/protocol are necessary to provide Telehospice services? How does the provision of hospice service via telemedicine differ from the provision of hospice service in person?
8. How does the use of telemedicine impact the provider-patient interaction (e.g., what subjects are discussed via telemedicine? What types of nonverbal communication are utilized during visits?
9. Are patients, caregivers and health care providers satisfied with the use of telemedicine to deliver end-of-life services directly into the home?

These goals are to be established by offering half of Hospice of Michigan patients the TelehospiceSM service. Those not offered the service will have visits video taped and charts will be carefully reviewed. Of the half offered, some patients will decline units and some will accept. Those who decline will also have audio taped visits and chart reviews conducted with proper consent. Those who accept TelehospiceSM will be asked to fill out a survey that will accompany each unit, and asked for consent to an interview and taping of their TelehospiceSM visits. Along with patient based research, providers will also be invited to participate in data collection via

interviews. These interviews provide insight into the ease and accuracy of Telehospice delivery through the provider's perspective.

When conducting Telehospice visits you will be asked to do a few simple things:

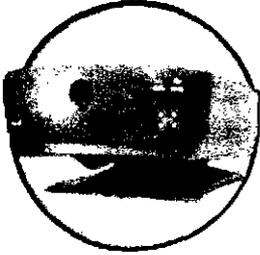
1. Collect TelehospiceSM surveys and give them to the appropriate staff member at your base station.
2. Obtain patient consent for video and audio taping of TelehospiceSM visits by having hospice clients review and sign the provided consent forms. Give the appropriate staff member the collected consent forms.
3. For each visit maintain a log sheet filled out in its entirety. (Appendix B)

Summary and Contact Information



A pilot Telehospice project at a Kansas City Area hospice has provided us with information from which to learn and from which to base this statewide project. Comments from caregivers and patients so far have been generally positive. People convey that TelehospiceSM provides an added sense of security and can help in situations of uncertainty. It also provides access to professionals when it would otherwise be impossible due to weather or distance, and that it is easy to use which puts people's minds at ease. The advantages of such systems can be further substantiated and expanded through careful execution of this project. It is also our hope that the advantages continue to grow as people explore new uses for the system. We hope that the disadvantages can be reduced or eliminated based on what we learn from you and your interactions.

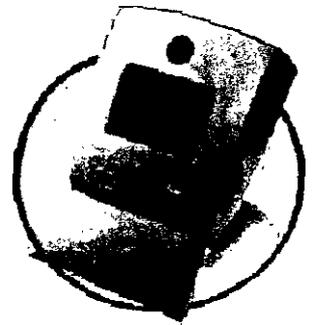
Remember that TelehospiceSM is intended as a tool for you to augment or add to the top-quality hospice care you provide on a daily basis. Feel free to explore new uses for this technology or to propose changes that will benefit those people who we are here to help. If there are any questions feel free to contact Michigan State University.



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APPENDIX G
Patient Consent Form

A Study of Telehospice Satisfaction and Utilization
Consent Form

Introduction

I understand that I am being invited to participate in an evaluation study of Telehospice™ services. Personnel from Michigan State University in collaboration with Hospice of Michigan will perform this study.

Purpose

The purpose of this study is to further examine satisfaction and utilization issues of Telehospice™.

Procedure

If I agree to take part in the study I will be involved in the following. I will be interviewed by personnel from Michigan State University. This interview will take place at my place of residence or through a telephone interview. If I have chosen to utilize Telehospice™ services, some of my interactions will be recorded (audio and visual) by personnel from Michigan State University. These recorded interaction will be kept confidential to all except the investigators. At the completion of the study, the recorded interactions will be kept as patient records. Throughout the study, all information from interviews or recordings will be coded to assure confidentiality of the subjects.

Risks/Costs

There are no known risks to me for participation in the study. The only cost associated with this study will be my time.

Benefits

This study will assist in the assessment of satisfaction and utilization trends of Telehospice™. This may benefit the use of Telehospice™ in the future along with improving overall hospice care.

Payment to Subjects

I understand that I will not receive monetary compensation for my participation in this study

Confidentiality

I understand the investigators will keep secret all research related records and information from this study. However, I realize sometimes the investigators will need to let others look at records of my participation. I agree to let someone from Michigan State University see my records. I understand the investigators will not reveal my identity if they publish the results of this study.

Questions

I have read the information in this form. The investigators have answered my questions to my satisfaction. I know if I have any more questions after reading this form, I may contact Dr. Pam Whitten at (517) 355-1332 at Michigan State University. If I have any questions about my rights as a research subject, I may call (517) 355-2180 or write the University Committee on Research Involving Human Subjects, Michigan State University, 246 Administration Building, East Lansing, Michigan 48824-1046.

Consent

The investigator(s) gave me information about what will be done in this research study. They also told me what I will have to do, and how long the research will take. They told me about any inconvenience I may experience due to this research. I agree to take part in this study as a research subject. I am aware that I may quit at any time. I understand that quitting will have no effect upon the medical care or treatment I receive in the future.

I understand that the investigators will give me a copy of this form to keep for my records.

Type/Print Subject's Name

Subject's Signature

Date

Witness Signature

Date

Responsible Investigator's
Signature/Telephone Number

Date

Appendix H

Presenting Telehospice to Patients and Family

Cheat Sheet

Telemedicine has the potential to address barriers to quality end-of-life care with the provisions of educational and clinical services. Hospice care may be delivered directly into a patient's home via telemedicine (telehospice) for clients in underserved rural and urban sites and for those with limited caregiver support.

Hospice of Michigan is launching a telehospice project using POTS (plain old telephone service) technology to reach rural underserved populations and those urban groups that have gone without services. Hospice of Michigan was chosen based upon its statewide presence, reputation for high-quality services, and enthusiasm for trying an innovative solution for access problems our clients face. Telemedicine units will be placed at the hospice office base stations. This project is part of a research grant with Michigan State University.

Telehospice will still provide traditional hospice services, however, telehospice allows you and your caregivers to quickly communicate with members of the hospice care team. A home-based telemedicine unit will be utilized to link your hospice care teams (nurse, social worker, and chaplains), your clients, and your caregivers. Tele-nursing visits will be conducted on a weekly basis at a minimum, with frequency of calls determined by your needs. If you decide to participate in this study, you will be able to use the equipment to reach a hospice nurse anytime you like. We will still be providing care to you in person as well. There is no extra cost to you as this is a federally funded research project. Our goal is to improve the level of care we provide. Your participation will benefit your own quality of life along with helping others by participating in this research. The ultimate goal of Telehospice is to bolster the hospice philosophy of care, while allowing patients to live in the familiar surroundings and comforts of their home.

Appendix I

Frequently Asked Questions

Frequently asked questions from the patient and caregiver.

Introduction To Telehospice

Q: Will the quality of care be the same with Telehospice as it is with traditional hospice?

A: **That is one of the research questions to be explored. Positive results from pilot study support a larger study. Telehospice is used in addition to traditional hospice care.**

Q: If I agree to participate in the study, can I quit at any time?

A: **Yes, a brief survey will be done at that time, if possible, to gain understanding of why the patient/caregiver decided to disconnect Telehospice.**

Q: Will this cost me anything, like equipment or phone calls?

A: **The project is supported by a federal grant. The Telehospice unit and telephone will be provided and set-up for you by the hospice care providers at no charge.**

Q: What if the equipment does not work?

A: **You may phone your hospice care provider for assistance.**

Q: Does everyone in hospice use Telemedicine?

A: **Telehospice is offered as often as possible. At this time, we have 40 units available to Hospice of Michigan patients.**

Q: Why should I help with your research?

A: **By collecting information about your experience with Telehospice, we will be able to improve the service to others.**

Demonstration of Telehospice

Q: Who will set-up the equipment and teach me how to use it?

A: **Your hospice care providers will set-up your equipment as soon as possible and teach you a few simple things that you need to know to use Telehospice.**

Q: Do I need special phone lines or a computer to use Telehospice?

A: **The Telehospice units use only a touchtone telephone line, which is commonly found in most homes. A speakerphone will be provided as part of your Telehospice unit. You may use the speaker option or speak directly into the handset.**

Q: May I use the phone you provided when I am not using Telehospice?

A: **Yes, the speakerphone may be used as you would any telephone as well as for Telehospice.**

-continued-

Q: Can the unit be moved later if I want it in a different location?

A: The unit may be moved. A set-up diagram will be provided or you may request assistance at your next in-home visit.

Q: Should I disconnect the unit during a severe lightening storm?

A: The unit should be disconnected; lightening striking near your home may permanently damage the unit.

Q: How do I clean the unit?

A: It should be wiped with a soft damp cloth. Do not use liquid or cleaners on the unit as it may enter the case and damage the unit.

Q: Does my family get to keep the equipment forever?

A: The Telehospice equipment will be picked-up along with any other equipment in the home when it is no longer needed.

Q: Will the equipment interfere with my regular telephone equipment?

A: Your phone service will continue as usual even when the Telehospice unit is in place. You do not need to unplug the unit to use the telephone for other calls.

Q: Will the Telehospice unit interfere with my answering machine?

A: The Telehospice equipment will not effect the operation of your answering machine. (If the answering machine is separate form your telephone, the Telehospice unit will be placed between the wall jack and the answering machine.)

Q: Can I use another phone in the house when a video call is in progress?

A: No. Picking up the handset of any other phone on the same line when a video call is in progress may interrupt your video call.

Q: What if I have "call waiting"?

A: It is recommended that you temporarily disable "call waiting" before you use the Telehospice unit. See the front pages of the white pages of the telephone book for instructions (usually, you can disable call waiting by pressing *, then 7, then 0). Call waiting is automatically restored when you hang up.