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Identification of Depressive Signs in Patients and Their Family Members During iPad-based Audiovisual Sessions

Carol E. Smith, PhD, RN* [Professor],

School of Nursing and Preventive Medicine & Public Health, University of Kansas Medical Center,
Mail-stop 4043, 3901 Rainbow Blvd., Kansas City, KS 66160-2033

Marilyn Werkowitch, BSN, RN,

School of Nursing, University of Kansas Medical Center

Donna Macan Yadrich, BS, MPA [Interventionist],

School of Nursing, University of Kansas Medical Center

Noreen Thompson, MSN, RN,

Psychiatric Nurse Specialist, University of Kansas Medical Center

Eve-Lynn Nelson, PhD [Professor]

Pediatrics, School of Medicine Director, KU Center for Telemedicine University of Kansas Medical Center

Abstract

Home parenteral nutrition requires a daily life-sustaining intravenous infusion over 12 hours. The daily intravenous infusion home care procedures are stringent, time-consuming tasks for patients and family caregivers who often experience depression. The purposes of this study were: (1) to assess home parenteral nutrition patients and caregivers for depression, and (2) to assess whether depressive signs can be seen during audiovisual discussion sessions using an Apple iPad Mini. In a clinical trial (N = 126), a subsample of 21 participants (16.7%) had depressive symptoms. Of those with depression, 13 were home parenteral nutrition patients and eight were family caregivers; ages ranged from 20 to 79 years (with M = 48.9 years; SD = 17.37); 76.2% were female. Individual assessments by the mental health nurse found factors related to depressive symptoms across all 21. A different nurse observed participants for signs of depression when viewing the videotapes of the discussion sessions on audiovisual technology. Conclusions are that depression questionnaires, individual assessment, and observation using audiovisual technology can identify depressive symptoms. Considering the growing provision of health care at a distance, via technology, recommendations are to observe and assess for known signs and symptoms of depression during all audiovisual interactions.

Keywords

distance health care; tablet audiovisual assessment; depression; home parenteral nutrition

*Primary Corresponding Author 913 588 1667, Fax 913 588-1660, csmith@kumc.edu.

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Introduction

Patients with chronic illness experience depression at a greater rate than the general population. Depression is identified by clinicians as episodes of extreme low moods. The signs and symptoms of depression most often include persistent sadness, anxiety, restlessness, irritability, or “blue” mood. The individual may experience feelings of hopelessness, pessimism, guilt, worthlessness, helplessness, or loss of interest or pleasure in hobbies and activities. Such feelings and symptoms can interfere with adherence to chronic illness management, contribute to denial of worsening illness, and even lead to thoughts of suicide.

Depression episodes are known to recur often when an individual has a serious medical illness, with symptoms lasting for 2 weeks or repeating over time. Depressed individuals may report decreased energy or fatigue, difficulty concentrating or sleeping, appetite changes, and thoughts of death or suicide. Any thoughts of death or suicide must be taken seriously and treatment sought.

This study included patients with chronic illness with severe malnutrition due to short bowel disease who require home parenteral nutrition (HPN), a life-sustaining intravenous (IV) infusion that provides nourishment and hydration.¹ Causes of bowel dysfunction vary, but all short bowel disease patients requiring life-long nutrition infusions have common disease characteristics. All patients with short bowel diseases which result in HPN treatment must meet criteria in terms of the length of functional bowel lost, dysfunctional valves in the bowel, laboratory evidence of electrolyte and fluid loss, extreme frailty, and a family member caregiver at home to assist with the infusions.

While HPN treatment has extended patient survival by 15 to 30 years, the stringent IV home care regimen requires significant daily efforts by the patient and family caregiver,² including twice-daily aseptic IV procedures and 12-hour infusions at home, usually during nighttime hours with frequent awakenings from IV pump noises, equipment alarms, and nocturia.^{3–7} The daily IV infusion schedule throughout the night results in sleep disruption, fewer social activities, and episodes of depression. The stress of the cognitive complexity of daily IV infusion procedures, HPN home-care problem management, and coordinating services across multiple professionals may also result in flat or negative mood and anhedonia.^{8–9}

Patients also report they get depressed due to worry over their ostomy care,^{10–11} HPN associated adverse events, and being stigmatized for their frail appearance and for their restricted ability to eat in social gatherings.^{12–15} Home parenteral nutrition patients and their family caregivers experience disrupted social activities, inability to work, and lack of interactions with others who have the same illness.^{16–17} Patients and their families also face daunting out-of-pocket expenses for insurance premiums and copayments,¹⁸ IV medications and supplies, as well as repeated hospital admissions.^{19–22} Olver and Hopwood²³ and other researchers conclude that depression among patients with chronic illness leads to decreased medical regimen adherence, increased medical morbidity and mortality, and increased functional disability.^{24–30} Pharmacologic treatment for depression may be problematic for some patients with chronic illness, and it is particularly challenging for patients with short

bowel disease because intestinal absorption of any oral medication is not tolerated.³¹ Transdermal depression medication patches may be prescribed and behavioral therapies have been found to be successful.^{32–33}

Assessment is a challenge with patients who require HPN because both bowel disease and depression can share common symptoms such as loss of energy, fatigue, poor appetite, and sleep disturbances.^{34–36} These symptoms, as well as negative thinking and impaired attention, may be present in both depression and grief reactions.^{37–40} Measuring and observing for depression in patients with chronic bowel disease is essential to help them maintain their ability to manage, adhere to, and troubleshoot their complex HPN infusion procedures.

The innovative approach taken in this study used Apple iPad technology (Apple, Cupertino, CA) to connect patients who require HPN and family caregivers at home with health professionals in their offices for videoconference discussions and assessments. This approach has advantages of decreasing the need for patient and family travel and exposure to infection risks in clinical agencies, as well as affording access to health professionals from a distance.

Purpose

The purposes of this study were to: (1) assess patients who require HPN and their family caregivers for depressive symptoms using a validated depression screening questionnaire and an individual assessment by a mental health nurse specialist; and (2) to assess whether participants' depressive signs can be observed during iPad audiovisual discussions among patients, their family members, and professionals. These discussion sessions were held so that participants could interact with other patients and family members having similar illnesses and IV challenges.

Methods

This study is a subset of a larger clinical trial that has been completed. Following Institutional Review Board (IRB) approval of all study procedures, consenting participants (patients who require HPN and their family caregivers) were enrolled. To control for heterogeneity of the sample, inclusion criteria were: (1) adult patients on HPN for short bowel disorders (not for malignant disease), and (2) who were sustaining calorie and micronutrient load for survival. Family caregivers included were involved in providing HPN care. Also, all participants were 18 years or older, alert and oriented, and able to read and write English and provide informed consent. Participants were enrolled regardless of socioeconomic status, ethnic background, or gender.

Participants were loaned a wireless Apple iPad Mini tablet computer to be used for the iPad audiovisual discussion sessions. Each iPad had a touch screen with a 5-megapixel camera. Each tablet had a fourth generation mobile telecommunications (4G) data plan for connection. These iPads allowed for audiovisual teleconferencing using Polycom Real software (Polycom, San Jose, CA) for encrypted connections between health professionals in their offices and study participants in their homes.

iPad Audiovisual Sessions

The iPad sessions incorporated strategies found effective in our previous clinical trials. Four multidisciplinary health professionals were present at each session: a licensed psychologist, a mental health clinical nurse specialist, an administrative counselor, and a telemedicine specialist for technical assistance if needed. During the iPad discussion, the counselor functioned as the primary facilitator, the psychologist and mental health nurse provided group counseling specific to patient needs, and all participants were given HPN care information. During each session, the staff encouraged participants to raise concerns and to share what had and had not been successful for HPN care. All participants were encouraged to contribute and to ask questions.

When leading discussions on HPN care information, the multidisciplinary staff adhered to the facilitator role, encouraging input from participants. To facilitate, trained staff were familiar with a variety of motivational counseling techniques such as reflective listening, use of open-ended questions, summarizing, and redirecting questions back to participants for problem solving. As needed, the facilitator and the other health professionals provided guidance if the group reached an impasse. This included correction of any misinformation, reinforcement of problem-solving skills, nonjudgmental promotion of information sharing, and encouraging discussion with primary care providers.

The primary facilitator began each meeting with introductions of the professional staff and study participants. Patients were reminded that they were not required to share any private health information during these sessions. If patients had questions that they preferred to discuss in private with the staff, they were asked to arrange a separate appointment. Each iPad appointment was prescheduled for 1 ½ hours, with the average lasting 56 minutes.

Sample

All the enrolled participants who required HPN underwent lifelong daily IV infusions due to short bowel disease. These patients and their family caregivers cope with complex HPN care procedures and side effects, restricted social activities, fatigue, and loss of sleep. In this study, 21 participants had elevated depression questionnaire screening scores, of which 13 were patients who required HPN and eight were family caregivers. Of the 21, just over three-quarters (76.2%) were female, and ages ranged from 20 to 79 years ($M=48.9$ years; $SD=17.37$). All were married with middle to low household incomes. All had completed high school, and 15 had completed college.

Procedures

Each participant completed the Patient Health Questionnaire (PHQ-9) for depression screening prior to the iPad sessions.⁴¹ This screening tool has been validated for identifying symptoms of depression.⁴² Within 1 week, an experienced mental health specialist (nurse A) conducted a clinical assessment of the 21 participants who had a depression score. Nurse A took extensive notes during her assessment and confirmed the presence of depressive symptoms.⁴³ Complete assessment notes for all participants were recorded, and content analysis was conducted on these notes to summarize the factors that were reported as

contributing to depression. Content analysis is an inductive approach used to generate new understanding by categorizing similar factors based on participants' spoken responses.

To evaluate whether depressive symptoms and signs can be observed in the iPad sessions, a second nurse (B) not involved in this study or in attendance at the iPad sessions reviewed a videotape of each discussion. Nurse B did not provide care for any of the participants in the study, but she had experience with other families managing HPN care. Nurse B was trained to identify depressive symptoms or exhibition of depressive signs that she observed in the videotapes. Participants also evaluated each iPad session anonymously.

Patient Health Questionnaire-9.—Due to its established psychometrics, the Patient Health Questionnaire-9 (PHQ-9) is among the most widely used depression screening questionnaires.^{44–45} This instrument was developed from the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria for depressive disorders. This instrument was administered at baseline prior to the iPad discussion sessions. The PHQ-9 was found reliable in this study and had a Cronbach's alpha of 0.90, indicating strong internal consistency.

Data Analysis Methods

Questionnaire Scoring.—The PHQ-9 instrument "Instructions for Use" was followed, and all participants with a PHQ-9 score indicating depressive symptoms were assessed by mental health specialist nurse A.

Visual Observation Methods.—A master's prepared nurse (B) external to the study team reviewed the videotapes of each iPad group session (average of 56 minutes each). This nurse was not involved in the videoconferencing discussion sessions but did have experience working with HPN patients. Nurse B used pre-established observable signs of depression in medically ill populations, including poor eye contact; limited interactions/verbalizations or engagement in the discussion; lack of responses to direct questions; sad or flat facial expressions or affect; appearance of inattention or restlessness; sharing worries or apathy; expressing feeling blue or describing low moods; expressing anger or irritability. If it was unclear whether an observation was a depressive sign, that videotaped segment was noted and a second chronic illness expert was consulted to clarify the observation. The nurse tabulated the participants with observable depressive signs.

Results

Participant Evaluation of the iPad Sessions

On the anonymous Evaluation of iPad Sessions the participants rated being highly satisfied (average 4.0 on a 1 to 5 scale) with each group session. Several patients wrote additional comments, such as that the iPad was the best way to learn how to cope with and manage their complex daily 12-hour HPN infusions and work with their physicians. Notably, patients used the iPads to send encrypted photos of their inflamed and potentially infected IV sites and leaking bowel fistulas to their physicians to obtain treatment without distant travel to a specialist's office. iPads were also used for tracking medications, supplies, and lab results.

The participants indicated that they were willing to pay \$25 to 50 for iPad sessions even if insurance would not cover this fee. The iPad sessions were free of charge during the study.

Patient Depression Questionnaire Scores

In the clinical trial study, 21 participants or 16.7% had elevated PHQ-9 scores indicating that they had depressive symptoms. Five of the 21 participants (three patients and two family caregivers) had PHQ-9 scores indicating a moderate level of depression; the remainder had mild depression scores.

Content Analysis of the Mental Health Nurse Specialist Assessment Notes

Based on content analyses of the clinical assessment data collected by the mental health specialist, five categories of factors associated with participants' depression were named. The participants' own words and direct quotes substantiated these mutually exclusive categories of factors. The five categories included: (1) bowel disease (i.e., "chronic abdomen pain is depressing me," "feeling down about all the details required in my day-to-day care," and one patient revealed psychiatric illness episodes related to his bowel disease); (2) grief (i.e., "ongoing grief related to living with my body and its demands," "loss of relationships," "death of family member"); (3) coping with illness and HPN care (i.e., "I miss out on many social activities," "working hard to deal with how much HPN changed my life," "difficult to go from my independent lifestyle to being a dependent adult living with parents"); (4) financial worries (i.e., "not being able to work," "loss of disability payment," "money is major stress in our lives"); and (5) fatigue (i.e., "chronically fatigued," "can't work, too much fatigue," "can't sleep due to ostomy drainage"). Of the 21 assessments, six participants (five HPN patients and one caregiver) described their depression-related factors as severe, and they related this to their confining 12-hour daily infusions or to chronic gastrointestinal pain. These six were referred for further mental health care. All participants were counseled in managing the specific factors they related to their depression.

Visual Observation of Depressive Signs

During the review of the videotaped iPad sessions, the observer of the sessions (nurse B), identified nine participants as displaying depressive behaviors. These behaviors included crying, sad affect, expressing worry or lack of engagement in the discussions, and anger which is common in depression. Depression-related signs observed were lack of response to questions, slouching posture, little eye contact, and withdrawn appearance. When participants displayed these behaviors, the facilitating interventionists at the sessions asked participants how they were feeling. The responses ranged from, "Daily life is too stressful; no one can really make this go away," to "Why did this happen to me?" Five of these nine participants also stated that their behaviors were related to feeling depression, the blues, or low moods. Nine is almost half of the 21 participants with depression scores on the PHQ-9. Thus, as seen clinically, signs or symptoms of depression are not always observable.

Discussion

The study findings support the conclusion that depressive symptoms in patients who require HPN and family caregivers could successfully be identified through the use of a validated

questionnaire, a nurse specialist assessment, and observations during iPad discussions. Of this total sample of 21 participants, 16.7% were identified as depressed on the screening questionnaire, which is higher than the 7–10% found in the general population. When individually assessed or asked in group discussions, most patients indicated that their depressive symptoms were related to their bowel disease and coping with the complex IV care, although other factors were identified.^{46–48} The research team members and the nurse (B) who reviewed the videotaped sessions all agreed that depressive signs were readily observed during the iPad videoconferences. Yet fewer than half of the participants who screened positive for depression were observed to have depressive signs in the iPad discussion sessions. It is not uncommon for patients to not express their depressive feelings or show signs during interactions with others. Professionals need to be cognizant that depression is not always observable, and thus a combination of questionnaire, nurse assessment, and observation in any iPad interaction is essential to pick up depressive signs.

These findings aligned with our previous studies, in which the mental health nurse specialist assessments identified depressive symptoms as well as other significant disease-related factors such as fatigue and difficulty coping with complicated home care.⁴⁹ Individual nurse assessments successfully distinguished factors associated with grief responses, illness adjustment reactions, and debilitating fatigue. Grief over loss of life activities (e.g., employment, sports, and hobbies, or having energy to help others) was common. Difficulty adjusting to the complex daily IV procedures and fatigue were found in both patients and family caregivers. Several HPN patients expressed worry related to family members' hypervigilance in monitoring their illness. Yet, in contrast, another patient worried about the lack of enough back-up support for their HPN procedures.

For patients with chronic illnesses such as short bowel disorders and their family caregivers, screening and assessment for depressive symptoms is imperative as depression often interferes with home self-management and is associated with poor outcomes. Assessing for the factors related to each participant's symptoms allows use of specific interventions to address them. During home telehealth or other iPad interactions, health professionals are encouraged to be alert to visual indicators of the patient's depression, to listen for verbalizations of negative thoughts, and to ask about depressive symptoms.

Implications for Clinical Practice

Because of the complex, technical caregiving demanded for IV infusion home care, clinicians and other healthcare professionals must routinely assess patients and family caregivers for depressive symptoms. Any patients observed to have poor affect or moderately severe to severe depression scores according to screening instruments should be referred to a mental health professional for further assessment to avoid complications in the management of home care for their chronic illness. Routine reporting of any negative psychosocial signs or depressive symptoms should also be shared with the patient's primary care physician and/or a mental health specialist.

Conclusion and Future Directions

As audiovisual interactions on technology devices continue to expand in the future, professionals need training in how to observe for signs of poor affect and depressive behaviors. Videoconferencing can support this assessment at a distance. Considering the anticipated increase⁵⁰ in delivery of individual and group counselling services using technology, further research is needed. Such studies should include how to assess verbal and nonverbal behaviors during audiovisual discussions to gain a better understanding of how professionals can best identify those needing mental healthcare services. Future research needs to address how iPad videoconferencing can be used to its full potential to support the challenges of families managing complex home care.

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Conflicts of Interest and Source of Funding

The authors do not have personal financial interests related to the subject matter discussed in the manuscript.

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