

# Demoralization in medical illness: Feasibility and acceptability of a pilot educational intervention for inpatient oncology nurses

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(RECEIVED December 30, 2016; ACCEPTED June 21, 2017)

## ABSTRACT

*Objective:* Demoralization is a common problem among medical inpatients with such serious health problems as cancer. An awareness of this syndrome, a knowledge of what defines it, and a plan for how to intervene are limited among nursing teams. Nurses are uniquely poised to efficiently provide brief interventions that address demoralization in their patients. To our knowledge, there are no interventions that train nurses to distinguish and treat demoralization in their patients. The objective of the present study was to determine the acceptability, feasibility, and impact of a novel educational intervention for nurses.

*Method:* An educational training video was created and delivered to staff nurses ( $N = 31$ ) at oncology staff meetings to test the feasibility and acceptability of this intervention. Assessments of nurses' knowledge about demoralization and intervention methods were administered immediately before and after the training intervention and through a web-based survey 6 weeks post-intervention. McNemar's test for dependent categorical data was utilized to evaluate change in survey responses at the three timepoints.

*Results:* Nurses' understanding of the concept of demoralization and appropriate interventions significantly improved by 30.3% from pre- to posttest ( $p \leq 0.0001$ ). These improvements persisted at 6 weeks post-intervention ( $p \leq 0.0001$ ). At 6-week follow-up, 74.2% of participants agreed or strongly agreed that the training had positively changed their nursing practice, 96.8% reported that this training benefited their patients, and 100% felt that this training was important for the professional development of nurses.

*Significance of results:* This pilot intervention appeared feasible and acceptable to nurses and resulted in increased understanding of demoralization, improved confidence to intervene in such cases, and an enhanced sense of professional satisfaction among inpatient oncology floor nurses.

**KEYWORDS:** Demoralization, Depression, Nurse education, Oncology

## INTRODUCTION

Demoralization is a dysphoric state triggered by life events and characterized by a sense of impotence, isolation, and despair. It occurs in a third of medical

inpatients (Kissane, 2014) and is clinically relevant in 13 to 18% of patients with progressive disease or who are near the end of life (Robinson et al., 2015). Loss of meaning and feelings of helplessness or being a burden on others frequently lead to desire for hastened death or suicide among those with demoralization (Kissane et al., 2001). The phenomena associated with the construct of demoralization are connected to such concepts as learned helplessness

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and dysfunctional attributional style (Seligman, 1972; Seligman et al., 1979), external locus of control (Rotter, 1966), and the transactional model of stress and coping (Lazarus & Folkman, 1984).

Because there is some overlap between the construct of demoralization and other conditions involving depression, it is vital to contrast demoralization with these conditions. Prior research validates demoralization as a phenomenological entity distinct from major depressive disorder (MDD) (de Figueiredo, 1993) and also from an adjustment disorder with depression (Slavney, 1999). Like MDD, demoralization may feature mood and sleep disturbances, changes in appetite, suicidal thinking (Slavney, 1999), and problems with adherence to medical treatment (D'Souza & Rodrigo, 2004; O'Laughlin et al., 2012).

Unlike MDD, however, demoralization is a universal human experience. De Figueiredo (1993) defined the primary difference between demoralization and depression as the presence of anhedonia in the case of depression and the preservation of responsivity of mood in the case of demoralization. It is this distinction that often makes demoralization respond rapidly to interventions.

There remains a debate in the literature about the diagnostic criteria for demoralization (Robinson et al., 2015). In a recent review of the construct of demoralization, Robinson and colleagues integrated existing work in this area and identified two main conceptualizations of demoralization. The definition initially proposed and then modified by Kissane and colleagues (2001) was used for this project (Robinson et al., 2015; 2016). This definition includes the following:

1. the experience of emotional distress, such as hopelessness and having lost the meaning and purpose in life;
2. attitudes of helplessness, failure, pessimism, and absence of a worthwhile future;
3. reduced coping and an inability to respond differently;
4. social isolation and deficiencies in social support;
5. persistence of the abovementioned phenomena for two or more weeks;
6. features of major depression have not superseded as the primary disorder. (Robinson et al., 2016)

Treatment for demoralization is specific and different from treatment of depression. Most notably,

antidepressant medications do not lead to improved outcomes in demoralization (Griffith & Gaby, 2005). Because responsivity of mood is maintained in demoralization, brief psychotherapy interventions that restore mood and allow the patient to access their previously developed coping techniques may be strikingly effective (Griffith & Gaby, 2005; Kimmel & Levy, 2012). Current treatment approaches include meaning-centered individual and group interventions, brief psychotherapy focusing on symptom relief, cognitive restructuring, setting behavioral goals, and providing empathic understanding (Breitbart, 2002; Clarke & Kissane, 2002; Breitbart & Popito, 2014). Basic therapy skills of witnessing and validating a person's authentic experience constitute an important component of any intervention for demoralization (Arman, 2007; Viederman, 1983). The most specific psychotherapy intervention was created by Griffith and Gaby (2005). In this approach, the authors encouraged identification of the specific existential components associated with demoralization. These "existential postures" are pairs of opposite terms that are often associated with the experience of demoralization. Just one example provided by the authors is the posture of "agency versus helplessness," in which feeling helpless is identified as having a causal role in demoralization, and interventions can then be targeted to help the patient regain a sense of empowerment by reconnecting them to experiences where they have felt empowered or can access coping strategies that improve agency (Griffith & Gaby, 2005).

The literature also validates an approach of improving the quality of nurse communication with patients about matters of emotional and existential importance. This is supported by studies of patient-provider communication demonstrating that, when communication is appropriately attuned to the patient, treatment adherence improves and patients have better psychological functioning (Arora, 2003). Ineffective communication with patients by medical personnel is associated with clinician stress, lack of job satisfaction, and emotional burnout (Fallowfield, 1995). For patients, this poor communication by medical personnel results in confusion (Lerman et al., 1993), increased psychological distress, and difficulty asking questions, expressing feelings, and understanding information (Lamont & Christakis, 2001; Maguire et al., 1996). Some clinicians utilize such avoidance strategies as denial of patients' emotional suffering by focusing on imparting only medical information (Razavi et al., 2002). These communication concerns may maintain or exacerbate demoralization among patients facing difficult life situations in the hospital. Thus, the need exists for interventions that improve nursing

communication in ways that specifically address demoralization. These interventions may assist in two ways: (1) by reducing nurses' avoidance of strong emotions exhibited by patients and (2) promoting exploration of existential issues with their demoralized patients. Such an intervention would aim to reduce patients' existential suffering and could also bolster job satisfaction and self-confidence in nurses (Akechi et al., 2010; Arora, 2003).

As part of their professional roles, inpatient oncology nurses develop personal relationships with their patients. Given the responsiveness of demoralization to brief therapeutic intervention and its high prevalence in the hospital setting, inpatient oncology nurses are uniquely poised to conduct brief interventions for demoralization.

To our knowledge, no other studies exist that document training for nurses to identify demoralization and then conduct an intervention as part of their "frontline" nursing roles. However, other groups have documented interventions designed to train nursing teams to intervene about existential concerns. Morita and colleagues (2007; 2014) developed a training program for nurses working with terminal oncology patients. This intervention provided communication skill-building for nurses around addressing the meaninglessness experienced by their patients. Featuring both lectures and simulations of clinical situations in a 5-hour training, it was well-received by the nurses.

Thus, although it is limited, the literature on training nurses to interact therapeutically with their patients around existential issues suggests three important factors: (1) direct education about the existential phenomenon; (2) education about effectively and authentically approaching this phenomenon in ways that encourage emotional expression and direct communication with patients; and (3) that observing or experiencing these techniques through a simulated clinical situation that resembles the "frontline" work of nurses is an effective approach to education (Morita et al., 2014; 2007).

## METHOD

The University of Colorado Hospital (UCH) is a 584-bed adult academic hospital in the Denver metropolitan area that serves patients from the Rocky Mountain region. Inpatient nurses at UCH frequently seek advice from the psychiatry consultation team, the palliative care team, and members of the psychosocial oncology team on management of the psychiatric and existential concerns of their patients. This project was initiated when a nurse on the psychiatric team provided a well-received in-service about demoralization to our advanced practice

nurses and an educational need was identified in this team. The research team received a quality-improvement grant to develop an educational intervention to equip nursing staff with the knowledge to properly identify demoralization in patients and intervene appropriately within their scope of practice.

An educational training video entitled "Demoralization in Medical Illness" provided information about the phenomenon of demoralization, what distinguishes it from depression, how to intervene, and when to involve the social work, psychology, palliative care, and/or psychiatry teams. The RNs were given a framework (see Figure 1) which described factors that may contribute to demoralization and instructions on how to structure a brief intervention with the tasks of witnessing, validating, and normalizing the patient's experience. Other basic therapeutic techniques germane to the concept of demoralization were also provided, such as asking open-ended questions and exploring patients' suffering with them in a nonjudgmental way. Nurses were provided examples of Griffith and Gaby's (2005) nine existential postures of vulnerability and resilience to illness, which were identified by these authors as common causes of concern for those with a medical illness.

For each existential component, simple therapeutic questions were offered that nurses could employ in clinical situations that might allow the patient to adopt a more resilient existential posture. We then included filmed vignettes of typical patient-clinician interactions to provide simulated clinical examples of how to identify the existential posture and then intervene in the case of a patient experiencing demoralization. The actors in the vignettes were medical and nursing staff that were part of our team (but not assessed in the training). They were paid for their participation.

We created a laminated card that included the basic concepts which define demoralization and questions that nurses could ask patients. The process of creating the card entailed several iterations. A small card was created that could fit on the ID lanyard worn by every member of our nursing team. Because of limited space, we condensed our message to four points: (1) the difference between MDD and demoralization; (2) basic questions to begin the intervention; (3) a reminder of the process of witnessing, validating, and normalizing the patient's experience; and (4) relevant intervention questions (see Figure 1). Although the DVD vignettes were created to show specific existential dilemmas (Griffith & Gaby, 2005), we omitted the list of existential dilemmas from the card, as nurses became too focused on trying to choose the "right" dilemma in complex patient situations. A nurse is shown using this card in one of the vignettes.

## Front of card

Distinguishing Demoralization from Depression		
Demoralization	Both	Major Depression
<ul style="list-style-type: none"> <li>· Mood is rapidly restored with interventions such as positive emotional experience</li> <li>· Pt <b>worries</b> about decision making</li> <li>· No improvement with meds</li> </ul>	<ul style="list-style-type: none"> <li>· Disturbance of Sleep</li> <li>· Appetite</li> <li>· Energy</li> <li>· Suicidal thinking</li> </ul>	<ul style="list-style-type: none"> <li>· Mood is often consistently depressed</li> <li>· Pt has <b>apathy</b> about decision making</li> <li>· Can be treated with meds</li> </ul>

**STEP 1:** *How are you feeling today?*  
*What's the most difficult thing for you now?*

**STEP 2: Witness:** Turn full attention to the patient and show you are listening through non-verbal behavior (nodding head, leaning forward)

**Validate:** Express understanding of patient's situation and emotions by summarizing and stating back to patient what he/she said

**Normalize:** Express that patient is experiencing a common and appropriate human reaction to the circumstances

## Back of card

- **What helps you stand strong against the challenges of this illness?**
- **How have you kept this illness from taking charge of your life?**
- **How are you making sense of what you are going through?**
- **For what are you most grateful?**

**Fig. 1. Demoralization Card.** This two-sided card was distributed to nurses and can be inserted into a hospital badge holder for quick reference regarding patient demoralization and depression.

The training occurred at a monthly charge nurse meeting in November of 2013 and included playing the 30-minute DVD with recorded vignettes of the techniques “in action,” facilitating a discussion about demoralization, answering questions, and fostering completion of the pre and post surveys. The staff gave permission to have 6-week evaluations sent to them by email using Survey Monkey. This video and the surveys employed to evaluate the program are available upon request from the corresponding author.

### Measures

The demographics collected were gender, age, years of nursing practice, and years practicing in a health-care setting. We used a 10-item questionnaire at three timepoints: pre, post, and 6-week follow-up. These survey questions assessed their understanding of the concept of demoralization, their confidence to intervene in cases of demoralization, and the impact on job satisfaction. Questions 1–7 required a binary response (yes or no), and 8–10 were presented

in 4-point Likert-type format. In the last survey at 6 weeks post-intervention, three additional questions were added to evaluate the impact of the training over time.

Some examples of the survey questions follow:

Binary choice:

“Demoralization is an abnormal response to illness.”

4-point Likert-type:

“I can differentiate between demoralization and depression.”

4-point Likert-type at 6-week follow-up:

“I have changed my nursing practice as a result of this training.”

Two qualitative items on the surveys solicited more in-depth information about the nursing staff's experience with the training that may not have been represented in the Likert-type scale questions.

## Statistical Analyses

The dataset consisted of pre-intervention, post-intervention, and 6-week follow-up survey responses from 31 nurses. For concept-based questions, the association of correct responses between the pre- and post-intervention surveys was assessed using McNemar's test for dependent categorical data. The same approach was applied for the comparison between the post-intervention survey and the 6-week follow-up as well as between the pre-intervention and 6-week follow-up survey. The difference in scores between the pre-intervention, post-intervention, and follow-up surveys were calculated for questions relating to: (1) an awareness of demoralization as a clinical topic, (2) the ability to distinguish demoralization from depression, and (3) confidence in intervening. The mean difference and standard deviation were calculated for each question. Paired one-sample *t*-tests and *p* values were calculated for comparisons between each set of comparison surveys. Univariate linear regression was performed to assess the association between years in nursing practice and years in a healthcare setting and change in score for confidence and professional development-based questions. The significance level of the tests was not corrected for multiple comparisons. The analysis was conducted using SAS/STAT<sup>®</sup> software (SAS Institute, Cary, NC).

## RESULTS

### Participant Characteristics

The participants in our study were nurses ( $N = 31$ ) who worked in oncology and attended a routinely scheduled charge nurse meeting. The majority of nurses who comprised the study were female (96%), with an average age of  $39.3 \pm 10.4$  years. The mean number of years in nursing practice was  $12.87 \pm 9.3$ , and the mean number of years in a healthcare setting was  $14.07 \pm 9.2$  (see Table 1).

### Comparison of Pre/Post and 6-Week Follow-Up Measures

The results of the pre-intervention, post-intervention, and 6-week post-intervention surveys were broken into three composite scores due to the differing styles of questions asked in the measure and for accuracy of reporting each item type. The first of the three composite scores summed up the number of correct answers for seven concept-based questions structured in a true/false format, which remained consistent across all time points. Pre/post comparison of these scores indicated a mean increase in correct answers across all nurses of 19.2% immediately

**Table 1.** Survey participant characteristics ( $N = 31$ )

Subject characteristics	<i>n</i> (%)
Age, mean $\pm$ <i>SD</i>	39.29 $\pm$ 10.41
Female	29 (93.55)
Current clinical role	
Associate nurse manager	2 (6.45)
Certified nurse	2 (6.45)
Clinical nurse educator	3 (9.68)
Clinical nurse specialist	1 (3.23)
Charge RN	18 (58.06)
Director medical/surgical	1 (3.23)
Nurse manager	3 (9.68)
Registered nurse	1 (3.23)
Years of nursing practice, mean $\pm$ <i>SD</i>	12.87 $\pm$ 9.31
Years in healthcare setting, mean $\pm$ <i>SD</i>	14.07 $\pm$ 9.21

RN = registered nurse; *SD* = standard deviation.

following the intervention (95% confidence interval [ $CI_{95\%}$ ]: 0.67, 2.03;  $p = 0.003$ ). Scores remained 9.71% higher at 6-week follow-up ( $CI_{95\%}$ : 0.08, 1.28;  $p = 0.0287$ ). For the sum of these questions, the intervention had a lasting effect on the number of correct answers, though this effect diminished somewhat at 6-week follow-up.

The second composite score included total responses for three detection/confidence-based questions in 4-point Likert-type format and were collapsed into a binary dichotomous variable (similar to the true/false questions) for ease of comparison and statistical analysis. When the pre- and posttests were compared, scores were found to have significantly increased by 56% ( $CI_{95\%}$ : 1.19, 2.16;  $p \leq 0.0001$ ) immediately after the intervention. There was no significant difference in responses between post-intervention and 6-week follow-up. As predicted, there was a significant long-term difference in responses from pre-intervention and follow-up of 1.71 more correct responses ( $CI_{95\%}$ : 1.23, 2.19;  $p \leq 0.0001$ ). For these three Likert-type questions, the intervention was found to have a lasting effect on the ability to detect demoralization, to differentiate it from MDD, and the confidence to intervene, and subjects' scores did not drop between post-intervention and follow-up.

The third composite or overall combined score comprised the responses among all 10 questions and followed a similar pattern to the composite score of the first 7 questions. The overall score increased significantly from pre- to post-intervention by 3.03 questions or 30.3% ( $CI_{95\%}$ : 2.15, 3.92;  $p \leq 0.0001$ ). Though there was a significant decrease in correct responses by 0.65 from post-intervention to follow-up ( $CI_{95\%}$ : -1.17, -0.12;  $p = 0.017$ ), the change between pre-intervention and 6-week follow-up remained

significant at 2.39 ( $CI_{95\%}$ : 1.56, 3.21;  $p \leq 0.0001$ ), suggesting that the intervention resulted in an improved understanding of demoralization that was maintained through to the 6-week posttest time-point.

### Self-Reported Impact of the Survey at 6-week Follow-Up

On the 6-week follow-up survey, 74.2% of nurses agreed that training on demoralization is vital for the professional development of nurses, and the remaining 25.8% strongly agreed. In response to whether a nurse's practice had changed as a result of the educational intervention, 64.5% agreed and 9.7% strongly agreed, while 25.8% disagreed. In response to whether patients had benefited from the demoralization interventions, 83.9% agreed and 12.9% strongly agreed, whereas 3.2% disagreed (see Table 2). Additional open comments on the survey showed that the nurses spontaneously reported increased job satisfaction and personal meaning derived from their work as a result of this training. The reported changes and the durability of these changes along with the almost exclusively positive qualitative survey comments made by nurses clearly indicate the acceptability and feasibility of this training.

## DISCUSSION

The first aim of this pilot study was to determine the feasibility and acceptability of the educational intervention. The nurses reported high levels of acceptance of this training, as indicated by the many survey comments in which they described feeling that the training had validated their work and

clarified concepts about which they had previously thought. In fact, because this standalone training can be run by any nurse who has been through the training, several of our nursing staff anecdotally reported continued use of the DVD intervention with nurses on their units to train others, and one unit has integrated it on their own accord into the training of *all* new nurses. This training efficiently uses the limited psychiatric and psychosocial resources in the hospital, thus allowing demoralization to be identified and treated by frontline healthcare professionals while also encouraging appropriate referral of other psychiatric concerns to an appropriate provider. This may also enhance its acceptability to the medical and psychosocial teams that cover the hospital environment.

As it relates to both acceptability and feasibility, many nurses expressed a sense that the increasing focus on the technical aspects of nursing and demands on their time have meant less focus on the "human" or existential side of their work. Consequently, many expressed renewed satisfaction at having the existential aspects of their work highlighted as a vital part of their nursing skill set. It is possible that training like this helps nurses reconnect to sources of meaning in their work and may also prevent demoralization and burnout in nurses. Prior work has discussed medical provider connection to patients at the end of life as an antidote to burnout and compassion fatigue (Kearney et al., 2009). If this were the case, this intervention would work to relieve demoralization in both nurse and patient in the face of difficult existential situations.

The results presented herein are similar to those found by Morita and colleagues (2007; 2014), who conducted a randomized controlled trial ( $N = 76$ ) for oncology nurses, with the intervention group

**Table 2.** Parameter estimates with corresponding 95% confidence intervals and *p* values for general linear mixed model of composite score across the three surveys for each subject

	Parameter estimate	$CI_{95\%}$	<i>p</i> value
Questions 1–7 composite score			0.0002*
Post-intervention vs. pre-intervention survey	1.3548	(0.6749, 2.0348)	0.0003
Follow-up survey vs. post-intervention survey	–0.6774	(–1.0239, –0.3309)	0.0004
Follow-up survey vs. pre-intervention survey	0.6774	(0.07554, 1.2793)	0.0287
Questions 8–10 composite score			<0.0001*
Post-intervention vs. pre-intervention survey	1.6774	(1.1909, 2.1639)	<0.0001
Follow-up survey vs. post-intervention survey	0.03226	(–0.3858, 0.4503)	0.8758
Follow-up survey vs. pre-intervention survey	1.7097	(1.2343, 2.1850)	<0.0001
Overall composite score			<0.0001*
Post-intervention vs. pre-intervention survey	3.0323	(2.1464, 3.9181)	<0.0001
Follow-up survey vs. post-intervention survey	–0.6452	(–1.1686, –0.1217)	0.0174
Follow-up survey vs. pre-intervention survey	2.3871	(1.5632, 3.2110)	<0.0001

\* Type 3 test of fixed effects where  $df = 2$ .

$CI_{95\%}$  = 95% confidence interval.

receiving two-day in-depth training to address the concept of meaninglessness in terminal oncology patients. Although the concept of meaninglessness is somewhat different than demoralization, both involve existential concepts highly relevant to nurses working with oncology patients. Morita's training was effective at improving nurses' confidence to address meaninglessness in their patients and also effected small changes in nursing attitudes. The training involved simulated clinical situations and engaged nurses in an interactive presentation. In comparison with the two-day intensive intervention conducted by Morita, the results presented here were achieved with a easily replicated one-hour video intervention occurring at a normally scheduled nursing meeting. The findings from our present study suggest that a brief intervention for nurses was successful in increasing understanding of the concept of demoralization, enhancing the ability to differentiate between demoralization and depression, and, in the case of demoralization, providing nurses with the confidence to intervene. Six weeks after the training, nurses reported increased job satisfaction and enhanced personal meaning in delivery of care. Therefore, brief interventions may be a well-accepted, efficient, and effective way to impart needed information about existential concepts, resulting in nurse satisfaction and nurse-reported improvement in patient care and an ability to intervene in cases of demoralization.

Of note, 25.8% of the nurses at the 6-week follow-up reported that their practice did not change as a result of the intervention. The reasons for this are not directly determinable due to the limitations of our survey. However, given the somewhat basic nature of our intervention and the high level of experience among the nursing team (an average of 12.87 years of nursing experience), it is possible that some nurses had sufficient previous understanding of how to assist demoralized patients and thus did not change their practice as a result of the intervention. Interestingly, only 3.5% of the nurses reported that their patients did not benefit from the training. Future research in this area should be conducted to better untangle the baseline understanding of oncology nurses about the phenomena associated with demoralization and their confidence to intervene effectively.

### LIMITATIONS OF THE STUDY

There are a number of limitations of this study. The largest one is that the impact of the nursing intervention on patient outcomes is currently unknown. Patient impact was not explored due to the limited resources available for this small pilot study, but

this opens up an area of needed future scientific inquiry. Other limitations include the small sample size, the limited scope of the study, with its focus on charge nurses, the utilization of a novel assessment tool, and the lack of data regarding the utility of providing nurses with a laminated "quick-reference" card related to demoralization concepts. Further, the acceptability and feasibility of the intervention was deduced from positive comments, improvements in survey responses, positive qualitative data provided by nurses, and the ongoing spontaneous use of this training by nurses *after* the end of our study. In the future, more formal means of assessing acceptability could be employed to better document this phenomenon. As this was a pilot study, additional research should also be undertaken, with a randomized trial design, to examine the effectiveness of this brief intervention and determine whether or not it is an optimal format.

### CONCLUSIONS

In conclusion, this brief demoralization training was acceptable to nurses and feasible to implement in an inpatient direct-care nursing environment. It resulted in an increase in nurses' understanding of the concept of demoralization, an improvement in their confidence to intervene in cases of demoralization, and an increase in the job satisfaction of the nursing staff who participated in the training. Future research should examine the impact of similar demoralization training for nurses on patient outcomes, patient satisfaction, nurse burnout/compassion fatigue, and the satisfaction of other non-nurse healthcare professionals.

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