

Secondary Analysis of Caregiver Pain Management Issues during Telehospice versus In-person
Interventions

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Abstract

Most hospice care in the US is provided in the home by lay family caregivers. These caregivers suffer physically, psychologically, emotionally, and socially from the burden of caring. The most often identified area of burden for caregivers is the management of end-of-life pain. Despite advances in pain management pharmacology and alternative therapies, unrelieved pain continues to plague patients and their care providers. Although pain management has been targeted as a national healthcare concern and research priority, specific issues of caregiver pain management remain vague and undefined. Understanding issues surrounding caregiver pain management may help clarify needs thus enabling the creation of cost effective tools, technologies, and interventions to help caregivers' and ultimately dying patient.

The purpose of this study was to describe caregiver pain management issues during end-of-life (EOL) care and compare issues identified by those caregivers receiving a telehospice intervention to those receiving a face-to-face intervention. The primary aim was to describe specific pain management challenges associated with home hospice caregivers. The secondary aim was to compare pain management issues using telehospice versus face-to-face interventions. A directed content analysis of secondary data was conducted to describe pain management issues expressed by caregivers during EOL care.

Six major themes, Caregiver-Centric Issues, Caregiver Medication Skills and Knowledge, EOL Symptom Knowledge Issues, Teamwork & Communication Issues, Organizational Skill Issues, and Patient-Centric Issues, were identified through a literature review. These themes, and respective subordinate themes, were the starting point for the directed content analysis. Audio sessions from 29 researcher-caregiver dyads, were reviewed and coded using NVivo 9 software.

Themes concerning Caregiver Centric Issues and Teamwork & Communication Issues were most prevalent in the data, with most subordinate themes frequently described as well. Rich, descriptive accounts of the themes were discovered in both the telehospice and the face-to-face groups. No significant differences were found between the two groups.

This study describes specific themes, identified by lay caregivers, which contributed to their pain management burden. By clearly identifying and describing these issues, perhaps more empirical research can be conducted to help advance more efficacious caregiver interventions.

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In the U.S., an estimated 1.58 million patients received hospice care in 2010, representing triple the number reported in 1998. Lay caregivers, usually a family member, provided the majority (66.7%) of that care in the home (Emanuel et al., 1999; National Hospice and Palliative Care Organization [NHPCO], 2011; NHPCO, 2012). These caregivers suffer physically, psychologically, emotionally, and socially from the burden of caring (Wolff, Dy, Frick, & Kasper, 2007; Williams & McCorkle, 2011). The most often identified area of burden for caregivers is the management of EOL pain (Demiris et al., 2010; Meeker, Finnell, & Othman, 2011; Oliver et al., 2008; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007). Although support of family caregivers is a central theme of hospice, little empirical evidence exists of efficacious caregiver interventions (Aoun, Kristjanson, Currow, & Hudson, 2005; Harding & Higginson, 2003; Higginson et al., 2003; Northouse, Katapoke, Song, Zhang & Wood, 2010; Sorensen, Pinquart, & Duberstein, 2002). Moreover, even less research exists concerning interventions tailored to caregivers' concerns about managing pain at the end of life (Candy, Jones, Drake, Leurent, & King, 2011; Hebert, Arnold, & Schulz, 2007; Keefe et al., 2005). Despite pain management being targeted as a national health concern (Brekken & Sheets, 2008; National Quality Forum, 2006; National Quality Forum, 2009; Stjernsward et al., 2007) and a top national research priority (Nowels & Lee, 1999), few interventions directly address one of the most important and stressful issues confronting family caregivers providing end of life (EOL) care: pain management for the dying loved one. One of the goals of hospice care is to keep the dying person as pain free as possible (NHPCO, 2011; Payne, Hilliar, Lanley-Evans, & Roberts, 1996). Understanding issues surrounding caregiver pain management may help clarify needs thus enabling interventions to meet this goal.

Telehospice interventions have the potential to meet the goal of improved pain management. Telehospice is broadly defined as telehealth technologies, including videophones, to overcome geographical distance in the delivery of hospice care (Oliver et al., 2012; Whitten, Holtz, Meyer, & Nazione, 2009). Interdisciplinary hospice teams used videophone technology to include lay caregivers in team meetings, with success, and thus improved pain management (Oliver et al., 2010). Professionals in other disciplines have used videophones successfully to deliver educational information and care albeit to patients directly (Chumbler et al., 2007; Fincher, Ward, Dawkins, Magee, & Wilson, 2009). Recently, Demiris, Oliver, Wittenberg-Lyles, and Washington (2011) used telehospice technology to deliver a cognitive-behavioral therapy to hospice caregivers. Post-intervention caregiver anxiety diminished and problem-solving confidence improved, thus proving the feasibility of using the videophone to administer a hospice caregiver intervention. However, no data analysis occurred of the concerns expressed by caregivers regarding specific pain management issues (Demiris et al., 2010). A clearer understanding of the issues surrounding caregiver pain management, using videophone or face-to-face delivery, may focus telehospice interventions to better facilitate caregiver pain management and therefore caregiver burden reduction. In a recent Cochrane meta-analysis of eleven randomized controlled trials (Candy et al, 2011), only low quality evidence existed that any interventions supported the caregivers and reduced the care burden. Moreover, only one of these studies addressed the priority issue of caregiver pain management (Keefe et al., 2005). Without issue clarity, intervention success may continue to be compromised.

The purpose of this study was to describe caregiver pain management issues during EOL care and compare issues identified by caregivers receiving hospice services via telehospice versus a face-to-face delivery. The data sets for this secondary content analysis were obtained

from a non-inferiority, feasibility study (R21 NR010744, G.Demiris PI, 2008-2010; Demiris et al., 2011; Demiris, Oliver, Wittenberg-Lyles, & Washington, 2011; Oliver & Demiris, 2010) of hospice services delivered as a telehospice (videophone) or face to face intervention. The content analysis of this secondary data and identification of specific pain management issues faced by caregivers may help inform research towards the development of assessment tools, outcome measures, and caregiver educational interventions administered via telehealth technology.

The primary aim of this study was to identify and describe specific pain management challenges faced by home hospice caregivers. The secondary aim was to compare pain management issues using telehospice versus face-to-face interventions. Identifying challenges and caregiver needs can lead to interventions that will remove barriers impeding care and patient management, and will inform future research design (Hegyvary, 2006).

Literature Review

Delivery of Interventions Using Telehealth and Telehospice Technology

In the past 10 years, only a small amount of evidence of medium strength has been identified for the use of telehospice (Oliver et al., 2012). Furthermore, a vacuum exists in well-designed research studies concerning home hospice caregivers and one of the most stressful aspects of EOL care: pain management. In one of very few empirical studies available, Oliver et al. (2010) addressed caregiver perceptions and EOL pain management. Researchers used videophone technology (videoconferences) to enable caregivers and patients, to participate in Interdisciplinary Team (IDT) meetings. As active participants, caregivers asked many questions about pain control. With caregivers present, over one third of the team discussion focused on pain management. Without the caregivers present, no discussion of pain management took place. Also of interest, 92% of the caregivers held perceptions related to pain medication that could negatively affect patient care. Further data analysis revealed that these perceptions were not known nor discussed during the IDT meetings. In essence, the caregivers did not know enough to talk about these issues and the professional members of the IDT did not think to ask. But, what exactly were these issues? The specific pain management issues were not characterized nor identified. Videoconferencing addressed the communication issue but not the issue causing the most anxiety: pain management. This thesis project may help identify and conceptually categorize these specific pain management issues, thus identifying caregiver issues acting as barriers to EOL pain management. Once identified, cost effective, technology based interventions may help meet caregivers' needs, and ultimately the needs of the dying patient.

Recently conducted Parkinson's disease (PD) research may offer a beginning blueprint (Fincher et al., 2009) toward this endeavor.

Although little research exists concerning the use of telehospice to support informal caregivers during EOL care, researchers have used telehealth tools to educate patients about medication regimens to manage well-known Parkinson's Disease (PD) issues (Fincher et al., 2009). As with hospice pain management, PD symptom management occurs primarily through complex medication management (Chan, Cordafo, & O'Rourke, 2008). In a mixed method study, PD patients learned medication and symptom management strategies through telehealth education counseling (Fincher et al., 2009). Randomly assigned patients received counseling via telephone or videophone. Both interventions proved useful; however, both nurses and patients identified benefits of videophones over telephones for the counseling sessions. Although this study focused on medication management for PD patients, the use of the telehealth tools enhanced the counseling sessions for the patients and the providers in addition to addressing medication safety issues. In this study, clearly defined PD issues helped researchers design education modules delivered via telehealth. Less clearly defined home hospice caregiver pain management issues act as barriers to the development of tools to assist caregivers in their rolls. This secondary content analysis aimed to identify and categorize the issues surrounding pain management for telehospice informal caregivers, and compare these issues with usual and standard care. Perhaps with clearly defined pain management issues, enhanced caregiver support may occur through improved education tools similar to the outcomes reported in the above study.

Interventions to Support Informal Caregivers

In the past three decades, several meta-analyses (Candy et al., 2011; Northouse et al., 2010; Sorensen et al., 2002) have illuminated the efficacy and effectiveness of interventions in supporting informal caregivers. Several informative literature reviews have also added to the body of evidence addressing the effectiveness of interventions in decreasing the burden of caregiving (Harding & Higginson, 2003; Meeker et al., 2011). Despite this research, clarity of issues and outcomes, involving caregiver pain management, remains elusive as does high level quantitative study design and methodology.

One meta-analysis of 78 studies from 1982-2001 was conducted to determine the effectiveness of interventions for family caregivers during EOL (Sorensen et al., 2002). Outcome variables of interest in the studies included: subjective well-being, uplifts of caregiving, ability/knowledge, symptoms of care receivers, depression, and burden. Researchers identified small to moderate effect size for all six outcome variables. Significant limitations in these studies, including gaps in the data and lack of randomization, hindered the accuracy of the results. Interestingly, the largest effects were seen for increasing caregiver ability/knowledge. Based on their findings, researchers concluded specific outcomes for caregivers require different sets of interventions, techniques, implementation strategies, and attention to different moderators. No study in the meta-analysis dealt directly with the caregiver pain management issues, however.

Another meta-analysis of 29 randomized clinical trials, conducted from 1983-2009, analyzed types of interventions offered to family caregivers of cancer patients and investigated caregiver outcomes (Northouse et al, 2010). Researchers investigated the efficacy of three types of interventions: psychoeducational, skills training, and therapeutic counseling. Although most

interventions were delivered to the patient-caregiver dyad, most were designed to address patient care directly. Intervention content for caregiver self-care was a secondary focus. Similar to another meta-analysis (Sorensen et al., 2002), effect sizes were small to medium but significant positive effects were realized on multiple outcomes: improved caregivers' ability to cope, reduced anxiety, increased self-efficacy, and improved aspects of quality of life. Although these outcomes were subject to various moderators (i.e. mode of delivery, intervention dose), other moderators were not examined (i.e. gender, education, age). The results of this meta-analysis were based on interventions conducted during the continuum of cancer care, including care administered during times when patients were feeling well. Thus, extrapolation of results to EOL care may not be appropriate. Of note, only one study in the meta-analysis addressed caregiver pain management, one of the most troubling aspects of caregiving and a primary caregiver concern (Keefe et al., 2005).

Keefe et al., (2005) conducted a double blinded, randomized controlled trial of 82 EOL patients and their caregivers to evaluate the efficacy of a partner-guided pain management intervention. The intervention, delivered in three, 45-60 minute sessions, integrated educational information (book and video) about cancer pain with a cognitive-behavioral pain coping strategy. Data analysis revealed that partner self-efficacy for helping patients manage pain significantly increased, even though patient pain levels were not significantly changed. Caregivers thought they were managing pain better but, in fact, were not. In addition, partner self-efficacy for helping patients with other EOL issues was increased. Researchers also reported a trend toward decreased caregiver strain, although this was not statistically significant. Since no outcome measures were reported for the educational information taught to caregivers and patients, it is unclear if increased partner self-efficacy could be contributed to the coping strategy alone, the

educational component alone, or a combination of coping strategy and pain education. As identified in one meta-analysis, intervention effects were largest for increasing caregiver knowledge/ability (Sorensen et al, 2002). Clarity is also absent concerning the trend in caregiver strain. Decreased caregiver strain may be a direct result of caregivers using their new coping skill strategies for their own stress management. A prominent feature identified by Keefe et al. (2005) and an integral part of that study protocol was to teach the coping strategy to both patients and caregivers for use in patient pain management as well as caregiver stress management. Although investigators evaluated the efficacy of a partner-guided pain management intervention, identification of clear and specific caregiver pain management concerns was not addressed, nor identified prior to study design.

In a Cochrane review, Candy et al. (2011) attempted to assess the effects of interventions that aimed to improve the psychological and physical health of informal EOL caregivers. Of eleven randomized clinical trials involving 1836 caregivers from 1984-2008, only nine interventions focused directly on the caregivers. The Keefe et al. (2005) study, discussed above, was one of the nine. In the review by Candy et al. (2011), researchers discovered only low quality evidence to indicate that direct support of caregivers can significantly reduce psychological distress. Researchers reported unclear risk of bias, and all trials underreported methods. Also, the generalizability of the findings were limited due to small sample sizes, and the large percentage of patients with end-stage cancer. Review researchers concluded, as did researchers in the Sorensen et al. (2002) meta-analysis, that practitioners should enquire about concerns of caregivers and address those concerns directly.

To date, only one quantitative study (Keefe et al., 2005) has partially addressed pain management as an intervention for caregivers. Keefe et al. (2005) used quantitative closed-ended

measures and prescribed items about caregiver pain management issues. In this secondary content analysis, the PD used a qualitative, open-ended approach, allowing for more inductive analysis of the data to derive meanings that might otherwise be missed with a closed-ended approach. Through content analysis, the PD hoped to identify and describe specific pain management issues to help inform future telehospice interventions, measures, and e-tools as well as advance future telehospice research. As noted in most of the recent meta-analyses, lack of clearly articulated concerns of caregivers prevents the development of quality outcome measures and tools to reduce caregiver burden. Without a clear understanding of the issues confronting caregivers during EOL pain management, good study design, good study methodology, and absence of bias will continue to be elusive. The thesis research study presented here aimed to identify, clarify, and describe caregiver concerns, using caregivers' own experiences and perceptions, in their own words.

Methods

Design

A directed content analysis of secondary data was conducted to describe and compare pain management issues expressed by caregivers during EOL care. In qualitative content analysis, characteristics of language are used to systematically code and classify the context and content of the text data (Hsieh & Shannon, 2005). This thesis study was a secondary data analysis of data sets obtained in an original larger study (R21 NR010744, G.Demiris PI, 2008-2010; Demiris et al., 2011; Demiris, Oliver, Wittenberg-Lyles, & Washington, 2011; Oliver & Demiris, 2010). This larger, parent study (R21NR010744, G. Demiris, 2008-2010) was a randomized, non-inferiority clinical trial, in which researchers taught caregivers problem-solving skills. These education sessions were audio recorded as were the exit interviews (Appendix A). In the parent study, caregivers received this Problem Solving Therapy (PST) intervention through home telehospice or face-to-face encounters. For more information about the PST, please refer to the original research (R21 NR010744, G.Demiris PI, 2008-2010; Demiris et al., 2011; Demiris, Oliver, Wittenberg-Lyles, & Washington, 2011; Oliver & Demiris, 2010).

The data sets for this thesis, a secondary analysis, were a part of the parent study, but also represented both the telehospice group and the face-to-face group (Demiris et al., under review; Demiris et al., 2011; Demiris et al., 2010; and Oliver & Demiris, 2010). The secondary data sets, used in this thesis study, consisted of de-identified, audio recordings of caregivers describing their caregiving problems, including pain management issues. Secondary data analysis of these audio files was economical, efficient, and an effective method for analyzing data to enhance understanding (Cavanagh, 1997). Additionally, using de-identified data protected patient

privacy. In the original parent study, a majority of caregivers identified “pain” as one of their top three concerns. Therefore, this secondary data set offered an opportunity to explore pain management problems in more depth with these caregivers.

This directed secondary content analysis used an existing construct (Lau et al., 2009) as a starting point, and then built on that research to describe the caregiver pain management phenomenon more completely. The goal of a directed approach is to validate or extend conceptually a theoretical framework, theory, or research. Existing research and theory help determine initial coding themes and relationships. Deductive category application is another term used to describe this process (Mayring, 2000).

Sample

In the original parent study (R21 NR010744, G. Demiris PI, 2008-2010), investigators enrolled informal hospice caregivers after approval of the appropriate Institutional Review Board. Two home hospice programs in the Pacific Northwest area were purposively selected based on size, Medicare/Medicaid certification, total number of admissions, daily census, and average length of stay. Caregiver enrollment occurred regardless of race, gender, or ethnicity. Moreover, researchers actively recruited racial and ethnic minorities to maximize the diversity of their sample. The secondary data analysis, presented here, relied on the parent study (R21 NR010744, G. Demiris PI, 2008-2010) data set; however, only caregivers of patients dying of cancer were included in the secondary content analysis.

Caregivers, referred to the primary study, met the following criteria: a family/informal caregiver of a patient enrolled in the outpatient hospice program, able to speak and read English, 18 years or older, without functional hearing loss or with a hearing aid that allows the participant

to conduct conversations, access to a standard telephone line at home, mild or no cognitive impairment, and with at least a sixth-grade education. De-identified audio files from caregivers completing all phases of the study, caregivers completing part of the primary study, caregivers whose patient died during the study, and caregivers who withdrew from the study were included in the secondary analysis. Caregivers, who withdrew from the primary study before completing any part of the intervention and caregivers of non-cancer patients, were excluded from the secondary data analysis.

Data from 125 researcher-caregiver dyads, participating in the primary study, were initially reviewed. This data consisted of discussions and educational sessions, conducted as a part of the larger parent study (R21 NR010744, G. Demiris PI, 2008-2010) following the Problem Solving Therapy curriculum used in the original study (Demiris et al., 2010). These caregivers consistently identified pain as one of their top three concerns. Due to the large volume of audio tapes available from the parent study for review, the thesis project was condensed. The project director (PD) and thesis chair postulated that the data set of caregivers, caring for loved ones dying of cancer, would offer a rich context of data for identifying pain management issues. Additionally, the largest hospice admission diagnosis category is cancer (35.6%) with heart disease (14.3%) and unspecified debility (13%) a distant second and third (NHPCO, 2012). Twenty-nine subjects caring for patients dying of cancer were identified for the secondary data analysis. PST intervention sessions, with each study subject, generated between 1 to 5 audio files per subject. These 29 subjects generated 87 total audio files, each approximately 60 minutes in length. Thus, the 87 audio files became the working data set for this secondary thematic data analysis.

The sample selected for the secondary analysis was not targeted toward a particular gender, race, or ethnic minority. However, hospice caregiver gender reported in the literature is overwhelmingly female and race is overwhelmingly White. In a Cochrane meta-analysis, female caregivers ranged between 62% and 99% (Candy et al., 2011). The primary study reported 98% female caregivers, consistent with these findings. Across 27 studies reviewed by Meeker et al. (2011), the majority of caregivers were White (82.3%), excluding four studies conducted in Taipei. Although the gender, race, and ethnicity of caregivers are homogeneous entities in the study sample, as outlined in Table 1, they appropriately reflect the current demographics of the target population.

Data Collection Method

This secondary content analysis of therapy sessions conducted as part of a larger study (R21 NR010744, G.Demiris PI, 2008-2010), enabled this PD to efficiently and economically describe and compare EOL caregiver pain management issues. Primarily a qualitative tool, directed content analysis offered a flexible way to identify and evaluate key issues in the data set (Hsieh & Shannon, 2005). In the primary study, pain was the most common caregiver problem identified. As such, this original data set held the potential to identify core themes associated with caregiver pain management.

Directed content analysis, using ideas from a framework developed by Lau et al., (2009), as well as other concepts central to EOL pain management, guided formulation of initial themes for the research. The construct described by Lau et al., (2009) identified initial themes associated with family caregivers and medication management for pain. Lau et al. (2010) enhanced the construct by including other factors influencing caregivers and medication management.

Medication management is only one aspect of caregiver pain management during EOL care. Therefore, other themes were added, after an extensive literature review, to extend the construct and validate the existing framework.

For the literature review, electronic databases were searched including: MEDLINE, CINAHL, PsycINFO and Cochrane Database of Systematic Reviews. Terms searched singularly and in combination included: pain, pain management, cancer, palliative care, caregiver, family caregiver, informal caregiver, end-of-life, EOL, hospice, telehospice, opioid, medication, and barriers. Following citations in articles, and snowballing identified other pertinent literature. Abstracts were reviewed and appropriate studies were examined in full for empirical rigor. Results were initially searched from 1998 until present but snowballing revealed useful articles prior to 1990. The search was thus expanded to include articles from 1980 to present.

After the literature review was complete, themes identified by Lau et al. (2009), and Lau et al. (2010) were expanded to include consensus themes discovered in the review. Major themes and sub-themes were developed, organized, and operationalized. For study clarity, the concept of pain was viewed as being experienced in four distinct, yet often intersecting domains: physical, psychological, social, and spiritual (Berry & Paice, 2010; Paice & Ferrell, 2011; Selman et al, 2011). Other outcomes of interest included any emerging pain management themes from the secondary data set. Comparative pain management relationships between the telehospice videophone (VP) group and the face-to-face (F2F) group represented another outcome of interest.

Concrete operational definitions of each theme and sub-theme were created along with a working codebook (Appendix B). In the development of these themes and the creation of the

codebook, all ideas were properly cited and not plagiarized. Quality evidence, transparently used to develop themes in the codebook, helped increase study trustworthiness.

The codebook included themes and sub-themes associated with caregiver pain management as well as detailed descriptions of each theme. Detailed and accurate operational definitions enhanced coding accuracy, as did inclusionary examples of each theme. Additionally, the codebook included text exemplars (emic examples) typifying quotes to be coded under each theme. Also included in the codebook were exemplars of theme exclusions. These exclusionary examples helped coders better understand the theme and address specific ideas that might cause confusion while coding. Peer review and debriefing of the codebook, by the thesis chairman, two hospice nurses, and a physician pain-management fellow, for theme completeness and discreteness, enhanced credibility and confirmability of the themes through external validation.

As a novice researcher in naturalistic inquiry, peer review, bi-weekly debriefing with the thesis chairman, and data triangulation (throughout the process) enhanced overall study quality. Data triangulation helped enhance study trustworthiness. Data triangulation occurred by comparing primary study field notes, and audio-taped conversations from healthcare professionals, with researcher-caregiver therapy sessions. This type of data triangulation helped clarify questions of meaning and context. The audio files themselves were another source of information. Caregiver inflection and overall emotion were evident through voice tone, tempo, and tenor. Written transcripts do not offer such rich context. Additionally, the primary study included assessment results from several instruments: the Caregiver Quality of Life Index-Revised (CQLI-R), the Problem Solving Inventory (PSI), the State-Trait Anxiety Inventory for Adults (STAI) and the Caregiver Reaction Assessment (CRI). These results added context and enhanced meaning also through data triangulation.

Detailed record keeping activities including decision logs with justifications, a reflective journal, and an audit trail enhanced the study rigor and trustworthiness. The study audit trail included the initial set of de-identified audio files, reduced data (e.g. words, phrases, sentences conveying concepts associated with each theme), process or methodology notes, codebook development notes (e.g. codebook drafts, peer reviewer suggestions), and data reconstruction products (thesis drafts and final reports). The qualitative software program, NVivo9, used to code the audiotapes, secondarily recorded many of these record keeping activities and acted as a backup and comparison to handwritten notes. Properly cited articles were entered into the codebook (e.g. high-level evidence in support of theme development) for ease of reference by peer reviewers and coders, as well as for increased study transparency and trustworthiness. Only the Principle Investigator (PI) of the primary study, the PD, and the coders had access to the study audio files, with the coders having only limited access to their specified files.

The secondary de-identified data used in this analysis are maintained by the primary study PI. The secondary data analysis remained within the scope and timeline of the primary study's IRB approval period.

Procedures

After obtaining approval from the thesis chairperson and committee, the PI shared data with the PD via Dropbox, an online secure medium, to ensure complete data transfer. This Dropbox folder could only be accessed by the PI and the PD. The PI of the parent study, also the thesis chairman, added the PD and research coders to the IRB approved primary study to allow easier data access. Additionally, the primary study's informed consent, allowed for secondary data analysis. In order to protect participants' rights and welfare, all data was de-identified before

being shared with the PD thus ensuring anonymity. All de-identified information was stored in a password protected master file on the PD's computer to ensure confidentiality.

After a preliminary review of the 126 subjects, the PD created a working audio file group consisting of 87 audio files from 29 cancer patient caregivers. These audio files were imported into NVivo 9 along with the subject's demographic data. A category, or node, was created for each research subject consisting of a subject number and their demographic attributes. Since data was de-identified, the node was labeled with the subject study number previously assigned in the parent study. The study subject node and the subject's audio files were linked through the NVivo 9 software. As per the primary study, each subject was assigned to either the F2F group or the VP group. This information was added as a subject attribute in the NVivo 9 software. The codebook themes and subthemes were also added as individual nodes at this time.

Using Sandelowski's (1995) guidelines of coding, the PD listened to all 87 audio files, in an attempt to identify additional concepts that might develop into new themes to be added to the coding schema. None were identified. The PD then proceeded with the initial coding using the NVivo 9 software to code directly onto the audio files. The NVivo 9 software also allowed the PD to make annotations or reminders in the files. These annotations and notes helped to create an audit trail and decision log. A paper and pencil decision log/audit trail was also kept for cross-reference. As coding decisions were made, the codebook was revised to reflect the decisions. Additionally, previous coded files were re-coded with the new decisions in mind. This iterative process continued throughout the research project. As coding progressed, audio files without utterances concerning caregiver pain management were moved to a separate file from the working data set.

The PD then transcribed pertinent sections of audio files, using tools within NVivo 9. These transcribed coded utterances were rich, evocative exemplars of themes within the codebook. These quotes were chosen as examples of themes that were particularly problematic for caregivers in managing loved ones pain during the end of their life. These descriptive and thematically rich caregiver exemplars, helped clarify and describe caregiver pain management challenges, thus helping to fulfill the primary aim of this study.

After completing coding, the themes and the assigned data were reexamined for sub-themes to prevent overlap. Individual themes (phrases, words, concepts) should not overlap to ensure trustworthiness. Individual themes must be exhaustive and mutually exclusive to ensure the results represent the texts completely and unambiguously (Krippendorff, 2004), thus enhancing descriptive validity. During reexamination, the data was once again reviewed for new emerging themes.

When all coding activities were complete, the PD examined descriptive validity (e.g. factual accuracy of specific caregiver pain management themes) and interpretive validity (e.g. the closeness of the code to the identified statements of the caregivers). Evaluating descriptive and interpretive validity enhances trustworthiness (Sandelowski, 1995). Members of the coding team also reviewed the coding themes, operational definitions, and emic examples at this point for factual accuracy and interpretive validity. Discrepancies were discussed and resolved.

Analysis

Along with the audio files, standard categorical caregiver demographics collected for the primary study including: gender, race, ethnicity, marital status, relationship to patient, education level, and the top three caregiver issues (originally identified from a checklist) were included in

the secondary data analysis. Patient's cancer diagnosis, time spent in the study, and death during study was also noted. Conversations with hospice personnel and field notes collected during the primary study were also part of the analysis. The continuous variable, date of birth, was included in the demographic data for secondary analysis. Continuous variable information such as Caregiver Quality of Life Index – Revised, The State-Trait Anxiety Inventory, and Problem-Solving Inventory, analyzed (using ANCOVA) to evaluate caregiver problem solving confidence, were not included in this study but preliminary results were available upon author request. These results were only used, when needed, to give context to a caregiver's pain management issues. Only caregivers of patients with cancer had demographic information entered into the password-protected software program, NVivo9.

After identification of specific pain management themes through literature review, and thematic peer review, a codebook was created. These codes were entered into the qualitative data analysis software, NVivo 9. Caregiver transcripts were evaluated for content involving these pain management themes, coded, and then analyzed using the software. The PD highlighted portions of audio files containing utterances pertaining to specific themes, and assigned that portion of the audio file to the appropriate code, known as a node in NVivo 9. Each node became a warehouse for text, words, phrases, and concepts relating to pain management issues. In essence, each node held all content related to one discrete pain management issue. Additionally, subject nodes, containing caregiver demographic data, were linked to the themes discovered in the audio files. In this way, pain management issues, the caregivers, and exemplars were identified and described as per the primary aim of this study.

The PD coded all 87 audio files and then re-coded one of every 10 files. Files were then compared for intra-coder reliability. Also at this stage, any questionable themes were checked

against the predetermined themes to ensure category exclusivity, again enhancing descriptive validity and category discreteness. After all coding was complete, the PD re-coded another six transcripts for a total of 28% of the audio files. Only one discrepancy was identified and re-coded.

Investigator triangulation was used to ensure thematic validity, discreteness, and inter-coder reliability. A coding team consisting of three Clinical Informatics Master's candidates and the PD was organized. The team met several times during a five-month period to discuss, review, and clarify themes, and also review specific coding examples and issues. The goal was to reduce PD idiosyncratic bias and enhance inter-coder reliability. After the initial coding of the audio files by the PD, the three coders independently transcribed and then coded 18% of the audio files. The coders met with the PD and discussed any inconsistencies. Codes were reviewed and adjusted to ensure discreteness. Differences in coding were resolved through discussion, until 100% agreement was achieved. Intra-coder reliability and inter-coder reliability helped enhance study trustworthiness.

Comparisons of the F2F group with the VP group transpired, as per the secondary aim. Since no unexplained differences occurred, data was combined for further analysis. The number of subjects contributing to each theme was tabulated and analyzed as were the total number of utterances per theme. The percentage of caregivers identifying each theme and sub theme was also tabulated. Analysis helped identify and describe the EOL pain management issues identified by all the caregivers. Analysis also helped identify which issues were most often identified by the majority of caregivers. Rich, in-depth exemplary quotes, of study themes and sub-themes, were collected to aid in meeting the primary aim of this study: to identify and describe pain management challenges faced by home hospice caregivers.

Risks and Benefits

As this is a content analysis of secondary de-identified information, risk and burden to participants was negligible. Privacy was not affected nor was physical or psychological comfort. No coercion or deception was used in the primary study or in the secondary data analysis. Since the PD and study coders were added to the primary study, the directed content analysis falls within the primary study IRB. Although the primary study recruitment is closed, the IRB has been renewed annually to enable future data analysis. The current IRB has been renewed until spring 2012 with the PI submitting an annual renewal report at that time. The use of de-identified data ensured anonymity. The use of password-protected files and encryption of files ensured confidentiality throughout the study. These steps also minimized the risks of harm and protected study subjects' rights and welfare.

There was no direct benefit to participants. However, findings about caregiver pain management issues may inform future telehospice interventions and future telehealth tools to help caregivers. By managing EOL pain more productively and with less stress, caregivers and hospice patients benefit. Additionally, these same themes and issues may be transferable and informative for professional caregivers including: nurses, palliative care providers, and more broadly anyone helping patients manage pain.

After the PD completes her thesis, March 2012, information in DropBox will be deleted. All files pertaining to the study will remain in a password protected master file on the PD's computer with a backup copy, triply encrypted, on a Carbonite server. The Carbonite server is also password protected.

Results

A total of 29 caregivers of patients dying of cancer were included in this secondary data analysis. These 29 caregivers were part of a larger data set from the original parent study (N21 NR010744, G. Demiris PI, 2008-2010). Demographics are summarized in Table 1. Caregivers' average age was 52 years old, with the majority (58%) of caregivers between the ages of 51 and 70. Most caregivers were married, White, female living with the patient at the time of the study. Most had at least some college education and several had masters or doctoral degrees (n=10). About half of the caregivers worked outside the home (55%) with 7 caregivers (24%) retired. Additionally, the majority of caregivers (83%) were either an adult child or a spouse/partner of the patient.

Patients' average age was 68 years old. Patients ranged in age from 40 to 89, with over half of the patients older than 71. All patients identified race as white/Caucasian with the exception of one who identified as multiracial. Race data was missing for one patient. One patient identified their ethnicity as Hispanic. Twenty-seven identified as non-Hispanic and for one patient ethnicity data were missing.

Detailed descriptions of major themes and sub-themes, used in the coding process, are listed in the codebook (Appendix B). All themes were independent and discrete. Definitions and examples were offered under each theme. In addition, exemplar quotes were included under most themes. Exclusions to specific themes were also included to enhance thematic clarity. The six major themes identified included: 1) Caregiver-Centric Issues, 2) Caregiver's Medication Skills

and Knowledge, 3) End of Life Symptom Knowledge Issues, 4) Teamwork and Communication Issues, 5) Organizational Skill Issues, and 6) Patient-Centric Issues.

Thirty-seven percent of all themes were identified under Caregiver Centric Issues. Only one caregiver in the study did not identify any Caregiver-Centric Issues. The next most frequently identified themes concerned Teamwork and Communication Issue. Eighty-six percent of caregivers identified themes concerning Teamwork and Communication. Table 3 and Table 4 offer a complete summary. The secondary data set offered many utterances associated with caregiver pain management. All caregiver themes and sub-themes used in the coding process are enumerated in Table 2. A detailed descriptions of each theme and sub-theme can be found in the Codebook (Appendix B).

The first major theme, Caregiver-Centric Issues, concerned all issues interfering with a caregiver's ability to manage, treat, assess, and attend to a patient's pain. This theme contained the largest number of sub-themes (n=8) with several sub-themes containing subordinate themes. Under this major theme, the Function Issues sub-theme was frequently identified in the data with 62% of caregivers identifying this as an issue. The Functional Issues theme included physical and psychological caregiver limitations, which prevent caregivers from adequately managing a patient's pain. For example, a caregiver that is physically unable to help a patient change position in bed might prevent that patient from being able to achieve pain relief or a caregiver suffering from arthritis may find it difficult to open pain medication bottles. One elderly caregiver had a recently diagnosed cardiomyopathy that limited his ability to walk for any distance. He also had some type of neuropathy affecting his legs and hips. He stated, "It's difficult for me....I feel unstable." Depression was a functional issue that prevented several caregivers from managing loved ones pain. One young single mother, caring for her own mother

dying of cancer as well as her active young child articulated thoughts about her depression. While her child was crying in the background, and through her own tears, she stated, “I get kind of sad because I feel depressed all the time. I try to work out what I can do to feel better. But I don’t know what to do. I just want to cry all the time cause my mom is sick. When I feel depressed, I just want to cry and I don’t want to live. I want to die...It started when my mom started getting really sick.” Exhaustion was noted by several caregivers as a Functional Issue interfering with a caregivers ability to address a patients pain. One caregiver stated, “... you can’t help when she gets up and it’s 11:30 and you just got to bed and you’re trying to sleep and you’re awake and she gets up and it’s 1:00 am and you’re awake, and she gets up and it’s 2:30 am and you’re awake you know. I haven’t done much work, I was going to go in today, but it became really difficult for me to just, I don’t want to leave her alone either and she’s not comfortable being with anybody else.” Another caregiver noted, “I was just exhausted. I couldn’t hear him [the patient] call. I didn’t know he needed more [pain] medicine.” Another caregiver noted, crying, “I just can’t do it, I just can’t. I was up all night with [the patient] then worked all day and then was up all night the again. I just can’t...” Not only are these passages examples of depression and exhaustion as a Functional Issue sub-theme, but also examples of another Caregiver-Centric sub-theme, Concurrent Responsibilities Issues. The Concurrent Responsibilities sub-theme was identified as a problem by 66% of the caregivers in the study. Concurrent responsibilities, interfering with pain management, were discussed by the most caregivers in the study. Concurrent Responsibilities recognizes that caregivers may have other ongoing responsibilities interfering with their ability to manage their loved one’s pain. Concurrent responsibilities identified in the data set included work outside the home, family responsibilities such as child care, and caring for other chronically ill family members. Also

included in this sub-theme were financial responsibilities that may prevent caregivers from affording pain treatments or medications. One caregiver of an older sibling dying of lung cancer best described the issue, “Well that's it...it's not fair. I was ready to start screaming at people. I felt I was almost in tears...he needs this stuff [pain medicine]....and I don't have any money.....Dealing with insurance companies and different medicines the insurance company don't cover. But we had to get an appeal form from the insurance company and the appeal process takes 3 or 4 weeks to complete...by that time, you know.... [his brother would be dead].

This excerpt also encompasses a sub-theme found under Teamwork and Communication:

Caregiver-Healthcare Delivery System Issues. This same caregiver described another issue in working and communicating with the Healthcare Delivery System. The caregiver stated, “For example, one of his [the patient’s] meds is not covered by hospice, so we have to go to the pharmacy, the pharmacy had a problem with the insurance company, they were all calling the doctor, da dah, da dah, da dah, da dah...everyone was going crazy and I need this medicine for [the patient]. And they wanted to give us something else. It took us a month to get this right medicine....it helps him sleep all night...and so I'm just starting to pop!I can just see myself screaming at a lot of different people. I actually tried to call. Someone called from the agency, left a name and a number. I called them back and got bounced around to seven different people and finally I got to someone completely unrelated to the problem. I said, I can not handle that!”

A majority of caregivers (52%) also identified their fears as an issue in pain management. Caregiver fear of over medicating or under medicating was mentioned on many occasions. One elderly caregiver described his issues in this way, “It is overwhelming...And the moment I needed the morphine [for the patient] was the moment I realized we ran out. We had another morphine bottle, but it was in a different container, uhm, I couldn't find it and then it was in a

different dispenser, it was an eyedopper thing and I never really used an eyedropper. And the level in the eyedropper kept going up and down and I didn't want to give her too much or too little. That was part of the call to hospice to determine how I was supposed to read the dropper.” Later in the audio tape he admitted, “I panicked. I tried to figure out how to solve the problem, looking at one thing at a time. I ran around like a chicken with it's head cut off.” This is also another example of a Caregiver Functional Issue in the inability to use the medication eyedropper to administer the pain medication. Another caregiver expressed fear using the eyedropper to administer morphine stating, “She (dying loved-one) has chronic pain...the morphine was in an unusual bottle and I was afraid to give her too much or too little and the dropper wasn't working. It was very scary.” A 37 year old caregiver, caring for her dying mother, identified Previous Life Experiences as a sub-theme. The caregiver was a cancer survivor and had fought through rhabdomyosarcoma and breast cancer in the past. She stated, “You can learn from it or you can drown in it.”

The next major theme had to do with a caregiver's Medication Skills and Knowledge. This theme dealt with the caregiver's working knowledge of medications including: pharmacology, polypharmacy, drug interactions, medication actions and side effects, and assessments and outcomes of pain management therapy. One exhausted caregiver, having difficulty sleeping, wanted to solve the problem by taking some of the patients medication, stating, “We have a veritable trove of drugs here and one that I thought I could try is one half Lorazepam...a sleep medication that I have never tried but it doesn't leave you with ill effects in the morning so I thought I might try that...” Lorazepam, a benzodiazepine, is used to treat anxiety, not sleep deprivation. Medication knowledge was missing in addition to the safety issue of taking someone else's medication. This statement was also coded under the sub-theme of

safety issues found in the major theme of Organizational Skill Issues. Another caregiver, trying to manage the pain medicine, morphine had difficulty in identifying her mother's pain level stating, "It is difficult trying to identify a person's pain level when they have dementia.

I...sometimes don't know and then kind of wait and then , of course, when the nurse comes she says just give it [morphine] every 4 hours. I felt like I was sort of drugging her...you know when you give somebody something and you see their tongue go to the side and you're not a nurse? That kinda stressed me out a bit, but I just watched her."

The third major thematic category was End of Life Symptom Knowledge Issues. This theme encompassed common EOL symptoms or assessments which caregiver's misperceive as needing emergency treatment. This theme also included caregivers inability to assess and treat symptoms that may increase the patient's pain load. The four distinct, yet often intersecting domains which contribute to this suffering include: physical, psychological, social, and spiritual issues (Berry & Paice, 2010; Paice & Ferrell, 2011; Selman et al, 2011). Under this theme, the EOL Symptom Assessment Issues, were most often identified. One caregiver, caring for a loved one with metastatic cancer, stated, "But even getting up to go to the bathroom she gets short of breath and then she starts to panic and we have to give her lorazepam to try to calm her down. And so now, like, a week ago it wasn't that big of a deal. But this weekend everything just changed."

The next major theme, Communication and Teamwork Issues, had a high frequency of caregivers in all sub-themes but particularly in the sub-theme of Caregiver-Family Communication. Sixty-four percent of caregivers identified issues in this sub-theme. One caregiver had difficulty giving her dying mother pain medication because her father (patient's husband) kept interfering. They were barely speaking. She stated, "I hate him...I hate my father

with a passion. My father's very angry again, very, very angry. Screamed and yelled at me last night. I've been his whipping post since the day I can remember. I hate him, I could care less if he keeled over and died right now. And I think I'm horrible for saying that right now. But, if he wasn't there, her [the patient] life would be so much easier. It could be such a better experience than what she will go through. At least I could give her the pain pills without sneaking them to her. I don't like to defend him. In his mind he thinks that if she doesn't take all the morphine and stuff maybe she will get better because the drugs are making her worse. In the small aspect of the big picture he is correct, of course it dulls her brain. That is absolutely 100% true. But the bigger picture is why would he let her suffer like this. Why keep her in this kind of agony. And his explanation, when I asked him was, 'well, I want to save them for when it is really bad and then we will give drugs.' O.K. So we will just make her lay in agony until you deem it really bad and then we will give her the drugs?"

Organizational Skill Issues was the fifth major category with two sub-themes. The Tracking and Recording sub-theme was concerned with caregiver's lack of organizational skills, which may cause problems with patient pain management. It included tracking and recording treatments, assessments, medication administration times, and outcomes. A mother caring for her dying adult daughter expressed frustration about the medication schedule, "when things were [getting bad], I had to get [my daughter] up at 7 a.m. to take her one pill before her 8 o'clock meds. She had to take some of them on an empty stomach, some of them with food, and there was a bunch of other stuff going on [vomiting] ...and so everything got cockeyed." Another caregiver was having difficulty dosing the morphine to meet the pain needs of her dying father. She did not have a record of how much morphine she had been giving and was not sure how to explain to the nurse that she had been giving more than the nurse had suggested. She stated, "the

nurse said 'what you are giving him should be fine, give him 5 mgs of morphine and then 5 mgs more every half hour', I don't know how much we can give him but I would start out with 10 mgs... and sometimes give over 20 mgs but over the course of what time? I guess that is a question we need to ask. Is that too much? It would be nice to have some endpoint parameters."

The other sub-theme identified under Organizational Skill Issues was Safety Issues. This sub-theme addressed caregiver's inability to safely store and discard medication. This theme included medications being stolen, abused, misused, or available to children. It also included equipment, such as syringes, not being safely disposed of or stored. One caregiver, identified above, thought about taking some of his dying wife's medication, "a veritable trove of drugs", to help him sleep. After a crisis in identifying medications late at night, another caregiver stated, "We name everything in the bottles by what it does, instead of trying to remember a 42 letter medical name. We have a label maker so we put the label on the bottle. And then we put all the bottles in a box and if we move to another part of the house, we just take the whole box with us."

The sixth major theme identified dealt with Patient-Centric Issues. This theme included many of the same sub-themes found in the Caregiver-Centric theme only from the patient's perspective. One major difference however was the sub-theme of Pain Assessment Congruency Issues. This sub-theme had to do with the caregiver either under-estimating or over-estimating pain as the patient perceived it. In essence, the patient and the caregiver do not perceive the pain experience in the same way, thus creating incongruences. All examples of Pain Assessment Congruency in the data had to do with patients hiding pain from the caregivers. One daughter, caring for her mother, described the situation by saying, "... she [dying mother] won't really talk about pain with us. And if she is in any pain she never tells us. She kinda suffers through it... later on if we go to the doctors appt. then she'll say 'oh yea, I was in a lot of pain', and we will

say well why didn't you say anything? We couldn't help you? We'll ask her if she wants something [for pain] and she'll say no. Then she gets up and gets it [pain medication] and takes it...[I feel] kinda helpless, how can I help her if she (inaudible and crying) won't let me help her?"

Of note, there were five sub-themes without thematic representation in the data set. These included three under the Caregiver Centric Issues major theme: 1) Cognitive Literacy or Education Level Issues, 2) English as a Second Language Issues (ESL), and 3) Cultural/Ethnic Norm Issues. Additionally, the sub-theme of Personhood Issues under Caregiver's Medication Skills and Knowledge was not identified in the data set. And, the sub-theme of Patient Mythical Belief Issues found under the major them of Patient-Centric Physical and Psychological Pain Issues was not identified in the data. The theme of Teamwork and Communication accounted for 38% of the total coded utterances. And the majority of those utterances (74%) were coded either under the sub-themes of Caregiver-Family Communication/Teamwork Issues or Caregiver Support Issues. The second most prominent theme, accounting for 12% of all coded utterances, was the sub-theme of Functional Issues. Figure 1 summarizes the coded utterances per sub-theme.

Twenty-eight, of the 29 total caregivers, identified at least one pain management issue and many identified several issues. Figures 2 and 3 summarize these findings. Only one caregiver did not identify any themes related to caregiver pain management. And, although this caregiver identified "pain" as the number one issue of concern during the primary study, no pain themes were identified in any of the audio files associated with this caregiver.

A total of 386 references were coded from 57 of the total 87 audio files. These results are summarized in Figure 1. Additionally, caregivers in the Videophone group (n=13) identified

similar issues as the Face-to-Face group (n=15). These findings are enumerated in Figures 2 and 3. All caregivers in the Face-to-Face (F2F) group and all but one caregiver in the videophone (VP) group identified issues in the Caregiver-Centric theme. And a majority of caregivers in both groups identified at least one issue in the Teamwork & Communication theme (VP= 87%, F2F = 85%). The VP group identified 25 of the 34 sub-themes and the F2F group identified 27 of the 34 sub-themes (Figure 2). As noted above, five subthemes were not identified by either the VP group or the F2F group. The largest discrepancy in caregiver issue frequency occurred in the Medication Knowledge theme (Figure 3). The F2F group identified only 10% of their issues under the Medication Knowledge theme. The VP group identified 22% of their concerns under the Medication Knowledge theme (See Table 5). The top three sub-themes most often identified by both groups included: Functional Issues, Concurrent Responsibility Issues, and Caregiver-Family Communication Issues.

Discussion

Twenty-nine family caregivers, of loved ones dying of cancer, described concerns surrounding loved one's EOL pain management. Although these caregivers identified pain as being among their top three concerns, none chose to work on pain management issues per se in the parent study (R21 NR010744, G.Demiris PI, 2008-2010). Furthermore, the parent study did not investigate pain management issues directly. That said, all but one caregiver, in the secondary data analysis, mentioned numerous pain management themes over the course of their discussions. Despite the fact that caregivers addressed issues as dissimilar as writing thank you notes or finding a new job, they frequently spoke about varying themes of pain management during their PST sessions. Additionally, more than one caregiver discussed most themes, identified in this expanded construct (See Appendix B).

Two themes, Concurrent Responsibilities and Caregiver-Centric Functional Issues, were discussed with the most frequency and by the most caregivers. Themes relating to Concurrent Responsibility were identified the most as issue interfering with caregivers' ability to manage their loved one's pain. These primarily female caregivers, working outside the home, had many family responsibilities including small children at home. These concurrent responsibilities prevented caregivers from devoting time to the issues surrounding pain management. Additionally, concurrent financial responsibilities prevented caregivers from affording expensive pain treatments and/or pain medicines. Caregiver-Centric Functional Issues were also discussed frequently by caregivers. Most caregivers (80%) were over 50 years of age, and 6 were over 71 years of age. Functional limitations increase with advancing age. Back pain and arthritis pain were noted functional limitations in the study population. Caregivers noted both physical and

mental exhaustion, as a common Functional Issue. Depression was also noted as a Functional Issue. While the issues of Caregiver Functional Limitations and Caregiver Concurrent Responsibilities were identified by the largest number of caregivers and with the most frequency, five sub-themes were not mentioned at all.

The sub-themes of Cognitive Literacy/Educational Level Issues, English as a Second Language (ESL), and Cultural/Ethnic Norm Issues found under the major theme of Caregiver-Centric Issues and the sub-themes of Medication Personhood and Patient Mythical Beliefs were not represented in the study data. Several reasons may account for these findings. First, in terms of the Caregiver-Centric Issues, the demographic distribution of caregivers (see Table 1) was homogeneous in terms of race, culture, and ethnic distribution despite the fact the primary study did not target a specific population. Findings of this study were not surprising as they mirror the current national demographic distribution in hospice care.

Most hospice researcher report the majority of caregivers as White, Non-Hispanic. Across 27 studies reviewed by Meeker et al. (2011), the majority of caregivers were White (82.3%), excluding four studies conducted in Taipei. And, of 116,974 family members, in a recent study by Rhodes, Mitchell, Miller, Connor, and Teno (2008), 97% were non-Hispanic, White. Because the homogeneity evident in my study population, as well as the current U.S. hospice caregiver population, ESL and cultural influences were not identified as issues nor were they expected. Additionally, the caregivers enrolled in the parent study had to meet the inclusion criteria of being able to speak and read English, making ESL and Cultural/Ethnic Norm Issues even less likely. Since 28 of 29 caregivers had at least a High School education (one caregiver's education level was unknown) and primary study inclusion criteria was mild or no cognitive

impairment, Cognitive Literacy/Education Level Issues were also nonexistent. This may account for the lack of identification of these themes in the study results.

Since no patients were interviewed in the primary study, pain management issues dependent on the patient's perspective may be under represented or non-existent as in the case of the Medication Personhood theme and the Patient Mythical Belief theme. The Medication Personhood Issues and Patient Mythical Belief Issues concerned patients' belief systems about pain and pain medicine specifically. Without patients' input or feedback, identification of both issues proved difficult. Of note, the themes identified by the least number of caregivers and also with the least frequency were those under the major theme of Patient-Centric Issues. Perhaps, lack of interview specific questions about the patient and pain management, or lack of the patients' perspective (no direct discussions with patients) attributed to the underrepresentation of these sub-themes.

When comparing caregiver issues identified by the telehospice group with those issues identified by the face-to-face group (Figures 2 and 3), two major themes differed by more than 4%: Caregiver Centric Issues and Medication Knowledge Issues (Figure 3). Caregiver Centric Issues differences (11%) were attributed to three F2F caregivers discussing issues of EOL pain management as it related to their religious and moral convictions. Each caregiver mentioned the issue only once. Therefore, only three utterances of the 386 total coded references, concerned religious, moral, or ethical issues. No caregivers in the VP group mentioned these concerns. Ultimately, overall differences may be due to small sample size (VP: n=13, F2F: n=15) and lack of directed questions concerning these caregiver issues.

Understandable differences also occurred in under the Medication Knowledge theme. The F2F group identified 10% of their concerns under the Medication Knowledge theme and the

VP group identified 23% of their concerns under this theme. These findings may be explained by two caregiver outliers. Two caregivers in the VP group accounted for 36% of the issues under the Medication Knowledge theme. Both caregivers were elderly (greater than 70 years old), male, and were two of four caregivers who had their loved one die during the study. Both caregivers discussed concerns about medication administration and medication side effects. Each of these two caregivers had 7 and 8 utterances, respectively, about Medication Knowledge. The majority of the other VP caregivers, identifying issues under the Medication Knowledge theme, had only one or two utterances. The overall findings of only minor differences in the descriptions of EOL pain management issues between the F2F group and the VP group are consistent with the non-inferiority results of the primary study.

Strengths

Although the interviewers did not specifically ask about pain management issues in the primary study, most themes were described in-depth by caregivers within the secondary study sample. Several themes were discussed by a majority of the caregivers. If these themes were evident in a sample of caregivers that was not asked specifically about pain management issues, there may be more information to be gained using this expanded construct as a framework in future research or in the development of clinical tools. Themes developed for this study may act as a basis for interview questions or pilot studies in future qualitative research concerning caregiver pain management issues. This expanded construct might also be used to develop and test clinical tools to evaluate or identify caregiver issues early in the hospice process. The issues and themes might also be extrapolated to all caregivers dealing with loved one's cancer pain management, not just limited to the hospice environment.

The thorough literature review used to expand the construct developed by Lau et al. (2009) and Lau et al. (2010) was also a strength. The literature review helped develop the comprehensive peer reviewed codebook which clearly articulated the themes and sub-themes of this newly expanded construct. Descriptions, inclusion and exclusion criteria, examples, and quotes made the codebook functional. This newly expanded construct was then validated by peer review and the in-depth study thematic analysis. These researcher-caregiver discussions offered thematically rich, descriptive, and contextual examples of the caregivers' perspectives of pain management issues. The majority of themes were identified in these conversations despite the fact that the caregivers were not specifically discussing issues of caregiver pain management. The detail of the codebook, could also be used as a tool to further investigate caregiver pain management issues both in the clinical setting as well as in the research setting.

Limitations

Study limitations included the restrictions of a secondary data analysis, the relatively small sample size, the homogeneity of the sample, and the lack of the patients' and professional hospice workers' perspectives. This study was also limited by the lack of directed questions concerning caregiver pain management issues. Although caregivers identified loved one's pain as a primary issue of concern, not one caregiver chose pain as the focus of the PST in the primary study. Another limitation was the lack of analysis of results based on demographics. Some researchers have found differences in overall caregiver burden based on caregiver age, sex, racial/ethnic status, relationship to the patient, education level and financial resources (Dumont et al., 2006; Goldstein et al., 2004). These variables, and other demographic variables were not evaluated in this study.

The small sample size (n=29) of this content analysis proved limiting. Small sample size limited the frequency of pain talk. And, the lack of focus on pain as the discussion topic in the sample may have limited the depth of the pain talk. Specific issues about pain were not the focus of the interview questions and pain talk was only discussed as an aside to the overall PST methodology. No questions were asked about specific pain themes identified for this study. In particular, medication issues and the patient's perspective were not discussed in this study. Future research might use the themes identified in this study as a prompt for a more focused qualitative study, including patients and professional hospice providers. Additionally, caregiver screening tools or questionnaires might be developed to focus resources on individual caregiver issues similar to the ones developed by Japanese researchers (Ishii, Miyashita, Sato, & Ozawa, 2011). These researchers developed a questionnaire of Family's Difficulty after interviewing 7 bereaved family caregivers and 5 home care providers. With results from the questionnaire, researchers created a 44-item valid and reliable Family's Difficulty Scale (FDS). The hope was to help hospice care providers assess family difficulties and then individualize the care based on specific family need (Ishii et al., 2011). Perhaps this secondary data analysis, and the resultant expanded construct, might offer researchers a starting point to develop a similar tool to help American hospice professionals and families address pain management concerns and individualize care. Individualized problem identification and interventions based on those individualized problems were the suggestions made in the meta-analysis by Sorensen et al. (2002), as some of the most effective strategies to help family caregivers as the struggle under the burden of care.

The second limitation was sample homogeneity. Although reflective of the current U.S. hospice caregiver population, this homogeneity prevents extrapolation of the findings to other

ethnic or minority groups. Several themes, Cultural/Ethnic Issues and ESL Issues, were not identified in this study due to the homogeneity of the sample. Extrapolation of this study's results to different populations will remain unknown due to lack of heterogeneity within the study sample. Recent research by Kreling et al. (2010), has addressed lack of heterogeneity in informal hospice caregivers and looked at cultural issues surrounding death and dying specific to the Latino culture. Kreling et al. (2010) reported that Central and South American Latinos were more secretive about death, and often kept important information about death from the dying from the dying loved one. Their study findings revealed denial and indirect communication about death and end-of life as a general cultural preference. Latinos also identified the family as the primary decision-maker, not the dying individual. The family hoped to shield their dying loved one from difficult or harmful information. Additionally, the Latino study subjects seemed to have less information about hospice services and the nature of hospice than the general population. The significant dilemma identified by Kerling et al. (2010) was how to discuss issues of terminal illness with Latino patients and family members who do not want to talk about terminal illness. Other researchers (Bradley et al., 2004; Dilworth-Anderson, Williams, & Gibson, 2002) have identified the significant role cultural values, beliefs, and norms have in influencing caregivers. These significant cultural differences were not captured in the current content analysis but the potential to capture them, using the expanded construct developed for this study, does exist. The significant differences concerning communication about death and lack of hospice knowledge in the Latino culture are clear indications that the homogeneity of the present study prevents extrapolation to the general population or to other cultures. Until this expanded construct can be examined in other cultural settings, or a more heterogeneous study sample, the ability to capture all caregiver pain management concerns will remain unknown. In addition to culture, other

moderators, such as caregiver's age, socio-economic status, gender, and educational level, were not examined or compared in this study.

The third limitation to this study is the lack of the patient and the professional caregiver perspective. Many themes refer to interactions between caregivers and patients. For example, Patient's Mythical Beliefs and Medication Personhood, both sub-themes not identified in this study, are difficult to describe without input from the patient. Interviewing professional hospice providers might also add qualitative depth and validate this framework. Including perspectives of patients and professional hospice care providers would enhance data triangulation and thus enhance study trustworthiness. The author recognizes the difficulty inherent in EOL research associated with adding the burden of interviews to patients in this domain.

Future Implications

Before healthcare and hospice providers can meet the goal of helping caregivers with the most often identified burden of caregiving, EOL pain management (Demiris et al., 2010; Meeker et al., 2011; Oliver et al., 2008; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007), the issues surrounding pain management must be clearly identified, described, and articulated. This research helps clarify, describe, and categorize the issues important to caregivers concerning management of their loved ones pain. The open-ended interview approach allowed for the identification of specific pain management issues. The six major themes and the subordinate themes offer hospice and telehospice researchers and clinicians a starting place in helping alleviate the burden of caregiving. As identified in a meta-analysis by Sorensen et al. (2002) and then again in a meta-analysis by Candy et al. (2011), caregiver concerns should be identified first and then dealt with on an individual basis. Sorensen et al. (2011) also noted that the most

effective way to address caregivers concerns was through increasing knowledge and ability.

Using this newly expanded construct in research and in clinical practice may help individualize care and education, but there are other important implications for this research in the U.S.

hospice system and for healthcare providers in general.

Early identification of caregiver concerns and individualization of help for the family unit in managing end of life pain will be more important than ever in the coming years. As the baby boomers age, most with multiple complex disease comorbidities, more and more pressure will be put on the hospice system. Add to that the lack of adequately trained hospice and palliative care providers (Bui, 2011), increasing workforce shortages (Juraschek, Zhang, Ranganathan, & Lin, 2011), and the high costs associated with EOL care (Hogan, Lunney, Gabel & Lynn, 2012) and a perfect storm will exist for deleterious effects on quality of hospice care and burden to family caregivers. These financial, workforce, and educational concerns may be ameliorated through the expansion of emerging technologies in the field of telemedicine, expanded into the hospice domain.

Recent advances in telehealth offer insight as to how the findings of this research might be used by hospice clinicians and researchers in the future. Telehealth has demonstrated feasibility and success in assessing and treating cancer patients' pain and depressions (Wilkie et al., 2009; Kroenke et al., 2010), administering different educational interventions to patients (Baker et al., 2011; Finlayson, Preissner, Cho, & Plow, 2011; Schweickert et al., 2011), assessing depression and prescribing early interventions in mental health issues (Godleski, Cervone, Vogel, & Rooney, 2012; Simon et al., 2011), and improving patients' medication management (Fincher et al., 2009; Ostlund, Dahlback, & Petersson, 2011). Telehealth research has also identified an ability to enhance healthcare provider education and healthcare provider

competencies (Haozous et al., 2010). Use of these types of technologies in the hospice field might also be beneficial provided they are based in evidence-based research, addressing clearly articulated challenges and clearly identified caregiver needs. Unambiguous caregiver needs will lead to interventions that will remove barriers impeding care and patient management, and will inform future research design (Hegyvary, 2006).

Wilkie et al. (2009) demonstrated acceptability and feasibility of using a pentablet-based software tool to access and treat hospice cancer patients' symptoms in their home. The patients were able to report their pain and symptoms in an efficient and accurate way while reducing the sources of bias in symptom assessment. Using this instant feedback technology, hospice providers were able to immediately identify pain and distress, and promptly intervene to improve outcomes before symptoms escalated. Similar results might be realized with the use of this expanded pain management construct, particularly if evaluation tools could be used at the beginning of hospice care. A pentablet-based software tool might be created, using results from this study, to identify areas of pain management concern. These individualized areas of concern might be used to teach caregivers about specific pain management issues early in the hospice experience. This type of intervention might save hospice caregivers time and ultimately money, not to mention improve patient care and diminish caregiver burden. These types of technologies would allow for needs to be identified early and addressed in a comprehensive care plan tailored to the family unit's issues.

Kroenke et al, (2010) reported the use of telecare management and automated monitoring to improve pain and depression outcomes in cancer patients receiving care in geographically dispersed urban and rural areas. Collaborative care teams used automated home-based symptom monitoring and centralized telecare management to improve outcomes. Evaluation and education

tools, created using the expanded framework of caregiver pain management themes, might enhance caregiver wellbeing, reduce stress, and prevent unnecessary hospital admissions. For example, caregiver issues concerning lack of knowledge of EOL symptom management could be addressed with web-based educational tools or direct interaction via videophone with a centralized hospice care manager. These tools would help bridge the geographical, socioeconomic, and cultural divide in hospice care. Additionally these tools might address the cost and manpower concerns in the current U.S. healthcare market. Again, these tools would help with the individualization of care and the delivery of appropriate support and educational resources.

Several research teams (Baker et al., 2011; Finlayson et al., 2011; Kobak et al., 2011; Schweickert et al., 2011) have had success in delivering educational interventions to patients and caregivers via different technology platforms. These technologies may be useful in EOL pain management considering increasing caregiver knowledge and ability was one of the most effective ways identified to decrease caregiver burden (Sorensen et al., 2002). In one clinical trial, Baker et al. (2011), used telephone reinforcement of heart failure related learning goals and self-management behaviors to improve knowledge, improve health behaviors, and improve quality of life. Schweickert et al. (2011) compared an in-person stroke prevention education session to a telehealth session delivered by videoconferencing. Both were readily acceptable by elderly rural adults and both were effective at improving knowledge of stroke and stroke risk. The educational sessions could be offered regardless of geographic location. In a randomized trial using a teleconference platform to deliver a fatigue management program to patients with multiple sclerosis, Finlayson, et al. (2011) found the educational intervention to be effective and efficacious in reducing fatigue impact and fatigue severity. The intervention also improved

patients quality of life. Interestingly, multiple sclerosis patients and hospice patients have similar dependency and care needs. Both groups are limited in their mobility, depending on the extent of their disease, and both groups have increasing caregiver needs through the progression of their disease. In another study delivering an educational intervention, Kobak et al. (2011) developed a web-based tutorial for parents caring for autistic children. The web-based tutorial was effective in increasing the caregivers' knowledge and had high user satisfaction ratings. Like hospice caregiver pain management, there are many and varied issues in autism care in which early intervention can prevent a negative cascade of effects. Early identification of individual issues is key. And educational opportunity, regardless of geographic location, is also important for many hospice providers and family caregivers. The 34 themes concerning caregiver pain management developed in this newly expanded construct might be used to create a clinical algorithm or an education intervention. Again, increasing caregiver knowledge and ability in pain management as an effective strategy to reduce caregiver burden (Sorensen et al., 2002). These interventions might then be administered via videophone, web, or teleconference. It is also important to recognize the 24-hour nature of hospice care and the need for information and help at all hours of the day and night. Telehospice educational information, regardless of technological platform, should be available to all caregivers, regardless of time or distance, on an on-call basis, and without regard to mobility.

Mobile telehospice solutions might also be effective. Several researchers (Simon et al., 2011; Godleski et al., 2012) used electronic messaging to assess mental health patients and intervene early to prevent emergency room visits, hospital admissions, and unscheduled urgent care visits. In the randomized controlled trial of depression follow-up using electronic messaging, patients had higher medication adherence, less depression and greater satisfaction

with depression treatment (Simon et al., 2011). Godleski et al. (2012) developed questions that were scripted according to the Disease Management Protocols for depression. The questions were delivered using electronic messaging. These questions identified early decompensating behavior and forwarded alerts to clinicians. The system also assessed quantitative symptom data (depression scale ratings, medication use) and included educational materials adapted from evidence-based treatments such as cognitive behavioral therapy and motivational interviewing. This type of system, used in the hospice setting, might draw on this researchers findings for the development of screening tools, or the development of algorithms to assess caregiver issues. In addition, quantitative caregiver e-tools to monitor symptoms or log medication administration could easily be created. Limits and alerts could be set to help caregivers and hospice professionals better manage pain. And, educational messages could be sent to guide caregivers. These mobile health applications hold promise for hospice care and pain management particularly if evidence-based recommendations and guidelines are integrated with personalized caregiver education (Chomutare, Fernandez-Luque, Arsand, & Hartvigsen, 2011; Simon et al., 2011).

Conclusion

Family members caring for loved one's dying of cancer suffer from the burden of this care through the course of the death and dying process. Caregiving is an active process, with burdens that change along the continuum of care. A direct consequence of this caregiving role, particularly in the palliative, hospice and bereavement phases of care, is the increased risk for physical and mental morbidity. Often, the psychological distress of the caregiver eclipses that of the dying loved one (Williams & McCorkle, 2011). This distress may have a negative effect on

the care provided and thus the well-being of the patient (Williams & McCorkle, 2011). In a recent Provisional Clinical Opinion issued by the American Society of Clinical Oncology (Smith et al., 2012), researchers acknowledged the continuous nature of caregiving and the caregiver burden and called for early integration of palliative care into standard oncology care in an effort to reduce caregiver burden, improve quality of life, and increase patient satisfaction. But, what specifically causes the most distress in caregivers and how might we, as healthcare professionals, diminish the caregiver burden?

This directed content analysis was conducted to describe and illuminate the issues experienced by caregivers in treating the most common cause of their burden: caregiver pain management. Issue clarity, early issue identification, and individualized treatment, education, and knowledge building are the keys to success in diminishing the caregiver burden. Hospice initiatives, including telehospice initiatives, may benefit from use of these keys in the design and implementation of tools to alleviate caregiver suffering.

Documented telehospice research is limited in the number of research studies and in study strength; however its pertinence is strong (Oliver et al., 2012). That said, caregiver pain management, in the context of telehospice, has only been addressed by one pilot study (Oliver et al., 2010). More research is needed to validate the clearly articulated caregiver concerns identified in this study. Once validated, researchers and clinicians can build upon the successes identified in other areas of telehealth, to create innovative telehospice solutions to address caregivers' concerns. Using telehospice tools to identify and address specific patient and family concerns, thus individualizing care, may also address the increasing costs and manpower issues prevalent in healthcare today. Enhanced, efficient resource utilization with improved patient and

caregiver outcomes, regardless of geographic location, is the goal for all. Telehospice may be part of the solution.

TABLE 1 Caregiver and Patient Demographic Variables

Variable		Caregiver (n=29)	Patient (n=29)
Sex			
	Male	11	9
	Female	18	20
Race			
	White/Caucasian	28	27
	Missing data	1	1
	Multiracial	NA	1
Ethnicity			
	Hispanic	2	1
	Non-Hispanic	27	27
	Missing data	NA	1
Marital Status			
	Never Married	4	2
	Divorced	1	3
	Married	24	19
	Widowed	0	5
Mean Age		52	68
Age Range			
	50 years or less	6	4
	51 - 70 years	17	10
	71 years or greater	6	15
Residence			
	Lives with Patient	21	NA
	Does not live w/ Patient	8	NA
Primary Study			
	Withdrew	NA	1
	Completed	NA	22
	Death	NA	6
Education			
	High School	4	NA
	Some college	14	NA
	Undergraduate	6	NA
	Graduate	4	NA
	Unknown	1	NA
Employment			
	None outside home	2	NA
	Full time	15	NA

TABLE 1 continued

	Part time	1	NA
	Retired	7	NA
	Missing data	4	NA
Relationship to patient			
	Spouse/partner	12	NA
	Adult child	12	NA
	Sibling	1	NA
	Parent	3	NA
	Other	1	NA

TABLE 2 - Themes and Sub-themes

1. CAREGIVER CENTRIC ISSUES

- 1.1. Functional Issues
- 1.2. Cognitive Issues
 - 1.2.1. Cognitive Pathology Issues
 - 1.2.2. Cognitive Literacy or Education Level Issues
- 1.3. Cultural Issues
 - 1.3.1. English as a Second Language
 - 1.3.2. Cultural and Ethnic Norms
- 1.4. Belief System Issues
 - 1.4.1. Religious, Ethical, and Moral Beliefs
 - 1.4.2. Mythical Beliefs
 - 1.4.3. Caregiver Fears
- 1.5. Caregiver Self-efficacy, Optimism, and Self-confidence
- 1.6. Duration & Extent of Caregiving and Proximity to Death
- 1.7. Previous Life Experiences
- 1.8. Concurrent Responsibilities

2. MEDICATION KNOWLEDGE

- 2.1. Pharmacologic Knowledge Issues
 - 2.1.1. Polypharmacy
 - 2.1.2. Side Effects of Pain Medication
- 2.2. Medication Administration Issues
- 2.3. Pain Assessment Issues
- 2.4. Personhood Issues

3. END OF LIFE SYMPTOM KNOWLEDGE ISSUES

- 3.1. Common EOL Symptom Management
- 3.2. Symptom Assessment Issues
- 3.3. Personhood Issues

4. TEAMWORK & COMMUNICATION ISSUES

- 4.1. Caregiver-Patient Issues
- 4.2. Caregiver-Healthcare Delivery System Issues
- 4.3. Caregiver- Family Issues
- 4.4. Caregiver Support Network

TABLE 2 continued

5. ORGANIZATIONAL SKILL ISSUES

5.1. Tracking and Recording Issues

5.2. Safely Issues

6. PATIENT CENTRIC ISSUES

6.1. Pain Assessment Congruency Issues

6.2. Psychological Well-being Issues

6.3. Nutrition and Hydration Issues

6.4. Inability to Verbalize Pain

6.5. Negative Existential View of Life and Negative Quality of Life

6.6. Patient's Belief System Issues

6.6.1. Patient's Mythical Beliefs

6.6.2. Patient's Religious, Ethical, or Moral Beliefs

6.6.3. Patient's Fears

TABLE 3 – Percentage of Sub-themes Identified by Caregivers Under the 6 Major Themes

<u>MAJOR THEMES</u>	<u>% of ISSUES</u>
CAREGIVER CENTRIC ISSUES	37%
MEDICATION KNOWLEDGE ISSUES	16%
EOL SYMPTOM KNOWLEDGE	11%
TEAMWORK & COMMUNICATION ISSUES	22%
ORGANIZATIONAL SKILLS	3%
PATIENT CENTRIC ISSUES	11%

TABLE 4 – Percentage of Caregivers Identifying Subthemes Under the 6 Major Themes

<u>MAJOR THEMES</u>	<u>% of CAREGIVERS</u>
CAREGIVER CENTRIC ISSUES	96%
MEDICATION KNOWLEDGE ISSUES	54%
EOL SYMPTOM KNOWLEDGE	12%
TEAMWORK & COMMUNICATION ISSUES	86%
ORGANIZATIONAL SKILLS	21%
PATIENT CENTRIC ISSUES	46%

TABLE 5 – Issue Frequency Comparison Between VP Group and F2F Group

MAJOR THEMES	% VP GROUP	% F2F GROUP
CAREGIVER CENTRIC ISSUES	31	42
MEDICATION KNOWLEDGE ISSUES	23	10
EOL SYMPTOM KNOWLEDGE ISSUES	10	11
TEAMWORK & COMMUNICATION ISSUES	20	24
ORGANIZATIONAL AND SAFETY ISSUES	5	2
PATIENT CENTRIC ISSUES	11	10

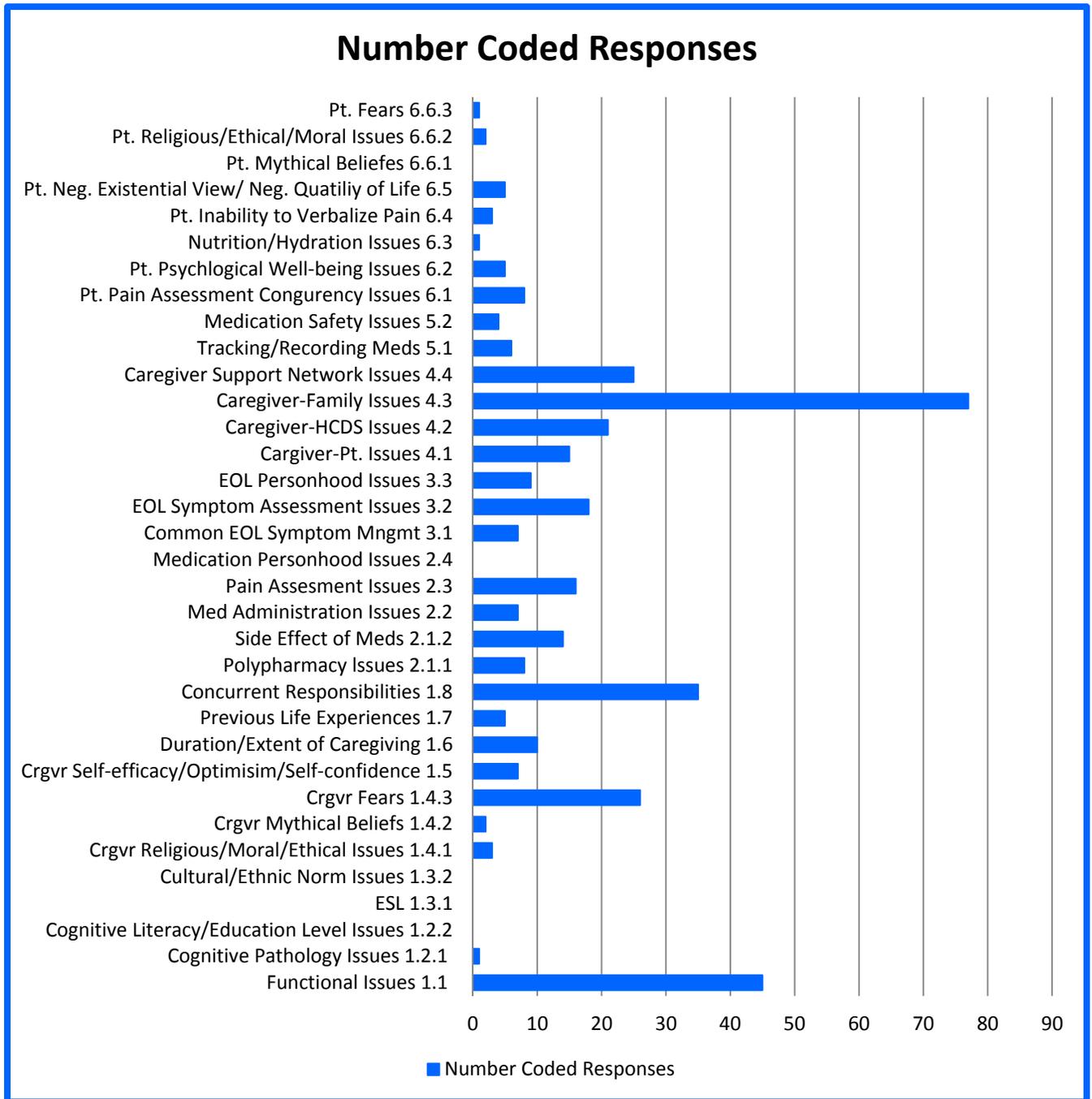


Figure 1 – Coded responses by Subtheme Issue

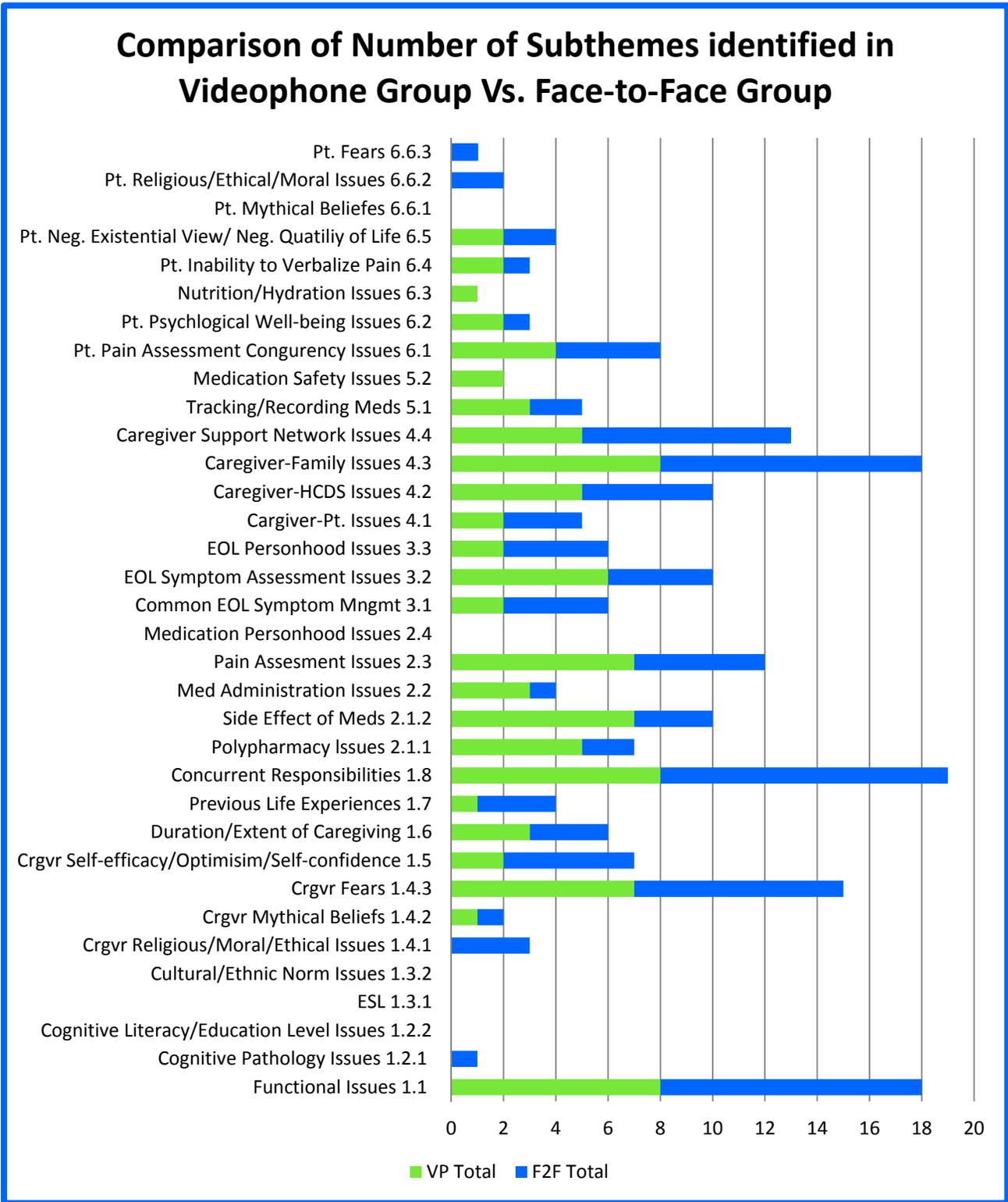


Figure 2 – Subtheme Comparison of VP to F2F

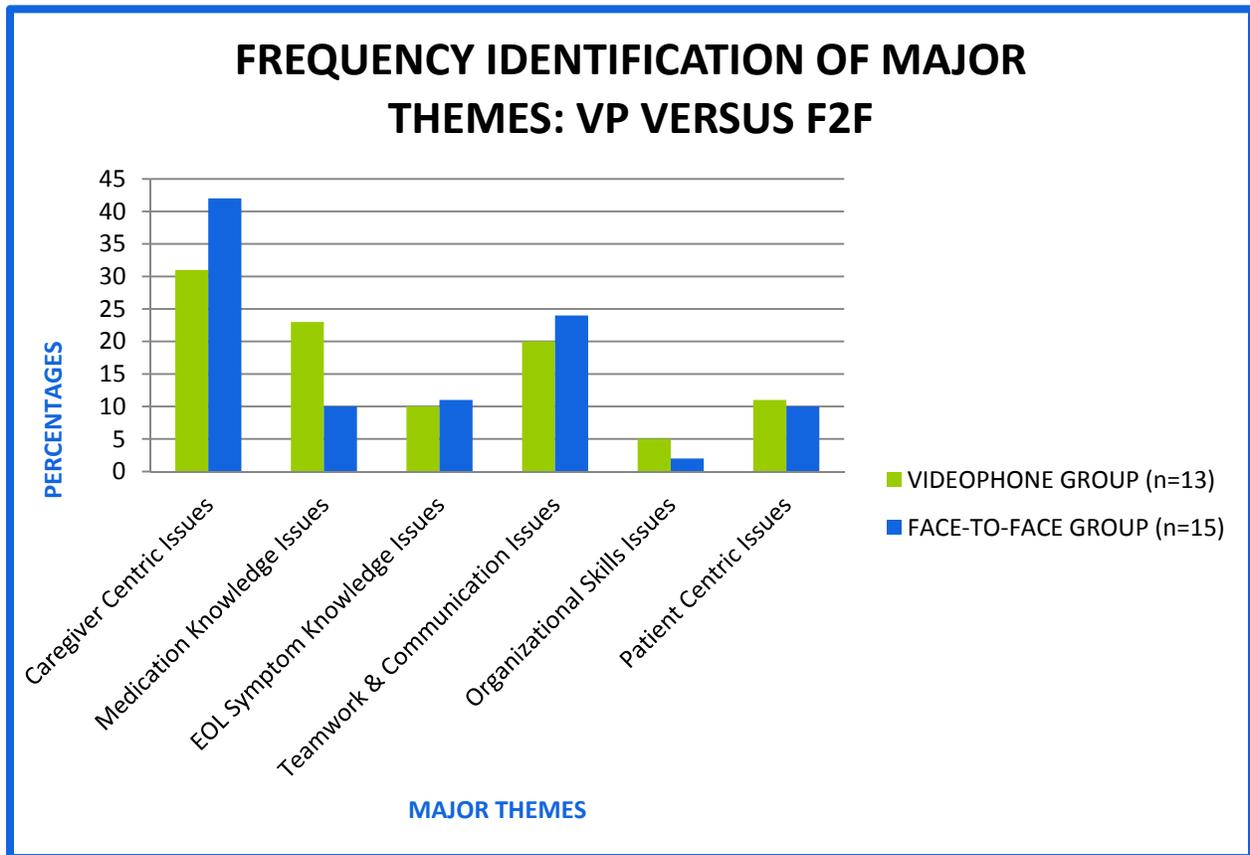


Figure 3 – Major Theme Identification by VP Group versus F2F Group

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Appendix A: Exit Interview

Did you find the problem solving intervention useful? (If so, why, how?)

Do you see any personal benefits for you resulting from this intervention?

What part did you like most about it?

Did you see any disadvantages or problems with the problem solving intervention?

Is problem solving training something that you think should become part of standard services of a hospice agency?

How would you rate your communication with the members of your hospice agency?

Do you think hospice services appropriately address your own needs and questions?

******Ask the following questions only of family members/caregivers of hospice patients**

residing in adult family homes:

How has your experience been with your [loved one] receiving hospice care while living in an adult family home (AFH)?

Have you experienced any problems since your [loved one] has been receiving hospice care while living in an adult family home? If so, how were they resolved?

Are there things that have gone well since your [loved one] has been receiving hospice care while living in an adult family home? If so, what?

How do you communicate with your [loved one's] health care providers?

(If probes are needed: How do you receive information about your [loved one's] care? Who is responsible for coordinating your [loved one's] care? How often do you receive information? How do your hospice providers work with the AFH caregivers?)

What advice would you give to someone else in your situation (i.e., with a family member living in an AFH while receiving hospice services)?

******Ask the following question of caregivers assigned to Group 2 (Videophone):**

We would like to get your feedback regarding the videophone you used to participate in this study. What did you think?

Appendix B: Codebook

Secondary Analysis of Caregiver Pain Management Issues during Telehospice versus In-person Interventions

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INTRODUCTION

A directed content analysis (Hsieh & Shannon, 2005) of data from a randomized, non-inferiority clinical trial (R21NR010744, G. Demiris, 2008-2010) was conducted to describe and compare pain management issues expressed by informal caregivers during end-of-life (EOL) care. Directed content analysis uses an existing construct or theory as a starting point, and then builds on that research to describe a phenomenon more completely. The goal of a directed approach is to validate or extend conceptually a theoretical framework, theory, or research. Existing research and theory help determine initial coding themes and relationships. Deductive category application is another term used to describe this process (Mayring, 2000).

For the proposed project, a construct described by Lau et al., (2009) identified initial themes associated with family caregivers and medication management for pain. Lau et al. (2010) extended the construct by including other factors influencing caregivers and medication management. Medication management is only one aspect of caregiver pain management during EOL care. Therefore, other themes were added after an extensive literature review.

For this literature review, electronic databases were searched including: MEDLINE, CINAHL, PsycINFO and Cochrane Database of Systematic Reviews. Terms searched singularly and in combination included: pain, pain management, cancer, palliative care, caregiver, family caregiver, informal caregiver, end-of-life, EOL, hospice, opioid, medication, and barriers. Following citations in articles, and snowballing identified other pertinent literature. Abstracts were reviewed and appropriate studies were examined in full for empirical rigor. Results were

initially searched from 1998 until present but snowballing revealed useful articles prior to 1990. The search was thus expanded to include articles from 1980 to present.

After the literature review was complete, themes identified by Lau et al. (2009), and Lau et al. (2010) were expanded to include consensus themes discovered in the literature review. Major themes and sub-themes were organized. The code book was then developed from the compilation of these themes and sub-themes. For study clarity, the concept of pain was viewed as being experienced in four distinct, yet often intersecting domains: physical, psychological, social, and spiritual (Berry & Paice, 2010; Paice & Ferrell, 2011; Selman et al, 2011).

The code book was organized by color for ease of reference. Major themes were identified in *red text* and sub-themes were identified in *blue text*. Descriptive examples (bulleted) and quotes (*in green*) were included under their respective theme or sub-theme. Items excluded from the theme were listed after the quote section. Additionally, a hyperlinked index was made available following the reference section for easy coder reference.

THEMES and SUB-THEMES

1 CAREGIVER CENTRIC ISSUES

Definition: This theme includes issues concerning the caregiver that might interfere with the caregiver's ability to manage, treat, assess, and attend to the patient's pain.

1.1 Functional Issues

(Lau et al., 2010; Kissane & Zaider, 2010; Paice & Ferrell, 2011)

Definition: This theme includes physical and psychological caregiver limitations, preventing caregivers from adequately managing patient's physical, psychological, social, and/or spiritual pain.

- Caregiver's physical ability to help patient change position in bed
- Eyesight issues – caregiver's inability to see and read medication labels
- Caregiver's inability to open a medication bottle due to arthritis
- Caregiver is experiencing physical pain which limits his/her functional ability to provide relief to their loved one
- Caregiver is experiencing physical and/or mental exhaustion
- Caregiver's depression, grief, or anxiety interfering with pain management (e.g. complicated grief)

1.1 Example:

“Liquid medication is particularly difficult to give. I can't see the tick marks on the dropper or the drops going under the tongue (Lau et al., 2010).”

“I averaged four hours of sleep...Last night, I dozed off, jumped up, and realized I forgot to give Mama her medications (Lau et al., 2010).”

Exclusions:

- This theme does not include caregivers with ADHD or attention disorders. Please see section 1.2.1 Cognitive Pathology Issues.
- This theme also excludes caregiver communication issues with the patient, family members, healthcare providers, or other healthcare agencies (Sections included under Teamwork and Communication Issues).

1.2 Cognitive Issues

(Lau et al., 2010; Lin et al, 2000)

Definition: This theme deals with issues of memory, language, thinking, and judgment. The theme includes normal age-related cognitive changes as well as any pathologic changes (Staff, 2011). It includes irreversible conditions that interfere with the caregiver’s abilities to think, plan, reason or understand. These issues hinder the caregiver in managing the patient’s pain. This theme does not include cognitive issues associated with fatigue or sleep deprivation.

1.2.1 Cognitive Pathology Issues

(Barry & Ward, 1995)

Definition: This theme includes age-related cognitive issues as well as disease-related cognitive issues making it difficult for caregivers to remember and address concerns of pain management for the patient.

- Caregivers with age-related cognitive issues might be unable to remember complex medication schedules or complex treatment instructions.
- Caregivers with early Alzheimer’s disease manifestations, memory issues, or brain injury (e.g. stroke, traumatic brain injury) affecting cognition would find it difficult to organize medications and remember when the next medication was due.
- Caregivers with ADHD or other attention deficit disorder that interfere with their ability to manage the patient’s pain.

1.2.1 Examples:

“Even if the nurse explained the information, I’d forget it later (Lau et al., 2010).”

“It is hard to remember what time to give the medicine (Letizia et al., 2004).”

“I’d like to know more about the tablets myself. Whether I could remember them, you see. I’d have to have them written down and described on a piece of paper, because the mind doesn’t absorb it all. I can take it in, but I forget about it (Oldham & Kristjanson, 2004).”

1.2.2 Cognitive Literacy or Education Level Issues

(Barry & Ward, 1995; Lau et al., 2010; Lin, 2000; Lin et al., 2000; Letizia et al., 2004; Mehta, Cohen, Carnevale, Ezer, & Ducharme, 2010; Schumacher et al., 2002; Smith, Francis, Gray, Denham, & Graffy, 2003)

Definition: This theme deals with caregiver’s formal education (or lack thereof) and how it may interfere with the ability of the caregiver to understand and manage pain.

- A caregiver that is unable to read and/or understand complex medical instructions (e.g. medication management instructions), would have difficulty balancing pain medication (opioid) side effects with patient’s increased opioid tolerance.
- A son with sever dyslexia, caring for his father, may have significant issues with measuring medication and calculating dosages.

1.2.2. Example:

“When the nurse talks about the ‘peak morphine levels’ and ‘medication interactions’, I just tune him out. I flunked out of 6th grade and never looked back. I never made it through high school.”

Exclusions:

- This theme does NOT include limited working knowledge of medications.
- This theme does NOT include limited working knowledge of EOL symptoms.
- This theme does NOT include issues related to ESL.
- This theme does NOT include issues related to lack of knowledge, only inability to cognitively attain, process, and use knowledge secondary to low literacy levels.

1.3 Cultural Issues

(Bullock, 2011; Kelley, Wenger, & Sarkisian, 2010; Kwak & Haley, 2005; Mitchell & Mitchell, 2009; Perkins, Geppert, Gonzales, Cortez & Hazuda, 2002)

Definition: This theme deals with issues that might interfere with a caregiver's ability to understand directions due to a language barrier which may negatively influence the caregiver's ability to manage the patient's pain. This theme also includes cultural or ethnic norms interfering with pain management.

1.3.1 English as a second language (ESL)

Definition: This theme includes the inability of the caregiver to communicate with the patient and/or hospice staff in written and/or verbal form due to a language barrier.

- Chinese caregivers trying to communicate with English speaking hospice provider may be unable to express patient's pain fully because of a language barrier. The patient may not receive adequate pain medication.
- Hispanic caregivers and patients for whom English is their second language find it difficult to find the English words to talk about EOL and pain, particularly if their interpreter is not always present.
- Caregiver's inability to speak the native healthcare community language.

1.3.1 Example:

"I am the only person in my family that can speak English. When I am at work, my sister cares for my mom but neither of them speaks English. They have difficulty trying to find an interpreter and then talking to hospice. They usually just wait for me to come home from work and then I call for more pain medicine or whatever."

1.3.2 Cultural and Ethnic Norms

(Kreling et al., 2010; Lin et al., 2000)

Definition: This theme includes cultural and ethnic norms or beliefs that might interfere in EOL pain management.

- A common Hispanic population perception of autonomy (e.g. we take care of our own) might prevent timely intervention or delay seeking help from hospice care providers.
- Some Asians and Latinos make decisions collectively within the family (family-centered decision making) which may interfere with timely medication administration due to inability to speak with all family members.
- Some Latino cultures do not talk about death. This interferes with caregiver's ability to "know" loved one's wishes.
- Many in the African American community view hospice as giving up, thus interfering with caregiver's ability to manage pain.

1.3.2. Examples:

One Latino woman and her five sisters made decisions for her mother. She said, "Talking about hospice (to her mother) was tricky. The last chemo she was feeling really, really bad, it just was brutal on her...we said Mom, we are going to stop treatment until you gain a little bit more weight...you can take the chemo again, we don't know how long it is going to be. And they (hospice staff) would use the badge that said palliative care. She didn't realize that she was having hospice care, no. I think that's probably because of what she and I had talked about way before during her first cancer that she just didn't want to know. And I think that's a pretty Latin American way of thinking (Kreling et al., 2010)."

From the Taiwanese culture - "It is more important for the doctor to focus on curing illness than to put time into controlling pain (Lin et al., 2000)."

1.4 Belief System Issues

(Ferrell, 2001; Ferrell et al., 1993; Ferrell et al., 2002; Redinbaugh et al., 2002; Taylor, Ferrel, Grant, & Cheyney, 1993)

Definition: This theme includes fears, myths, and religious beliefs that interfere with the caregiver's ability to manage pain.

1.4.1 Religious/ethical/moral beliefs

(Edrington et al., 2009; Ferrell et al., 2002; Lau et al., 2010; Lin et al., 2000; Taylor et al., 1993)

Definition – caregivers religious, ethical, or moral beliefs that are at odds with patient's wishes and/or hospice philosophy.

- Religious fatalism – Some Taiwanese family caregivers believe that pain has religious meaning and significance. These caregivers believe pain needs to be experienced for spiritual reasons (Lin et al., 2000). This may cause a caregiver to withhold pain treatments or medication, which is in direct contradiction to the hospice philosophy.
- The use of Palliative Sedation (the controlled induction of sedation, to the point of unconsciousness, to relieve severe refractory suffering from pain, dyspnea, seizures, etc.) may be interpreted by caregiver as assisted suicide (Krakauer & Quinn, Chapter 19.2, p. 1560). Although palliative sedation is controversial in the medical community, in some cases it may be warranted. However, if the caregiver is Catholic, the issue may create more concern as it may be viewed as assisted suicide.
- Other concerns including moral imperative, informed consent, principle of double effect, artificial nutrition/hydration, and legal issues common to hospice (comfort care only measures) but unknown or misunderstood by caregivers may create ethical dilemmas between caregivers, patients and hospice services (Krakauer & Quinn, Chapter 19.2, p. 1560-1568), and may interfere with pain relief for the patient. For example, a caregiver, with medical power of attorney, uses it as a reason to withhold medication for her dying mother, despite the fact that the mother is fully alert and oriented when not sedated. The caregiver is confused about the meaning of medical power of attorney.

1.4.1 Example:

“We only give medication when the pain is present, not on a regular schedule (Lin et al., 2000).”

1.4.2 Mythical beliefs

(Ferrell et al., 2003; Lin, Chou, Wu, Chang, & Lai, 2006; Lin et al., 2000; Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997; Wells, Hepworth, Murphy, Wujcik, & Johnson, 2003)

Definition: This theme includes beliefs by caregivers that they “feel” are correct or have been “told by friends” are correct but have no base of evidence.

- Caregiver believes pain medications should only be given when pain is severe.
- Caregiver believes treatments other than opioids are ineffective in controlling pain.
- Caregiver believes low doses of medication should be given first to save doses for when pain is worse.
- Fear that an increase in pain signals a progression of the disease and/or increased proximity to death
- Fatalism: Caregiver believes pain is inevitable at the end-of life
- Stoicism: Caregiver believes patient should be strong and tolerate discomfort without complaint.

1.4.2 Examples:

“It is not realistic to expect that pain can be controlled (Letizia et al., 2004).”

“People in pain should not complain about their pain (Letizia et al., 2004).”

Exclusion:

- This theme does NOT include conflicting beliefs due to conflicting advice given by healthcare providers.

1.4.3 Caregiver fears

(Ferrell et al., 2003; Kimberlin, Brushwood, Allen, Radson, & Wilson, 2004; Lau et al., 2009; Letizia, 2004; Oldham & Kristjanson, 2004; Paice, 2010; Paice et al., 1998)

Definition: This theme concerns caregivers’ fears and worries interfering with pain management.

These fears or worries may prevent caregivers from acting in a prudent, timely manner to relieve the patient’s pain.

- Fear of addiction and tolerance for the patient

- Fear of uncontrolled pain
- Fear that caregivers actions will hasten death
- Fear the process of death and dying
- Fear of discomfort of injection
- Fear of medication side effects
- Caregiver fears that they will die first and will be unable to address loved ones pain.

1.4.3 Examples:

“I am afraid of doing something wrong when I give the pain medication (Letizia et al., 2004).”

“It is dangerous if patients become addicted to pain medications (Parker Oliver et al., 2008).”

“Patients should take less than the prescribed dose to avoid side effects (Letizia et al., 2004).”

“And I worry about, as I told you before, I don't want to go before she goes. I don't want to leave her alone. I know our daughters would take over, but it is my commitment.”- S176

1.5 Caregiver Self-efficacy / Optimism / Self-confidence

(Lau et al., 2010; Mehta et al., 2010, Keefe et al., 2003; Porter, et al., 2002; Schultz & Beach, 1999; Yates et al, 2004)

Definition: Feelings of self-efficacy/optimism /self-confidence (faith in making decisions and overcoming fears; positive feelings about outcomes) correlate positively with caregiver’s ability to manage pain adequately. The converse is also true.

- Caregiver does not feel adequate in his/her ability to control patient’s pain. The caregiver becomes indecisive and unable to administer needed medications.
- Responsibility of around-the-clock medication becomes overwhelming for caregiver. The caregiver gives up and does not administer the medications.

1.5 Example:

“I’ve been taking care of my mom and my own kids...but I froze when [my mom] moved into my place [after hospice enrollment]...I started doubting myself with her medications (Lau et al., 2010).”

1.6 Duration & Extent of Caregiving and Proximity to Death

(Dumont et al., 2006; Grunfeld et al., 2004; Kris et al., 2006; Lau et al., 2010;)

Definition: Number of days, months, or years that caregiver has been providing care and number of days until patient's death.

- After months of stable caregiving, care requirements change as patient's death approaches. Caregiver's own grief increases and may interfere with pain management.

I.6 Example:

A nurse said, "I had a patient whose husband was so paralyzed by grief...he had to relinquish his caregiving responsibilities so he could be the husband again."

1.7 Previous Life Experiences

(Lau et al., 2010; Mehta et al., 2010)

Definition: Experiences or lack of experience of caregivers may interfere with pain management.

- Caregiver may have previously cared for a family member and the experience may have been negative thus increasing the caregiver's fears and anxieties.

1.8 Concurrent Responsibilities

Definition: Caregiver may have ongoing responsibilities that interfere with pain management or their ability to deal with patient's pain.

- Concurrent employment responsibilities may prevent adequate time to manage patient's pain.
- Financial responsibilities may prevent caregiver from affording treatments and medications for loved one.
- Family or dependent responsibilities may take time away from caregiving.
- Caregiving for another loved one may limit time for adequate pain management.

I.8. Example:

"When I have to clean up after my son or do housework, I can't keep a constant watch of my mom or give her medications always on time (Lau et al., 2010)."

2 CAREGIVER'S MEDICATION SKILLS AND KNOWLEDGE

(Lau et al., 2009; Vallerand et al., 2007; Keefe et al., 2005; Letizia et al., 2004; Ward, Berry, & Misiewicz et al., 1996; Wells et al., 2003)

2.1 Pharmacologic knowledge issues

(Lau et al., 2009; Vallerand et al., 2007; Ward et al., 1996; Yates et al., 2004)

Definition: This theme deals with the working knowledge of medications including:

pharmacology and basic understanding of how medications work, issues related to polypharmacy and drug interactions, side effects of medications, and assessments and outcomes of pain management therapy.

- Caregiver does not understand onset, peak effect and duration concepts for various opioid medication – potential for overdose or under-dose.
- Caregiver does not understand concept of brand name and generic name for same drug – drug confusion – under-dose or overdose potential.

2.1 Examples:

“It is hard to decide what amount of pain medication to give (Letizia et al., 2004).”

“The nurse called the drug Lorazepam and I didn't think I had it. It turned out to be Ativan but I didn't know there were two names.”

Exclusions:

- This theme does NOT include limited working knowledge of EOL symptoms.
- This theme does NOT include issues related to ESL.
- This theme does NOT include issues related to inability to cognitively attain, process, and use knowledge because of cognitive ability.

2.1.1 Polypharmacy Issues

(O'Mahony & O'Connor, 2011; Stevenson, Abernethy, Miller and Currow, 2004)

Definition: Complex interactions of medications and physiological changes at end of life may inhibit pain management.

- Caregivers are confused by too many medications and do not give the right drug for the correct symptom.
- Concurrent medications interfere with absorption and distribution as well as effect (pharmacokinetics and pharmacodynamics) of pain medication, and caregivers do not understand these complicated issues. They may inadvertently give medications that, when combined, cause harm to the kidneys or liver.

2.1.1 Example:

“It is hard to decide which medication to give (Letizia et al., 2004).”

2.1.2 Side Effects of Pain Medication

Definition: This theme deals with the side effects of pain medication. It includes the way side effects cause caregivers to change pain management.

- Opioids cause constipation. Some caregivers are unable to balance side effects with therapeutic action and may stop giving the opioid to treat the constipation, thus causing the patient more pain perhaps even the pain of withdrawal. The caregiver may be unaware that other alternatives are available to treat the constipation.

2.1.2. Examples:

“It is easier to put up with the pain than the side effects that come from the pain medication (Oliver et al., 2008).”

“So there are things that perhaps you should be told and will happen a lot. For example, if you're on a medication that can cause side effects, they don't tell you the side effects because the side effects do not necessarily occur in every person. And then, when the side effects do occur, what are you supposed to do? You don't know about it (Mehta et al., 2010).”

2.2 Medication Administration Issues

Definition: Caregivers inability to administer all forms of medication: pill, liquid, sublingual, transdermal in a safe manner.

- Caregiver crushes extended release tablet, which may cause overdose.
- 2.2 Example:

“Sometimes she chokes when I give it too fast. She cannot swallow easily now and it is scary when the liquid stays in her mouth (Letizia et al., 2004).”

2.3 Pain Assessment Issues

(Mehta et al., 2010; Redinbaugh et al., 2002; Vallerand et al., 2007; Yeager, Miaskowski, Dibble, & Wallhagen, 1995).

Definition: This theme deals with the caregivers lack of skills needed to assess pain adequately, treat pain, monitor the treatment, and then reassess pain to insure the desired outcome. This theme includes the caregiver’s inability to recognize and treat different types of pain including: breakthrough pain, chronic pain, acute pain, and neuropathic pain.

- Caregiver may not know the difference between how to treat breakthrough pain versus chronic pain.
- Caregivers do not have the ability to assess pain (Mehta et al., 2010; Redinbaugh et al., 2002). A caregiver does not use the 0-10 scale to assess pain and is unable to reassess after the pain medication is given. Caregivers have no way of knowing how long the pain medication works or if it works at all. Therefore, the patient may be under-medicated.
- Caregiver’s inability to make decisions about treating pain because of lack of knowledge (Brown & Stetz, 1999) causing under-treatment of pain.
- Caregiver’s inability to seek information and/or help with pain management (Mehta et al., 2010) from hospice or primary care providers may interfere with pain management. Caregivers may not even know what they need to ask, making pain management all the more challenging (Oliver et al., 2008).

2.3 Examples:

Caregiver comments on lack of knowledge of pain assessment and pain types, and what they do not know, “Practically everything because unless you’re aware of how to manage it [pain] you don’t know what there is to manage...you need the whole thing, you need to start from the beginning (Oldham & Kristjanson, 2004).”

“I don’t know anything. I’m just learning as we go along, you know (Oldham & Kristjanson, 2004).”

“When she’s really in pain she goes very, very white (Mehta et al., 2010).”

“I am sometimes confused about waiting for the patient to state there is pain versus consistently using the pain medication (Letizia et al., 2004).”

2.4 Personhood Issues

(Lau et al., 2010; Letizia et al., 2004)

Definition: This theme involves the ability to understand a patient’s wishes about medication management and the caregiver refusing to act in accordance with those wishes.

- A patient refuses to take medication (issues of non-compliance and medication refusal) but caregiver adds the medication to the patient’s food.
- A patient wishes to avoid all suffering through medication management but the caregiver worries about the patient being sedated all the time. Patient may be under-treated for pain.
- Caregiver expresses frustration and worry at patient’s refusal of pain or other medication (Letizia et al., 2004).

2.4 Examples:

“I am a nurse and I am always cautious about giving too much medication and decreasing the breathing capacity although I know that pain control is extremely important (Letizia et al., 2004).”

“Some of our family members are reluctant to give mom the medicine because they want mom to be alert (Letizia et al., 2004).”

“Well, I put it out...I’ll leave him sitting in a chair...I keep going back and going back. He won’t want to know, and I’ll scream, some days it could be as many as six times, I have to keep on. He would not take them himself, he would never think of taking them (Smith et al., 2002).”

“It’s hard for him [the patient] to accept his current state and relinquish independence...He refused his medications to take back control over his life (Lau et al., 2010).”

Exclusion:

- Does NOT include patient refusing food or water, or other treatments.

3 EOL SYMPTOM KNOWLEDGE ISSUES

(Lau et al., 2009)

Definition: This theme encompasses issues of common end-of- life symptoms or assessments which caregiver's misperceive as needing emergency treatment. This theme also includes caregivers inability to address any symptoms that may increase the patient's pain load. The four distinct, yet often intersecting domains which contribute to this suffering include: physical, psychological, social, and spiritual issues (Berry & Paice, 2010; Paice & Ferrell, 2011; Selman et al, 2011). Increased EOL symptoms may exacerbate any of these issues.

3.1 Common EOL Symptom Management

Definition: Expected events in hospice are not considered crisis by hospice personnel but may be perceived as such by caregivers. This theme is concerned with a caregiver's inability to respond to such events without anxiety and panic.

- A caregiver may consider patient's inability to clear secretions from throat during the active phase of dying as a medical emergency and calls 911 instead of the hospice nurse.
- Patient may be unable to identify the need to use the toilet. Caregivers may see this as a need for the patient to be hospitalized. Normal course of the disease is not considered a crisis by hospice but may be seen as such by the caregiver.

3.2 Symptom Assessment Issues

Definition: This theme deals with the caregivers lack of skills needed to assess symptoms adequately, treat symptoms, monitor the treatment, and then reassess symptoms to insure the desired outcome.

- Patient unable to move due to fatigue and caregiver does not know to turn patient every two hours to prevent pressure ulcers. This would add to the patient's pain load.
- Caregiver does not know to elevate the head of the bed to help patient breath and handle secretions.

3.2 Example:

“When mom started grinding her teeth, the hospice nurse asked if I had thought about giving my mom anti-anxiety medicine. It worked (Oldham & Kristjanson, 2004).”

Exclusion:

- This theme does NOT include assessing, monitoring, and interpreting pain.

3.3 Personhood Issues

Definition: The caregiver has the ability to understand the patient’s wishes but refuses to act in accordance with those wishes.

- A cognitively intact patient, suffering from stomach cancer, refuses to eat due to nausea, vomiting, and pain. The caregiver insists that the patient eat.

3.3 Example:

“I know he doesn’t want to eat and that it hurts when he does, but he just has to eat to stay strong.”

Exclusion:

- Does NOT include patient refusing pain medication.

4 TEAMWORK & COMMUNICATION ISSUES

(Lau et al., 2009; Lau et al., 2010; Steinhauser et al., 2000)

Definition: This theme deals with all issues surrounding teamwork and communication that may make pain management difficult for the caregiver.

4.1 Caregiver - Patient Issues

(Kimberlin et al., 2004; Lau et al., 2010; McCaffery & Pasero., 1999; Mehta et al., 2010).

Definition: This theme deals with the breakdown of interpersonal communication and teamwork between the patient and the caregiver. This breakdown in communication can negatively affect the ability of the caregiver to manage the patient's pain.

- The caregiver does not ask about the patient's pain (forgets or just does not think to ask), making assessment and treatment less than adequate.
- Caregiver has an adversarial relationship with the patient preventing good communication. Patient may not want to bother caregiver about pain medicine for fear of making caregiver angry.
- The caregiver's relationship is too close to the patient thus clouding judgment and ending in over-treatment or under-treatment of the patient's pain.
- Caregiver relationship is superficial and not therapeutic thus hindering pain management.
- Caregiver is a non-family member who may create issues with family members. Caregiver may not listen to patient's request, may listen only to family requests for pain management.

4.1. Example:

“Well, I put it out...I'll leave him sitting in a chair...I keep going back and going back. He won't want to know, and I'll scream, some days it could be as many as six times, I have to keep on. He would not take them himself, he would never think of taking them (Smith et al., 2002).”

4.2 Caregivers - Healthcare Delivery System Issues

(Mazanec et al., 2002; Mehta et al., 2010; Oliver et al., 2008; Oliver et al., 2010; Schumacher et al., 2002).

Definition: This theme addresses issues created when communication and teamwork breakdown between the caregiver and the hospice care team. This theme encompasses other parts of the healthcare delivery system including but not limited to: hired help, pharmacists and pharmacies, insurance companies, equipment delivery services, and others outside the family. This theme also includes issues associated with poor hospice provider care, which influences caregivers' ability to manage patient's pain. It also includes caregivers' inability to navigate the complexity of the healthcare delivery system.

- The caregiver does not discuss pain management issues with hospice, so hospice does not know to intervene. The patient may have their pain under-treated.
- The hospice provider (nursing staff) does not think to ask about pain management issues or offer information about pain management.
- The caregiver does not call hospice at night or in a timely manner because the caregiver does not understand the 24/7 nature of the service.
- Lack of insurance coverage or misunderstanding about coverage for special pain medications may delay pain relief.
- Limited availability of analgesics from various pharmacies may delay pain relief.
- Caregivers receive conflicting or incomplete information on pain management from different hospice providers
- Caregivers unable to attend scheduled appointments, arrange rides, and deal with insurance issues.
- Caregivers unable to afford medication or treatment

4.2 Example:

“I did not want to bother the nurses at night.”

“I really didn't pay attention to when the pain started or what was going on around that time.”

“My wife administered the pain medication without letting me know. My dad (hospice patient) got a double dose.”

“I’m learning now that the doctors and the nurses are really in a hurry most of the time, so you’re just getting snatches of information, when you can catch them (Schumacher et al., 2002).”

“I kept asking but hospice was not straight forward in telling me the symptoms to expect. They might think they were trying to protect me but instead I felt ill prepared.”

“I don’t know how we’re gonna get that (his pain scores) changed because we really haven’t got the money to change this thing and now we’ve burned up our allotted year. So I just don’t know what the hell we’re gonna do. A guy can say you should take this and you should take that, but if you haven’t got the money to get it, that’s trouble (Schumacher et al., 2002).”

“I didn’t know what to do when the doctor’s orders didn’t match the increments on the eyedropper (Letizia et al., 2004).”

4.3 Caregiver - Family Issues

Definition: This theme deals with conflict in communication and teamwork between and among family members and caregivers. It also deals with psychological pain that family members may be experiencing which demand the primary caregiver’s attention and time, thus diminishing time for patient and pain management.

- Caregiver (mother) spending time trying to protect daughter from psychological pain of watching her father’s (husband) physically decline and death. Caregiver able to meet daughter’s needs but not the dying patient’s needs.
- Long standing family conflicts interfere with pain management especially when everyone wants to be in charge or has an opinion about the pain management.
- Family members unable to support caregiver with respite relief or other emotion and psychological support. Interference may in fact make the job of caregiving more difficult.

4.3 Example:

“Certain family members are making it difficult because they are concerned about ‘dope’. I am unhappy about being accused of keeping my dad ‘doped up’ (Letizia et al., 2004).”

Exclusion:

- Does NOT include communication breakdowns between family members and NON-family caregivers (hired caregivers).

4.4 Caregiver Support Network Issues

(Lau et al., 2010)

Definition: This theme addresses the caregivers need for a support network. Without such, caregiver strain and stress can negatively affect the caregiver’s ability to manage patient pain.

- Caregiver lacks support of social friendships thus increasing the stress of the caregiver role.
- Caregiver lacks community engagement and is unable to find time to break away from the role and engage in other activities to maintain mental health. Caregiver starts to make medication errors because of the stress.
- Respite care, in the community, is unavailable to the caregiver. Therefore, the caregiver never gets a break from the job of caregiving and suffers anxiety attacks. Under such stress, the caregiver can no longer care for the patient, much less manage medications.

4.4 Example:

“It is hard because I am alone most of the time (Letizia et al., 2004).”

Exclusion:

- Does NOT include support from family members (see 4.3 Caregiver-Family Issues).

5 ORGANIZATIONAL SKILL ISSUES

(Lau et al., 2009)

5.1 Tracking and Recording Issues

Definition: This theme is concerned with caregiver's lack of organizational skills, which may cause problems with patient pain management. It includes tracking and recording treatments, assessments, medications, and outcomes.

Caregiver cannot recall when last dose of long-acting opioid was given, because he/she forgot or did not write it down.

5.1 Examples:

"It is hard to remember what time to give the drug (Letizia et al., 2004)."

"We ran out of pills before it was time to refill."

5.2 Safety Issues

Definition: This theme addresses caregiver's inability to safely store and discard medication.

This theme includes medications being stolen, abused, misused, or available to children. It also includes equipment, such as syringes, not being safely disposed of or stored.

- Medications are located at patient's bedside and small children are in the home.
- Opioid patches are thrown in the trash.
- Used needles are not securely stored and disposed of via medical hazardous waste rules and regulations.
- Medication use by other than the intended patient

5.2. Example:

"When the patient is throwing up it is hard to figure out where you can find the drugs."

6 PATIENT-CENTRIC PHYSICAL AND PSYCHOLOGICAL PAIN ISSUES

(Lau et al., 2010; Krakauer & Quinn, 2010).

Definition: This theme deals with the patient's total pain also known as the pain load. Pain and suffering occur in four distinct yet intersecting domains: physical, psychological, social, and spiritual (Berry & Paice, 2010; Paice & Ferrell, 2011; Selman et al, 2011). This theme also includes fears, myths, and religious beliefs that affect the patient's pain management.

Additionally, this theme includes the patient's assessment and perception of his/her pain and other issues that may potentiate the pain experience in the above four domains.

5.3 Pain Assessment Congruency Issues

(Dar, Beach, Barden, & Cleeland, 1992; Elliott, Elliott, Murray, Braun, & Johnson, 1996; McCaffery et al., 1999; McMillan & Moody, 2003; Miaskowski et al., 1997; Redinbaugh et al., 2002; Riley-Doucet, 2005).

Definition: This theme deals with the caregiver either under-estimating or over estimating pain as the patient perceives it. For a variety of reasons, the caregiver and the patient do not perceive the patient's pain the same way thus creating incongruences.

- Caregiver only gives medicine when patient says the pain is “really bad” because caregiver thinks that this is only mild pain. Caregiver does not understand the hospice concept of the gold standard of pain – pain is whatever the patient says it is.
- The patient hides pain making it difficult for the caregiver to manage the pain.

6.1. Examples:

“Sometimes, it is difficult to know if my dad is in pain because he often tries to hide it (Letizia et al., 2004).”

5.4 Psychological Well-being Issues

(Keefe et al., 2003; Miaskowski et al., 1997; Redinbaugh et al., 2002)

Definition: This theme deals with the patient's psychological health. Patients who are dealing with psychological issues of death and dying, psychological components of physical pain, and psychological pain are included in this theme. Negative psychological well-being may cloud the patient's ability to report pain, and respond to pain management. Additionally, negative psychological well-being can be caused by psychological pain alone.

- A patient is depressed and experiencing psychological pain. Because of the depression, both psychological and physical pain gets under-reported.
- Depressed patients may have altered responses to pain and pain medication, making it difficult for caregivers to manage the pain.

5.5 Nutrition and Hydration Issues

(Miaskowski et al., 1997; Redinbaugh et al., 2002)

Definition: This theme has to do with the physical consequences of malnutrition and dehydration and the interaction of these factors in pain management. It includes fatigue, decreased BMI and overall wasting as well as other physiological markers. These factors negatively affect pain management from a physiological standpoint including: 1) altered absorption, metabolism, and excretion of medication, 2) different pharmacodynamics and pharmacokinetics, and 3) different drug interactions and side effects.

- A malnourished and dehydrated patient is experiencing fatigue, which may decrease his pain tolerance.
- Malnourished patient may have altered responses to pain medication due to decreased body fat and decreased protein binding.

5.6 Inability to Verbalize Pain

(Mazanec et al., 2002)

Definition: This patient centered theme describes patient's inability to verbalize pain to the caregiver. This theme impedes pain management because of the inability of the caregiver to assess and manage the patient's pain.

- Patient is cognitively impaired and unable to report pain. The caregiver has to rely on non-verbal cues to manage pain. The caregiver may or may not be skilled in this type of assessment. If not the patient's pain will be under-treated.

5.7 Negative Existential View of Life or Negative Quality of Life

(Miaskowski et al., 1997; Redinbaugh et al., 2002)

Definition: This theme concerns the patient negative view of his or her overall life as well as the current daily quality of life. This theme also encompasses social and spiritual pain loads.

- A patient may be unable to interact socially with family and friends because of constant pain. This lack of social interaction may increase pain management needs.
- The patient may be filled with regrets and disappointments about his/her life experience. It may be difficult for the patient to initiate conversations with others about these things, causing distress. Caregivers who love these patients, perceive this distress, and attribute it to pain. Thus, the patient may be over-medicated.
- Patient is quiet and does not want to reflect on the past. Doesn't initiate conversations about his or her life journey.

6.5 Example:

“Sometimes my dad said hurtful things to me but he might be upset with the world... (Lau et al., 2010).”

5.8 Patient's Belief System Issues

Definition: This theme includes the patient's fears, myths, and religious beliefs that interfere with pain management.

5.8.1 Patient's Mythical beliefs

(Ferrell et al., 1997; Ferrell et al., 2003; Miaskowski et al., 1997; Riley-Doucet, 2005; Wells et al., 2003)

Definition: This theme includes beliefs that are untrue or in direct contradiction to hospice philosophy. These beliefs interfere in the ability of caregivers to manage the patient's pain adequately.

- Patient believes pain medications should only be given when pain is severe.
- Patient believes treatments other than opioids are ineffective in controlling pain.
- Patient believes low doses of medication should be given first to save doses for when pain is worse.
- Fatalism: Patient believes pain is inevitable at the end-of life
- Stoicism: Patient believes he/she should be strong and tolerate discomfort without complaint.

6.6.1 Examples:

"Sometimes, it is difficult to know if my dad is in pain because he often tries to hide it (Letizia et al., 2004)."

"People in pain should not complain (Letizia et al., 2004)."

"It is not realistic to expect that pain can be controlled (Letizia et al., 2004)."

5.8.2 Patient's Religious, Ethical, or Moral Beliefs

(Ferrell et al., 2002; Lau et al., 2010; Lin et al., 2000; Taylor et al., 1993)

Definition: This theme deals with the patient's religious, ethical, or moral beliefs that are at odds with caregiver or family wishes and/or hospice philosophy.

- Religious fatalism – the belief that pain has religious meaning and significance and needs to be experienced for spiritual reasons. This may cause a patient to refuse pain treatments.
- Patients may interpret the use of Palliative Sedation (the controlled induction of sedation, to the point of unconsciousness, to relieve severe refractory suffering from pain, dyspnea, seizures, etc.) as assisted suicide (Krakauer & Quinn, Chapter 19.2, p. 1560). See Caregiver Beliefs above.
- Other concerns including Moral Imperative, Informed Consent, Principle of Double Effect, artificial nutrition/hydration, and legal issues common to hospice but unknown or misunderstood by patients may create ethical dilemmas between caregivers, patients, and hospice services (Krakauer & Quinn, Chapter 19.2, p. 1560-1568).

5.8.3 Patient's Fears

(Ferrell et al., 1997; Ferrell et al., 2003; Lau et al., 2009; Paice et al., 1998)

Definition: This theme deals with issues that patient's fear surrounding EOL and may interfere with pain management.

- Fear of addiction and/tolerance prevents patient from taking medication around the clock.
- Fear of pain increases the patient's anxiety making physical pain worse.
- Fear that caregivers actions or medication will hasten death
- Fear the process of death and dying

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