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## Caregiver Participation in Hospice Interdisciplinary Team Meetings via Videophone Technology: A Pilot Study to Improve Pain Management

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### Abstract

This paper discusses a pilot study testing a videophone intervention enabling hospice patients and caregivers to remotely participate in interdisciplinary team meetings, with the goal of improving pain management. The aim of this study was to test potential outcome measures, and combine the data with qualitative observations to assess the overall feasibility and promise of the intervention. The outcomes evaluated included hospice patient quality of life, caregiver perceptions of pain medications, caregiver quality of life, and caregiver anxiety related to team participation. The pilot study showed that caregiver participation in the care planning process is feasible and may change caregiver perceptions of pain medication, potentially improving pain management for hospice patients.

### Keywords

Hospice; CPMQ; caregivers; interdisciplinary team; caregiver quality of life

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Hospice care is provided to over 1.3 million Americans each year, with nearly 80% of all patients aged 65 years or older (1). Hospice in the United States is largely a home-based service. Most services (74.1%) are delivered in patients' homes by an informal, unpaid caregiver (1). Family members and friends are essential to successful hospice care, yet are invisible in the hospice statistics. The physical and mental health of these individuals directly impacts the ability of patients to die comfortably in their home setting (2,3). Central to the philosophy of hospice is that the unit of care involves both the patient and the family. The model of care is based on the concept of self determination and the active participation of patients and family in the decision making process.

Every week hospice staff from different disciplines including nursing, social work, spiritual care, and medicine collaborate in an interdisciplinary team meeting (IDT). The goal of the meeting is to develop and coordinate plans of care for hospice patients and their family. So critical are these meetings that the Medicare Conditions of Participation mandate not only the frequency but also the composition of the team (4,5). Team members gather in the hospice office for 1–4 hours discussing each of their patients and working to manage the many difficulties that their patient's experience. Absent from these discussions are the very people it matters to the most, the patients and their family members (6). Due to numerous barriers including geographic distance, caregiving demands, and the frail condition of the patient, hospice caregivers and patients are not routinely in attendance at their interdisciplinary team meeting (6).

The home of a dying patient becomes as demanding as an acute hospital with medical equipment, medications, and visits by professionals becomes the norm. Informal caregivers are expected to manage all aspects of patient care without formal education, often 24/7 and with minimal or no relief, leaving them anxious, exhausted, and burdened (7). They must also deal with the emotional, physical, and financial burdens presented by the disease, while providing primary care for their loved one (8–10).

These informal caregivers face adverse health effects (11–14). Stress can negatively impact morbidity and mortality among informal caregivers of hospice patients (15). They experience anxiety, depression, issues in their social relationships, and physical symptoms (16–20). This is especially significant among older informal caregivers, for whom the combination of dealing with the expected loss of a loved one, chronic emotional distress, the physical demands of caregiving, and the biological vulnerability of older adults combine to increase the risk for health problems and early death (15,21). The emotional needs of individuals caring for dying persons in their home receive too little attention (22), and there are too few tested interventions offering support to hospice informal caregivers (23).

More than one-third of hospice families have concerns about the amount of information they received regarding what to expect when the patient was dying (24). Caregiver age, fears, beliefs, lack of assessment skills, burden and strain are barriers to informal caregivers' ability to manage pain (25–28). Many informal caregivers (46 percent to 94 percent) have concerns about reporting pain and using analgesics to manage pain (26,29). They must deal not only with the emotional, physical, and financial burdens that the disease presents, but also provide primary care to manage the disease and pain symptoms (8–10). They are ill-trained to administer pain medication (30). Despite their lack of training, informal caregivers make numerous decisions regarding the patient's level of pain, making hourly choices about how to administer medication to combat the pain. Informal caregivers must manage complicated medication administration schedules, often for narcotics. Finally, they are asked to assess pain and administer "extra" narcotic pain medicine to their loved one "as needed" (PRN) for "break through" pain. For many informal caregivers it is frightening to shoulder the responsibility of keeping a loved one

comfortable by using an otherwise illegal and controlled narcotic. And yet, hospice patients and hospice staff alike rely heavily on informal caregivers to make these care decisions. A confident, skilled and trusting informal caregiver is their best ally in preventing pain and implementing feasible pain control strategies (31).

In this study we report the results of a two year project funded by the National Cancer Institute (NCI), testing an intervention to address the perceptions of caregivers related to pain medication by enabling patients and caregivers to participate as a member of the interdisciplinary team. The ACTIVE (Assessing Caregivers for Team Intervention through Video Encounters) intervention used commercially available videophone technology to overcome existing barriers and bring caregivers of hospice patients into the hospice interdisciplinary team meeting. The overall hypothesis for the study was that the participation of caregivers in hospice interdisciplinary team meetings would result in reduced caregiver concerns related to pain medication. The aim of this study was to test potential outcome measures, and combine the data with qualitative observations to assess the overall feasibility and promise of the intervention.

## Theoretical Model

The theoretical model underlying the development of this intervention is outlined in detail elsewhere (32). The model is modified from Saltz and Schaefer's (33) framework for family participation on health care teams. This framework identifies four components of an IDT model inclusive of family: context, structure, process and outcomes. The organization context, influences team structure, which in turn impacts team processes, which ultimately determine how teams evaluate outcomes. Saltz and Schaefer suggest that family involvement may influence process elements of team functioning, especially assessment, care planning, and implementation of plans. The Saltz and Schaefer model maintains that, when family input into problem-solving or decision making is lacking, care plans suffer due to incorrect assumptions about the patient/family perspectives that influence the process. Finally, families influence team outcomes by providing feedback about the team as a whole (33).

In this intervention the videophone provides a context for participation, eliminating logistical barriers. Principles inherent within hospice provide the team with a supportive structure that acknowledges patient/family feedback as valuable. In addition, the videophone provides opportunity for temporary team membership. Patients/families are viewed as "specialists," with important information and knowledge required for assessment, care planning, and evaluation. The interdisciplinary process, as discussed by Bronstein (34), outlines successful collaboration between hospice staff, patients, and families: the team will become interdependent with patient/family goals, and will create new activities and roles for patients/families within the team, requiring flexibility among individual members' role definitions. The patient/family involvement will require collective ownership of all goals by all team members, and the care outcomes are evaluated through a reflection on the team process, again including feedback from patients/families (32).

Based on this theoretical model, it was hypothesized that participation in the IDT would result in: 1) Improved pain management, changing the perceptions of caregivers toward pain medication as a result of improved communication, 2) Improved communication through the active participation of patients and families communicating bio-psychosocial concerns and their satisfaction with the IDT process, and 3) Improvement in the quality of life for the patient and family caregivers.

## DESIGN AND METHODS

The study had a sequential mixed method two phase design, Phase 1 served as a historical comparison for Phase 2, the intervention phase. Following consent and enrollment into the study, patients and caregivers were asked to complete baseline measures. When possible, follow-up measures with patients were taken by phone every two weeks and with caregivers every 30 days. All hospice interdisciplinary team meetings were video-recorded in both phases. Finally, caregivers in the intervention group and hospice staff were interviewed at the end of the study. Traditional hospice care continued to be offered for Phase 1 participants. For Phase 2 participants, traditional care was delivered and a videophone was installed allowing caregivers (and some patients) to participate in the team meeting.

The intervention enabled family members of hospice patients to participate in the team meeting, connecting them virtually using a plain old telephone system (POTS) videophone to the hospice office. Research staff placed one videophone unit in the home of the family, which was connected to a compatible unit in the hospice office. The office unit was unique as it could be projected onto a television screen for the view of the entire hospice team. This connection over the regular telephone allowed family members to have a visual image of the team as well as a two way conversation with them.

### Setting and Participants

Data were collected from consenting hospice patients and caregivers in two rural hospice programs in the Midwest. All caregivers and patients had to be enrolled in the hospice, without cognitive impairment, consent to participate, and be over 18 years of age. Participants were enrolled between October 1, 2006 and May 15, 2008. Ethical approval for the study was gained through the University of Missouri Institutional Review Board.

### Primary Outcomes

Based on Saltz and Schaefer's (35) theory and the research related to caregiver concerns related to pain medication, it was hypothesized that the caregivers perceptions related to pain medications would be the primary outcome of this intervention. The caregiver's perceptions of pain medication can indicate potential barriers for pain management. The hypothesis was that caregiver participation would allow for additional education and the opportunity to address caregiver concerns related to pain medication, resulting in changes in perception and improved pain management. The Caregiver Perceptions of Pain Medicine Questionnaire (CPMQ) was the primary outcome measure for this study. It is a 22 item self administered instrument (26). Each of 22 items is scored on a 4-point Likert scale of agreement with a fifth point of no opinion. There is evidence from previous work of strong internal consistence (26).

Letizia et al. developed the CPMQ by first modifying an existing instrument that measured concerns regarding pharmacological pain management that were expressed by ambulatory cancer patients (36). The instrument contains three subscales: concerns about reporting pain, concerns about administering analgesics, and difficulties administering pain medications (26). The CPMQ items related to the subscale reporting of pain measure the degree to which respondents agree with two core beliefs. The first, fatalism, is the belief that pain is inevitable and cannot be adequately controlled by existing medications or technologies. The second, stoicism, refers to the belief that individuals should be strong and tolerate discomfort without complaint. Items in the subscale that measures caregiver concerns regarding medication administration record the degree to which respondents agree with statements indicating fears of pain medication addiction, side effects, and tolerance. Respondents who express agreement with these items replied positively to statements such as "*It is dangerous if hospice patients become addicted to pain medicine*". Finally, items in the third subscale describe caregiver

difficulties administering pain medications but are not divided into specific subcategories (26).

Data were collected upon enrollment to the study. Follow-up measures were done by the project graduate research assistants who contacted caregivers via telephone every 30 days to review the questions on the CPMQ (26). Each of 22 items were recoded for analysis to reflect an ordinal variable with scores of five (no opinion) being recoded to 3, a score of 4 recoded to 5 and a score of 3 recoded to a 4. A low number indicates a high level of agreement and greater concern about the issue.

In an effort to assess a relationship between patient pain and caregiver perceptions of pain medicine, the 14 item Hospice Quality of Life Index (HQLI) was used (37). The instrument is modified from a 28-item self report instrument to assess the overall quality of life for hospice patients. The HQLI uses a 0 (severe problem) to 10 (no problem) scale for each item with a total score of 0 to 140. The scale has been tested with hospice cancer patients and has strong validity and reliability. The Cronbach's alpha for the total index is 0.88 (37). A 15th item to assess pain relief was added, in the same way McMillan added it to an earlier study (38). Because this item only makes sense for patients with pain, if a 0 (no pain) was given on the 15<sup>th</sup> item, a score of 10 was automatically awarded for pain relief (to avoid artificially lowering the QOL score if they indicate no relief). Similar to other palliative care studies (18), patients were assessed every 14 days due to the continuing decline in their condition.

## Secondary Outcomes

**Caregiver Quality of Life**—As caregiver interaction with the hospice team was enhanced it was hypothesized that the caregiver's quality of life would improve in response to the increased participation in decision making. The Caregiver Quality of Life-Revised (CQLI-R) (39), a measure of informal hospice caregivers' quality-of-life and revised from earlier work by McMillan and colleagues (2,39) was used to test this hypothesis. It includes four subscales: emotional, social, financial, and physical. The instrument uses an 11-point scale anchored with 0 to indicate "lowest quality" and 10 to indicate "highest quality." The maximum score for each dimension is 10, with a total maximum score of 40. The Cronbach's alpha for the revised instrument in earlier hospice studies was reported to be 0.77 initially and 0.71 upon retest (39).

**Communication Anxiety**—Research in hospital settings where family has participated in hospital rounds has noted that they experience anxiety over participation (40). The Communication Anxiety Inventory-the State form (41) is a 21 item instrument to measure the "here-and-now" anxiety experienced as a result of an interaction. The instrument has a possible range of scores from 17–68 with higher scores indicating higher anxiety. In use with undergraduate students the instrument has a reported Cronbach's alpha reliability score of 0.91. This instrument was used to assess the anxiety experienced by the caregivers in the intervention group following their participation in at least one team meeting. The CAI was administered to caregivers once during their initial 30 day follow up call by the graduate research assistant.

## Statistical Analysis

Data were entered by a graduate research assistant into an SPSS 15 spreadsheet for analysis. Data were then cleaned and analyzed by the study statisticians (JC, AA). Data were screened for missing data and normal distribution. Missing data were left out of the analysis. Normal distribution was determined using normal curve graphs and kurtosis and skewness analysis (42). For each instrument, total scores and subscale scores were computed and compared with last follow-up, the final measure taken prior to discharge or death of the patient.

Univariate analysis was done to compare the measures of caregivers with cancer and non-cancer patients. Each of the main outcome scores at last follow-up were examined by phase using Mann-Whitney analysis. To assess the significance of the effect of the intervention upon the outcome score, considering the baseline score and length of time in the study, separate linear regression analysis were carried out for the three major outcomes, patient quality of life (HQLI), caregiver perceptions of pain (CPMQ) total scores, and caregiver quality of life (CQLI-R), with the appropriate baseline scores entered, plus 'time in study', and phase of study.

## RESULTS

There were 68 patients who participated in this study, 38 in Phase 1 and 30 in Phase 2. Of the 68 patients 45 were able to be "active participants" and complete the HQLI instrument. These 68 patients were cared for by 75 caregivers, there were seven patients who had more than one active caregiver. Of the 75 total caregivers, 69 completed baseline measures and 34 were enrolled in the intervention phase. Two patients died prior to a team meeting leaving the remaining 32 caregivers to attend between 1 and 9 team meetings. A total of 89 meetings were attended by the 32 caregivers. The median number of meetings attended was 2. The interaction between caregivers and the team averaged slightly over 6 minutes per meeting.

Caregivers in both phases were predominantly female (77%), white (97%), and caring for their loved one at home (85%). Slightly more than half of the patients in both groups had a cancer diagnosis. The average age of phase 1 caregivers was 57.59 years and phase 2 caregivers 59.2 years. Patients were older than caregivers with those in phase 1 averaging 75 years and those in phase 270.89 years. Demographic characteristics and baseline measures of patients and caregivers in the two groups are compared in table 1. There were no significant differences between the two groups of patients or caregivers.

The median length of stay in hospice for these patients was 52 days (24.5 IQR) in phase 1 and 59 days (25 IQR) in phase 2. The median time of enrollment in the study was 46 days (18.7 IQR) in Phase 1 and 25 days (14 IQR) in phase 2. Death of the patient was the most common reason for incomplete data. High attrition (greater than 40%) was problematic as patients often died or their condition worsened before they were able to complete follow-up instruments. Likewise, a considerable number of patients agreed to consent to the study but refused to answer all of the HQLI questions due to fatigue (33.8%). Upon enrollment, 66% (45) patients were able to complete the instrument. Decline in patient status affected the response rate as only 55% of the 45 were able to complete a second measure two weeks later, and 44% (20 of 45), 30 days later. Two thirds of the patients completing the baseline measures, or 20% (9 of 45) of the entire consenting patient participants, were unable to respond with follow-up after 8 weeks. Table 2 summarizes the number of participants completing measures at each follow-up by phase.

A summary of outcome measures and their subscales by phase are noted in Table 3. The table summarizes the sample size, median score, interquartile range (IQR), range of scores, mean rank, and differences in means. The secondary outcomes of communication anxiety (CAI) and caregiver quality of life did not yield significant results. The CAI was completed by 24 respondents following their first interaction with the hospice team. The median score was 20.5 and the range of scores was 17–37, indicating that participants did not appear to experience anxiety as a result of their participation.

The CPMQ data revealed that hospice caregivers have perceptions related to pain management that can be considered barriers. In both phases of the study 92% (63 of 69) of caregivers reported agreement with at least one statement on the CPQM upon enrollment. In both groups, on last

follow-up, the percentage of caregivers responding with agreement to at least one statement had changed to 87.5% (35 of 40). The intervention group had the largest change with 92% (28 of 31) reporting agree or strongly agree with at least one statement at baseline, and 82% (13 of 16) agreed or strongly agreed with at least one measure at last measure.

Mann-Whitney analysis showed there were no significant differences between the baseline and the last follow-up HQLI scores, CPMQ total scores, or CQLI-R. The CPMQ subscales showing significant changes between the CPMQ subscale scores of “tolerance” and “stocisim” showed significant associations with the phase of the study ( $p=.020$  and  $p=.017$  respectively). The subscale “reluctance to report/communicate” was significant by phase, but occurs with multiple testing. The most sensitive instrument for testing the outcome of the intervention was the CPMQ. A surprising number of caregivers (43%) reported that they did not administer medication, resulting in high amounts of missing data for the third subscale, measuring the difficulty of administration of pain medications.

In a multivariate analysis of the main outcomes by phase of study, the model for the total CPMQ score regressed with phase, baseline score, and time in study explained <1% of the variance. Phase was not significantly associated with the last follow-up CPMQ scores, nor was time in study, or baseline total CPMQ scores. Subscale scores showed more significant outcomes and explained larger amounts of the variance. The subscale reluctance to report was significantly associated with phase ( $p<.01$ ) and with baseline score ( $p<.03$ ). There was no statistically significant effect of dose (number of meetings attended) of the intervention on any of the outcome measures, even when adjusting for baseline score and time in the study.

## DISCUSSION

### Limitations of study

The exploratory and pilot nature of this study holds numerous limitations. The phased design allows comparison between standard care and intervention participants, however, prevents generalizations. The sample was small and not randomly selected nor allocated and thus selection bias could impact results. The statistical analysis for this study should be viewed cautiously as the small sample size and attrition rate prevent drawing of conclusions or generalization of any findings. Despite the limitations imposed by design and sample size, the intervention demonstrated promise and yielded important experience and lessons for further research.

### Outcome measures

In evaluating the instruments to test the intervention outcomes it is important to note that there were no challenges or hesitations for caregivers in answering the caregiver instrument questions. The CPMQ offers the most sensitive outcome measure for future research related to this intervention. Based on these data, 272 participants in each group, completing at least one CPMQ post-baseline, would have 90% power to detect a difference in means of 2.5 points. We would suggest a difference of 2.5 points on a 5-point scale to be clinically significant because it indicates a complete change in perception from agreement to disagreement or visa versa. This power analysis is based on a significance level of 0.05 and a standard deviation of 9 points estimated from pilot data.

While the CPMQ was shown a useful tool, the HQLI, even in its shorter form, was not a useful measure in this context given the number of patients unable or unwilling to complete the measure upon enrollment to the study. Given the limited number of respondents, a link between the changes in caregiver perceptions of pain management and the patient’s level of pain or quality of life were not assessed. A review of medical records documenting the patients

recorded pain level by the hospice nurses would be one suggestion for a better method of obtaining data on patient pain, without adding burden to hospice patients.

The timing of repeated measures proved to be difficult as a result of the death of the patients, contributing to the loss of a great deal of data. By repeating the second set of caregiver measures at 30 days post study enrollment, we experienced a 40% attrition rate. An important finding in this study was establishing that had we instead repeated the measure with the caregivers after 14 days, as we did the patients, the attrition rate would have fallen to 8%.

Related to the secondary outcomes, the CQLI-R was not sensitive enough to detect differences, at least in this small sample. The CAI was helpful in assessing caregiver anxiety following their experience with the team. Data from the CAI suggests that caregivers were not intimidated or anxious following their participation.

### **Analysis of outcomes combined with qualitative observations**

Several analyses of the team meeting videotapes and interviews have been completed and are detailed elsewhere. To summarize, team meetings are normally held in the hospice office away from patients and family, in a “backstage setting” (43). The meetings are led primarily by nurses (44), where interpersonal communication and information flow are not always efficient (45), and there is sometimes a struggle for control rather than collaboration (46). Team members have high perceptions of collaboration and requests for clarification and the offering of information are the most common collaborative acts. Caregivers are active participants (47) when involved in the meetings and ask numerous questions, especially related to pain control (48). Caregivers and staff are comfortable with the technology, reporting that it allows the “voices and faces” to become real which facilitates trust between them (49). Finally, although pain issues make up more than a third of the team discussions, if caregivers are not present, their perceptions and concerns about pain management issues are not discussed (50).

As noted by the CPMQ in these data, 92% of caregivers hold perceptions related to pain medication that can impact patient care. The CPMQ data show caregivers have a reluctance to report pain involving fatalism, the belief that pain is inevitable and cannot be adequately controlled by existing medications or technologies and, stoicism, the belief that individuals should be strong and tolerate discomfort without complaint. The data shows the intervention holds promise to change these perceptions. In the control phase, qualitative analysis of videotapes of team meetings found that these caregiver perceptions of pain medications are not known or discussed by hospice teams as they seek to manage patient pain (50). Likewise, when caregivers participated in the intervention phase, questions arose related to pain (48). The qualitative analysis of videotapes and interviews revealed that the intervention provided the opportunity for caregivers to express concern and provide information that may not have otherwise been shared (49).

### **Feasibility of intervention**

The intervention was feasible as caregivers were able to use the technology to participate on the team. Not only was the intervention feasible but also caregivers and staff reported that it enriched the relationship between them as caregivers reported the feeling of getting a “hug” from the phone (49). The phased design allowed the research team an opportunity to refine data collection and recruitment prior to the implementation of the intervention. The study aims did not include the building of evidence for the effectiveness of the intervention, rather the exploring of outcomes and instruments and testing of feasibility related to implementation. Through this intervention the team was able to overcome structural and technical challenges in implementation and test specific instruments for future work. Additionally, the pilot offered



an important opportunity to build a descriptive dataset on hospice caregivers, their perceptions of pain management, and their quality of life.

## Conclusions

The results of this exploratory intervention pilot study show the ACTIVE intervention as a promising way to improve hospice care, specifically pain management. Videophone technology was a feasible way to overcome traditional barriers preventing participation. This study found that this intervention is feasible and the CPMQ is a sensitive instrument which can measure the impact of participation on caregivers perceptions of pain medication. This measure, together with the observation of team meetings and interviews with staff and caregivers lend experience and evidence to further test the intervention using a randomized design.

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**Table 1**

Nonrandomized Equivalent of Groups at Baseline by Phase

<b>Patients n=68</b>	<b>n=38</b>	<b>n=30</b>	
<b>Variable</b>	<b>Phase 1</b>	<b>Phase 2</b>	<b>p value</b>
<b>Sex</b>			p=0.54
Male	18	12	
Female	20	18	
<b>Race</b>			
White	37	30	
African American	1	0	
Missing			
<b>Residence</b>			p=0.52
Home	32	26	
Nursing Home	6	3	
Missing	0	1	
<b>Cancer Diagnosis</b>			p=0.70
Yes	21	18	
No	17	12	
<b>Marital Status</b>			
Married	15	14	
Widowed	19	12	
Other	4	4	
<b>Education</b>			
Less than high school	13	6	
High School	9	9	
Some College	8	9	
Other	8	6	
<b>Age</b>			p=0.33
Mean (SD)	75 (12.66)	70.89 (15.06)	
Median (IQR)	75.0 (66.5–86)	71 (59–85)	
<b>Baseline Measures</b>			p=0.398
HQLI Mean (SD)	94.0 (21.66)	97.2 (16.61)	
HQLI Median (IQR)	97 (80.75–112.25)	99.0 (83.0–108)	
<b>Caregiver n=75</b>	<b>n=41</b>	<b>n= 34</b>	
<b>Sex</b>			p=0.27
Male	5	7	
Female	34	24	

Patients n=68	n=38	n=30	
Variable	Phase 1	Phase 2	p value
Missing	2	3	
<b>Race</b>			
White	38	30	
African American	1	1	
Missing	2	3	
<b>Marital Status</b>			
Married	28	21	
Divorced	7	4	
Other	4	5	
Missing/unknown	2	4	
<b>Education</b>			
Less than high school	3	1	
High School	7	7	
Some College	15	14	
Undergraduate degree	6	4	
Graduate degree	6	5	
Missing/unknown	4	3	
<b>Relationship to patient</b>			p=0.20
Adult child	18	11	
Spouse/partner	12	10	
Other	9	9	
Missing/unknown	2	4	
<b>Employment</b>			p=.57
Full time	7	1	
Part time	2	10	
None	27	19	
Missing/unknown	5	4	
<b>Age</b>			p=0.83
Mean (SD)	57.59 (15.21)	59.22 (13.59)	
Median (IQR)	59 (46–67.25)	59 (49–71)	
<b>Other caregiving responsibilities</b>			p=0.80
No	21	18	
Yes	18	12	
Missing/unknown	2	4	
<b>Distance from patient</b>			p= 0.71
Mean number of miles	4 (9.77)	3.18 (7.74)	

Patients n=68	n=38	n=30	
Variable	Phase 1	Phase 2	p value
Median number of miles	0 (0–1.5)	0 (0–5)	
<b>Baseline Measures</b>			
CPMQ Mean (SD)	74.5 (14.74)	74.77 (13.25)	p=0.800
CPMQ Median (IQR)	76.5 (62.75–85.25)	74.0 (64.0–83.0)	
CQLL-R Mean (SD)	30.18 (5.94)	28.55(7.80)	p=0.073
CQLL_R Median (IQR)	30.5 (24.75–35.0)	30.0 (22.0–35.0)	

**Table 2**

## Numbers Completing by Occasion

<b>Time of Measure</b>	<b>Patients completing HQLI <sup>a</sup></b>	<b>Last measure</b>	<b>% of total sample lost)</b>
Baseline T1	45	18	40%
T2	25	7	55%
T3	20	10	77%
T4	9	2	82%
T5	8	4	91%
T6	3	0	91%
T7	4	4	91%
<b>Time of Measure</b>	<b>Caregivers completing CPMQ&amp;CQLI-R <sup>b</sup></b>	<b>Last measure</b>	<b>% of total sample lost</b>
Baseline T1	69	27	61%
T2	42	17	64%
T3	25	10	78%
T4	15	15	100%

<sup>a</sup>HQLI completed every 14 days

<sup>b</sup>CPMQ and CQLI-R completed every 30 days

**Table 3**

Summary of Outcome Measures

Measure	Phase	n	median	IQR	Range	Mean rank	P value (M-W)
<b>CPMQ total</b>	1	24	76	64.25–86.75	46–92	21.90	p=0.569
	2	17	76	65–82	54–92	19.74	
CPQM fatalism	1	24	8	8–8	6–10	19.50	p=0.268
	2	17	8	8–9	5–10	23.12	
CPQM stoicism	1	24	8	8–9	6–10	17.42	p=0.017*
	2	17	10	8–10	6–10	26.06	
<b>CPQM report*</b>	1	24	16	16–17	12–19	18.23	p=0.072*
	2	17	18	16–19	12–20	24.91	
CPMQ addiction	1	24	12	8.5–13	4–15	19.71	p=0.405
	2	17	12	9.5–13.5	8–15	22.82	
CPMQ side effects	1	24	25	20.25–27.0	14–31	20.24	p=0.709
	2	17	25	21.5–27	20–33	21.82	
CPMQ tolerance	1	24	8	6–8	4–10	17.48	p=0.020*
	2	17	8	8–9	6–10	25.97	
<b>CPMQ reluctance to report**</b>	1	24	44.5	32.5–47	24–52	20.0	p=0.524
	2	17	44	39.5–47.5	36–58	22.41	
<b>CPMQ difficulty</b>	1	18	20	19–20	12–21	13.06	p=0.976
	2	7	20	18–20	9–23	12.86	
<b>HQLI</b>	1	20	98	87.25–114	77–130	14.08	p=0.934
	2	7	95	87–115	70–122	13.79	
<b>CQLI-R Total</b>	1	24	27	20–31.5	9–38	21.77	p=0.869
	2	18	25.5	15.75–32	8–40	21.14	



Measure	Phase	n	median	IQR	Range	Mean rank	P value (M-W)
CAI***	2	24	20.5	18.25	17-37	NA	NA

\* CPQM report combines fatalism and stoicism

\*\* CPMQ addiction, side-effects and tolerance combined

\*\*\* CAI only done on Phase 2