Integration of Personalized Narrative to Inform Improved Communication for Patients with Life-Limiting Illness

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ABSTRACT

Narrative intervention has proven to be an effective method of allowing informed decisions, considering patient comfort, improving treatment outcomes, and more. A narrative intervention approach entails prompting patients to share their histories and identities to allow healthcare professionals a more comprehensive view of the patient. This study implemented a person-centered treatment plan for patients afflicted with life-limiting illness. A more holistic view of the patient was integrated into their Electronic Health Record (EHR) to improve physician-patient communication and patient experience. Narrative intervention outcomes were quantified via three field surveys distributed to patients. Significant results of linear mixed models indicate improvement in intervention groups in two of the three themes evaluated: Feeling Cared for as a Person/Respected in your Beliefs, and General Communication with the Nurse/Feeling Heard and Understood. For Feeling Cared for as a Person/Respected in your Beliefs, intervention resulted in an improvement of 0.87635 while control showed a -0.72109 decline. For General Communication, intervention reflected an improvement of 0.41378 while control yielded a -0.09366 decrease. The control group experienced a greater improvement (-0.349865) than the intervention (-0.1271034) in Emotional Wellbeing. Personalized narrative intervention is indicated to be an efficient method of optimizing nurse to patient communication while taking a patient’s wants and needs into consideration. Narrative intervention is not shown to benefit the emotional wellbeing of patients. Future directions can examine its impact on more specific realms of patient satisfaction as well as the feasibility of the method.
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INTRODUCTION

The organization and application of treatment within the healthcare system has transformed substantially over time. While developments certainly promote efficacy and capability in the medical field, the industry’s objectives steer away from altruistic, high-quality care. A particular emphasis on financially beneficial practices has emerged. With such motivations, it seems inevitable that other aspects of healthcare will lose consideration and their value will decline. The quality of health care is customarily evaluated via care procedures and clinical outcomes, while patient experience and assessment is often overlooked. Although successful medical treatment and procedures are important to healthcare, there are other factors that can influence a patient’s overall experience. Innovation within the healthcare system has eradicated numerous diseases, lengthened the average lifespan, among other benefits; nonetheless, these advances can culminate in a weakened patient-provider relationship.

The patient experience is integral to not only ensuring a favorable psychological state but also positive health outcomes. Patient satisfaction plays a considerable role in health care, influencing treatment results, retention rates, etc. A disparity in provider-patient communication can lead to a greater potential in medical error, unsatisfactory symptom treatment, and adverse outcomes, and even ongoing unwanted care. An patient dissatisfied with their experience may decide to trust a different practice that meets their needs and expectations while delivering a more effective, involved approach to treatment. Moreover, the consideration of patient preference, values and beliefs generates a greater sense of physician accountability, allows informed decisions, and enables alternative methods of care if needed. A palliative and comprehensive approach to health care enhances communication, allowing for a better patient quality of life. In sum, it has been established that patient satisfaction impacts numerous medical facets and its oversight can exacerbate one’s health, both physically and mentally. In the face of growing health care consumerism, a prioritization of patient experience has become even more vital in the success of medical practices. Despite this, discordant protocol endures due to insufficient awareness of a patients spiritual, social and psychological needs. To remedy this negligence, person-centered care can be implemented for an increased understanding of patients’ needs. This approach will also assist physicians
in devising tailored treatments to maximize patient satisfaction. Patient-centered care has recently emerged as a driving factor behind quality care. This method includes collaboration between a patient and healthcare provider to build a relationship, accounting for patient desires and goals in medical regimen, etc. This concept will be addressed in detail in the subsequent section. Included within the “quality chasm” report released by the Institute of Medicine; person-centered care was recognized as 1 of 6 crucial fundamentals to providing exceptional care.9

Within this study, person-centered care is considered as a potential means of maximizing patient satisfaction. A central tenant of person-centered care involves joint decision-making to allow for the consideration of a patient’s circumstances and preferences, and in turn, make the individual feel more “heard”.10 Collaboration between health care professionals and patients establishes a basis of trust and entitles patients to a greater sense of control over their situation. This form of care calls for training healthcare providers to adopt more attentive and empathetic behaviors in practice. Subsequently, physicians will no longer appear to be a figure of authority but rather an ally prioritizing cooperation, respect and compassion.11 Another application of person-centered care is narrative intervention, which allows a patient to share an account of themselves and their history with their provider, by telling stories. To adequately assess this method, an understanding of meaning-making and story theory is needed.

The concept of meaning-making is the process by which individuals purposefully establish their own sense of reality.12 Following life experiences, individuals may sense discrepancies between these events and their pre-existing knowledge of themselves and the world; to close these gaps, one must attribute meaning to and make sense of these events. Meaning making is a crucial element of identity enactment, as the very core of a person derives from their interpretation of situations, relationships, and their selves. Correspondingly, a patient’s self culminates from their experiences, responses, and the meaning assign to the aforementioned. The role of meaning-making in originating identity has been elucidated, yet a means by which patients can communicate their identities to physicians must be established as it is fundamental to narrative intervention.
Story theory and its associations to “meaning-making” allow for a reasonable practice of person-centered care. This approach uses intentional patient-provider dialogue in which a patient reflects on their background and experiences with their illness through storytelling. Physicians can gain a sense of a patient’s “self” through narrative means allowing self-in-relation, deliberate dialogue, and an increased sense of ease. With story theory, physicians can achieve a more holistic view of patients and their personal attitudes and beliefs. These exchanges provide a treatment complete with narrative intervention. Narrative intervention allows patients to convey their life within social, spiritual, and psychological spheres while providers can establish greater connections and communication with their patients. In palliative care patients, narrative intervention was found to reduce depression and lengthen survival.

In a fast-paced healthcare environment, the inclusion of storytelling (narrative) for direct transference of a patient’s principles to a physician is problematic as it can be a lengthy, effortful feat. The electronic health record (HER) is considered as the method of narrative intervention implementation within this study, though alternative approaches such as digital storytelling and telephone-based reviews exist. The EHR is the leading form of information storage about patients. EHRs are “a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data, and radiology reports”. While these records do contain much detail, they remain predominantly provider centered. The EHR provides the opportunity for important patient details to be conveyed without a direct conversation between patient and physician, which can be a time-consuming process. Patient stories gained via narrative intervention can be uploaded into their corresponding EHR, permanently available for physician review. Integrating a more holistic sense of a patient as an individual into the EHR allows competent conveyance of their values to their healthcare team, effectively improving communication.

With the established importance of a person-centered focus within the healthcare setting, some research has been conducted to gain further insight. One study made use of narrative intervention as a means of eliciting a behavioral change in Khmer mothers and daughters. Researchers tested the efficacy
of videos encouraging HPV vaccination through methods of narrative theory on vaccination rates. The study found successful preliminary results and feedback deemed the method as a feasible and potentially effective mode of narrative intervention. An exploration of narrative intervention for individuals afflicted with dementia produced significant results. Patients were given daily narrative exercises for a 40-day period and were seen to have substantial improvements in memory, language, etc. The study indicates narrative intervention as an efficient non-pharmacological regimen with cognitive benefits.

Another study conducted on African American women at higher risk for breast cancer worked to develop a culturally conscious narrative approach to encourage genetic counseling.

It has been established that the integration of narrative-based approach to treatment is vital to not only patient comfort and satisfaction, but also successful treatment and outcomes. Yet despite the existing literature, little research has been conducted on the assimilation of patient narrative into the EHR. This study investigates prospective methods of incorporating narrative intervention into patient EHRs. The principal hypothesis of this proposal is that obtaining person-centered narratives from hospitalized patients will allow improved patient-nurse communication as well as improved social and psychological states of patients. Specifically, this integration is predicted to have three primary outcomes: the first of which is the enhancement of patient care by accounting for an individual’s beliefs and culture. The second outcome is an increased opportunity for communication between provider and patient. The last outcome is a positive effect on a patient’s psychosocial well-being.

To measure these possible effects, this study was conducted with a specific aim; to evaluate the outcome of the intervention. This was achieved by comparing the effects of the treated group, those receiving narrative intervention, to the control group, patients receiving traditional care. Outcomes were quantified via field analysis in the form of surveys distributed to the principal participants; patients afflicted with life-limiting illness. Participants reported scores for various aspects of their care and health. These measurements allowed for evaluation of a primary result of communication quality as well as secondary results regarding a patient’s general wellbeing; including scores for depression, anxiety, physical functioning, fatigue, pain interference and intensity, ability to participate in social roles and
psychosocial illness experience. This study extends upon a previous K99 study which aimed to (1) recognize motivators and obstacles impacting narrative intervention implementation and (2) evaluate the practicality of narrative intervention from the point of patients and acute care bedside nurses. The study enrolled 20 patients and 18 nurses and found that narrative intervention effectively allowed patients to share experiences with their illness. Nurses reported improved patient communication and relations, and positive evaluations on the System Usability Scale. Low scores were assigned for EHR integration, related to the lack of a designated EHR spot for patient narratives. Time was deemed the greatest obstacle to intervention, for patients and nurses. The K99 study concluded narrative intervention as reasonable and functional means of patient-centered care for patients and nurses. This study, considered the R00 phase, will conduct further preliminary trials to evaluate narrative intervention in patients undergoing palliative care.
EXPERIMENTAL METHODS

Sample/Setting.

The experiment was conducted at the University of Colorado Hospital within Aurora, Colorado. Participants comprised of patients afflicted with life-limiting illness, receiving acute treatment. For this group, 48 individuals were enrolled. With a focus on palliative care, these participants were admitted to acute care treatment for either heart failure or end-stage renal disease (ESRD). In terms of patient eligibility criteria, all individuals selected were 18 years or older, able to read English and provide informed consent, and were diagnosed with at least one serious illness. The study-specific consideration of serious illness included New York Heart Class III or IV heart failure, and/or dialysis dependent renal failure. The selected patient group had a median predicted survival rate of around 2 years.

Study Design.

The experiment aimed to test narrative intervention in the following ways: 1. the impact on quality of patient-nurse communication, as quantified by the patient, 2. the consequence on a patient’s comprehensive biopsychosocial condition, as quantified by the PROMIS 29 survey, and 3. the effects on the psychosocial illness of a patient, as quantified by the PROMIS psychosocial illness survey. To conduct this evaluation, patient entrance and exit surveys were used. This study follows a mixed methods design. The quantitative data involves the self-reported patient scores obtained via the surveys. The qualitative data involves patient illness narratives as well as the patient exit interviews. The timeline for the R00: Narrative Intervention Study is three years, with the specific steps outlined in Table I.

Table I. Timeline for the R00: Narrative Intervention Study.

<table>
<thead>
<tr>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain IRB approval</td>
<td>Recruit patients Collect baseline data and randomize patients Conduct intervention</td>
<td>Prepare next phase- R01 Submission Publication</td>
</tr>
<tr>
<td>Review/finalize procedures</td>
<td>Conduct intervention Data analysis: Quantitative Data analysis: Qualitative Dissemination</td>
<td></td>
</tr>
<tr>
<td>Recruit patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collect baseline data and randomize patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct intervention</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6
**Recruitment.**

Patients were recruited from three separate units located at the University of Colorado Hospital: dialysis, cardiac progressive care, and cardiac-medical. Charge nurses identified prospective participants in their respective units and reported individuals to a member of the research team within a weekly meeting. Pending approval, the researcher proposed the study to the patient and presented the informed consent form and patient recruitment flyer. Upon patient agreement, baseline measurements were taken. Each participant received a compensation of $25 initially and another $25 following completion of data collection.

**Baseline Data Collection.**

At baseline, data on demographics were collected. All patients provided their age, race, ethnicity, marital status, gender, years of education, religious identity, average monthly and yearly level of income, existing comorbidities, and illness severity characterized by a health score.

**Randomization.**

To limit bias, randomization at the patient level following baseline data collection was used. Enrolled patients were separated into two distinct groups: one receiving narrative intervention care and one undergoing the traditional care with no alterations. Randomization was achieved on SAS software via a computer-generated random allocation sequence. An allocation ratio of 1:1, random block sizes, and stratification by illness group was used. The allocation sequence was uploaded into Redcap. Following, each participant was assigned a participant identifier to allow for data set anonymity.

**Traditional Care Group.**

To allow for comparison, a control group of patients underwent the typical medical care with no alterations or implementation of a narrative-based approach.

**Narrative Intervention Group.**

The narrative intervention tested within the study was implemented via an open-ended interview between a patient and a researcher. Within this study, interviews were conducted with a researcher to
allow for consistent, unbiased interactions with all patients enrolled. For future implementation, this intervention would be overseen by acute-care bedside nurses. Patients were asked about their experience with their illness through leading questions. These prompts included questions like ‘what has your experience with your illness been like’, ‘what effect has your illness had on your emotions’, ‘tell me about how your illness has impacted relationships’, etc. During the interview, the researcher audio-recorded the patient's responses and wrote observations. Interviews lasted between 60-90 minutes and occurred at a private location, either a conference room or an inpatient room. Following the conclusion of the interview, the audio recorded was transcribed in its entirety meeting the specific following criteria; written in the patient’s first-person perspective, captures the patient’s authentic voice, nonjudgmental, is non-diagnostic, and accurately reflects the conversation. The interview transcription was given to the patient within the following 48 hours. The patient was then provided the opportunity to modify and add information to the record at a follow-up interview. This second interview lasted about 30 minutes and occurred at either the first location, or, in the case of discharge, over the telephone. Upon patient approval, the narrative transcription was uploaded to the patient’s EHR for the medical team to access. The process of narrative intervention can be viewed in **Figure 1**.

**Figure 1.** Narrative Intervention Flow Diagram.
**Primary Outcome Data Collection.**

The primary outcome, quality of communication, was measured via the Quality of Communication (QOC) survey which was adopted from an established study done on quality of communication pertaining to end-of-life care.\(^22\) This questionnaire examined patient satisfaction on communication quality with bedside nurses. The survey covers 19 aspects of nurse communication, allowing patients to assign a score between 0 (worst) to 10 (best). The survey was conducted at three separate times (Table II) to obtain consistent data: once at time 1 (baseline), once at time 2 and once at time 3. There was 24-48 hours allotted between each survey distribution to allow for adequate time for the processing and upload of patient narratives into the EHR.

**Secondary Outcome Data Collection.**

The secondary outcomes, biopsychosocial domains, and psychosocial illness impact were quantified two separate PROMIS surveys. The PROMIS-29 profile v2.0 survey measured the former outcome by examining physiological, psychological, and social effects.\(^23\) The survey’s 29 items pertain to patient physical functioning, depression, anxiety fatigue, pain interference and intensity, ability to participate in social roles and psychosocial illness experience. The PROMIS Psychosocial Illness Impact survey quantified the latter outcome by assessing the positive and negative elements of a patient's experience with their illness.\(^24\) The PROMIS positive form contains 8 questions assessing positive illness outcomes that can arise because of one’s encounter with mortality such as improvements in relationships, a greater appreciation of life, etc. The PROMIS negative form contains 8 questions assessing negative psychosocial effects of illness, separate from a general sense of emotional despair. The two parts of the survey do not encompass functional or physical effects. Like the QOC survey, the PROMIS-29 profile v2.0 survey and the PROMIS psychosocial illness impact survey were conducted three separate times (Table II).
**Table II. Survey Collection Timeline.**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Time 1: Baseline</th>
<th>Time 2: 24-48 hours post baseline</th>
<th>Time 3: 24-48 hours post Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Quality of Communication (19) *</td>
<td>Quality of Communication (19) *</td>
<td>Quality of Communication (19) *</td>
</tr>
<tr>
<td></td>
<td>PROMIS Psychosocial Illness Impact (16) *</td>
<td>PROMIS Psychosocial Illness Impact (16) *</td>
<td>PROMIS Psychosocial Illness Impact (16) *</td>
</tr>
</tbody>
</table>

**Data Analysis.**

The collected data underwent statistical analysis on R Studio. Data was converted from wide format to long format to allow for easier examination, using the `gather()` and `spread()` functions from the `tidyr` package. Columns containing exclusively null values were removed from the data set. An assessment on basic demographics was conducted by constructing a table with summary data within R Studio using the `table1()` function of the `table1` package. Questions from each survey were classified into distinct, comprehensive issues at the discretion of researchers. Columns containing these survey questions were condensed into the three overarching categories; Feeling Cared for as a Person/Respected in your Beliefs (Feeling Cared For), General Communication with Nurse/Feeling Heard and Understood (General Communication), and Emotional Wellbeing. This change allowed for a broader analysis of trends. The individual questions that were aggregated to create the three encompassing themes can be seen in Table III below. To adjust for differences in scaling ranges, data was recoded to lie within a specific range to ensure no column contributes more weight to a combined outcome. This was achieved using the `vec_range1()` function contained within basic R programming installation. For the theme Feeling Cared For, data was recoded to lie between a range of 0-10, designating 10 as the ideal score. For General Communication, data was scaled between a range of 0-10, with 10 as the best score. For Emotional Wellbeing, data was adjusted to lie between a range of 1-5, with 1 specified as the perfect score.

Cronbach’s alpha was run to measure the internal consistency of the resulting, combined categories and
ensure data reliability. The Cronbach alpha tests were run in R Studio using the `cronbach.alpha()` function in the ltm package. Spaghetti plots were constructed to allow for a better visualization of the trends throughout measurements. Each plot was constructed in R Studio using the `ggplot()` function within the ggplot2 package. Linear mixed models were run to achieve a numerical reflection of both trends and variability in the data. The models were made within the R Studio software with the use of the lme4 package and `lmer()` function.

**Table III.** Table containing the specific survey questions that were combined to form the three overarching themes; Feeling Cared for as a Person/Respected in your Beliefs (Feeling Cared For), General Communication with Nurse/Feeling Heard and Understood (General Communication), and Emotional Wellbeing. The three themes are bolded and listed across the top row. The row underneath includes the underlined section header with the prompt for the survey questions below. The third row contains the individual questions that were clustered together to yield the comprehensive themes. Each question contains its code, corresponding to the respective survey and question number. For example, “qoc_6: Caring about you as a person” is question 6 from the Nurse Quality Communication Survey and “promis29_5: I felt fearful” is question 5 from the PROMIS-29 Profile v2.0.

<table>
<thead>
<tr>
<th>Feeling Cared For</th>
<th>General Communication</th>
<th>Emotional Wellbeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>When talking to your nurse about important issues like becoming very ill, how good is he/she at…?</td>
<td>When talking to your nurse about important issues like becoming very ill, how good is he/she at…?</td>
<td>Please respond to each question or statement by marking one box per row.</td>
</tr>
<tr>
<td>qoc_6: Caring about you as a person</td>
<td>qoc_1: Using words that you can understand</td>
<td>promis29_5: I felt fearful</td>
</tr>
<tr>
<td>qoc_14: Asking about things in life that are important to you</td>
<td>qoc_2: Looking you in the eye</td>
<td>promis29_6: I found it hard to focus on anything other than my anxiety</td>
</tr>
<tr>
<td>qoc_15: Respecting the things in your life that are important to you</td>
<td>qoc_3: Including your loved ones in decisions about your illness and treatment</td>
<td>promis29_7: My worries overwhelmed me</td>
</tr>
<tr>
<td>qoc_16: Asking about your spiritual or religious beliefs</td>
<td>qoc_4: Answering all your questions about your illness and treatment</td>
<td>promis29_8: I felt uneasy</td>
</tr>
<tr>
<td>qoc_17: Respecting your spiritual or religious beliefs</td>
<td>qoc_5: Listening to what you have to say</td>
<td>promis29_9: I felt worthless</td>
</tr>
<tr>
<td>qoc_19: Overall, how would you rate this nurse’s communication with you?</td>
<td>qoc_7: Giving you his/her full attention</td>
<td>promis29_10: I felt helpless</td>
</tr>
<tr>
<td></td>
<td></td>
<td>promis29_11: I felt depressed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>promis29_12: I felt hopeless</td>
</tr>
</tbody>
</table>
RESULTS AND DISCUSSION

**Table of Demographics.** This study aimed to evaluate the outcome of narrative intervention regarding sense of patient care, quality of communication, and a patient’s general wellbeing. For improved understanding of participants surveyed, a comprehensive demographic analysis was conducted. A table was constructed with summary data to provide a general understanding of who the study serves and to provide a clear sense of diversity within the data set. Derived data can be viewed in Figure 2 and demonstrates a sufficient distribution of representation in demographic categories surveyed, with at least one participant characterized by each subcategory. The sole categories reflecting limited representation are health score, with no individuals with an “Excellent” health score, and average monthly income, with no individuals comprising the $1-$500 subcategory. The lack of representation for an “Excellent” health score can be attributed to the population surveyed, as all participants required a diagnosis with at least one serious illness. Overall, the study accounted for a vast diversity within participants; thus, any conclusions formed will be applicable to the greater population, rather than a specific demographic.

**Table IV.** Table of basic demographic details of group surveyed. This table was created within R Studio using the table1 function of the table1 package. All demographic categories surveyed contained at least one individual representing each subset classification. The sole exceptions were the categories of Health Score and Average Monthly Income. The general diversity present within the sample surveyed is presented.
**Cronbach alpha.** Given that responses to certain survey questions were grouped together to form broader categories or themes, it was necessary to measure their internal consistency. To test the reliability of the merged survey questions, a Cronbach’s alpha test was used. A Cronbach’s alpha test ensure that all questions are sufficiently related to be grouped together. The themes captured in Cronbach's alpha test yielded desirable alpha values reflected in Table III. An alpha score of 0.7 or higher is generally considered "reliable". Feeling Cared For had an alpha value of 0.960, General Communication had an alpha score of 0.949, and Emotional Wellbeing had an alpha score of 0.935. With all alpha scores above 0.93, the three overarching categories had a good internal consistency and served as a statistically reliable means of measuring the three themes. Any conclusions formed in these three categories can be thought of as reliable due to their credible score.

**Table V.** Application of Cronbach’s alpha test to themes captured in surveys. Test was run in R Studio using the cronbach.alpha function within the ltm package. The three broad themes are listed in the left column and their corresponding alpha-values are included in the column to the right. Given the alpha values are all above the accepted value of 0.7, the three combined themes reflect a statistical reliability and conclusions made can be trusted.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Alpha-value (α)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling Cared for as a Person/Respected in your Beliefs</td>
<td>0.960</td>
</tr>
<tr>
<td>General Communication with the Nurse/Feeling Heard and Understood</td>
<td>0.949</td>
</tr>
<tr>
<td>Emotional Wellbeing</td>
<td>0.935</td>
</tr>
</tbody>
</table>

**Spaghetti Plots.** Spaghetti plots were made to allow for easier visualizations of trends; Feeling Cared For (Figure 3.), General Communication (Figure 4.), and Emotional Wellbeing (Figure 5.). The plots demonstrate how patients self-reported scores changes over time as well as where scores were generally populated. In each figure, the left graph (blue) represents the control group, and the right graph (red) represents the intervention group. Along the y-axis is the score, with a specification as to which number is considered best, and along the x-axis is the survey collection timeline. Baseline collection falls at 1 on the axis, Time 1 is at 2, and Time 2 is at 3. A line begins at a patient’s score along the y-axis at
baseline upon the x-axis. For example, one line within the Feeling Cared for the control group plot (Fig. 3) begins at a score of 10 at baseline (1 on the x-axis). At Time 1 (2 on the x-axis), the line drops down to show a score of about 1.3, then at Time 2 (3 on the x-axis), the line rises to an improved score of about 8.8. Lines end when the data collection proves ends for a patient.

For Feeling Cared For, a score of 10 is denoted as the best. As such, lines going down indicate a decrease in score, which signals a decrease in quality and vice versa. In Figure 3, the lines of the intervention group populated a higher area. Higher lines, closer to 10, are indicative of a patient’s satisfaction with their experience. The control group reflected lines concentrated in a lower scoring area. The control group also appears to contain a more scattered distribution of lines, meaning that patients scores experiences more sporadic changes while that of the intervention group appears to be more consistent. Comparing these two plots, the success of narrative intervention in improving a patient’s perceived sense of feeling cared for and feeling their beliefs are respected can be seen.

![Feeling Cared for as a Person/Respected in your Beliefs](image)

**Figure 3.** Spaghetti plot for the Feeling Cared for as a Person/Respected in your Beliefs theme. Plots were constructed in R Studio using the ggplot function within the ggplot2 package. Along the y-axis is a patients score and along the x-axis is the time of survey distribution (1: Baseline, 2: Time 1, and 3: Time
The plot on the left (red) is reflective of the control group and the plot on the right (blue) demonstrates the narrative intervention group. The intervention group populates a higher-scoring area than the control, indicating the success of narrative intervention in improving a patient’s sense of Feeling Cared for as a Person/Respected in your Beliefs.

For General Communication, a score of 10 is denoted as the best. Once again, lines going down indicate a decrease in both score and quality of general communication and rising lines are reflective of an increased score and quality. Similar to the previous theme, in Figure 4, the lines of the intervention group populate a much higher scoring area than that of the control. The lines reflecting the scores of individuals within the control group appear to experience a greater dispersion towards lower scoring areas than the intervention group does. The control group plot demonstrates one individual that reports a much lower score than any subject in the intervention group, around 1.3. Through comparison, it is displayed that the narrative intervention group experienced an elevated sense of positive General Communication.

![General Communication with Nurse/Feeling Heard and Understood](image)

**Figure 4.** Spaghetti plot for the General Communication with the Nurse/Feeling Heard and Understood theme. Plots were constructed in R Studio using the ggplot function within the ggplot2 package. Along the y-axis is a patients score and along the x-axis is the time of survey distribution (1: Baseline, 2: Time 1, and 3: Time 2). The plot on the left (red) is reflective of the control group and the plot on the right
(blue) demonstrates the narrative intervention group. The intervention group populates a higher-scoring area than the control, indicating the success of narrative intervention in improving a patient’s sense of General Communication with Nurse/Feeling Heard and Understood.

Unlike the previous two themes, for the theme of Emotional Wellbeing, a score of 1 is denoted as the best. As such, lines going down indicate a decrease in score, which signals an increase in quality, while a line going up signals an increase in score and decrease in quality. In Figure 5, it appears that the control group populates lower scoring areas when compared to the intervention group. The intervention group reflects multiple lines, and corresponding subjects, that reported both higher scores and a greater distribution of scores. This would indicate that the control group was more content with their emotional wellbeing.

Figure 5. Spaghetti plot for the Emotional Wellbeing theme. Plots were constructed in R Studio using the ggplot function within the ggplot2 package. Along the y-axis is a patients score and along the x-axis is the time of survey distribution (1: Baseline, 2: Time 1, and 3: Time 2). The plot on the left (red) is reflective of the control group and the plot on the right (blue) demonstrates the narrative intervention group. The control group populates a lower-scoring area than the intervention group. This indicates a lack of success of narrative intervention in improving a patient’s sense of Emotional Wellbeing.
**Linear Mixed Models.** Linear mixed models were run to quantitatively analyze the trends reflected in the three categories. This particular model accounts for variability present within the starting points, or the baseline scores of subjects, by normalizing the data. This allows differences present between each subject to be appropriately evaluated by balancing the data set.

The two categories of Feeling Cared For and General Communication were analyzed on a scale of 1-10 with 10 serving as the best outcome. As such, an increase in score implies improvement. For the theme Feeling Cared For, the control group had an overall decline of -0.72109 while the intervention group showed an improvement of 0.87635. So, it can be determined that narrative intervention helped improve a patient’s sense of feeling cared for. For the theme of General Communication, the control group yielded a decrease of -0.09366 and the intervention group reflected an improvement of 0.41378 in score. This score difference demonstrates that, while the control group experienced a decrease in quality of general communication, narrative intervention helped to improve general communication within the intervention group.

Emotional Wellbeing was analyzed on a 1-5 scale, with 1 signifying the best outcome. Thus, a decrease in score will signal improvement. For the theme Emotional Wellbeing, there was an improvement of -0.349865 within the control group which is about 2.75 times greater than the -0.1271034 decline of the intervention group. Therefore, while the intervention group does demonstrate a score decrease and corresponding improvement in emotional wellbeing, the control group experiences a much larger score decreases and emotional wellbeing improvement. Despite narrative intervention proving some benefit, it does not prove to be as effective as the control, or standard patient care. This decrease could be related to a number of things, one of which is patient condition. As all participants have life-limited illness, emotional wellbeing experiences fluctuations and it is difficult to control exclusively to the discretion of narrative intervention.
Table VI. Fixed effects from Linear Mixed Models for the three themes; $^1$10 is the best (1-10 scale), $^2$1 is the best (1-5 scale). Models were run in R Studio using the lmer function within the lme4 package. The first three rows correlate to the scores obtained at the three survey distribution times for the control group. The second three rows correlate to the scores obtained at the three survey distribution times for the intervention group.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Feeling Cared for as a Person/Respected in your Beliefs$^1$</th>
<th>General Communication with Nurse/Feeling Heard and Understood$^1$</th>
<th>Emotional Wellbeing$^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>8.18611</td>
<td>8.25198</td>
<td>2.177083</td>
</tr>
<tr>
<td>Time 2</td>
<td>-0.81866</td>
<td>-0.38397</td>
<td>-0.161047</td>
</tr>
<tr>
<td>Time 3</td>
<td>0.09757</td>
<td>0.29031</td>
<td>-0.188818</td>
</tr>
<tr>
<td>Intervention</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>0.55903</td>
<td>0.58770</td>
<td>0.343750</td>
</tr>
<tr>
<td>Time 2</td>
<td>0.93663</td>
<td>0.49454</td>
<td>0.008936</td>
</tr>
<tr>
<td>Time 3</td>
<td>-0.06028</td>
<td>-0.08076</td>
<td>-0.127997</td>
</tr>
</tbody>
</table>
CONCLUSION

This study aimed to analyze the impact of incorporating narrative intervention into EHR on satisfaction of patients afflicted with life-limiting illness. Results were obtained via three separate surveys distributed at three separate times. Significant alpha values on Cronbach’s alpha test ensured that the themes captured in each survey were highly reliable as grouped (Feeling Cared For: $\alpha = 0.960$, General Communication: $\alpha = 0.949$, and Emotional Wellbeing: $\alpha = 0.935$). As such, conclusions formed from these themes can be deemed statistically reliable. The spaghetti plots visually demonstrated an overall distribution for each of the themes, showing differences between the control and intervention groups for each. For Feeling Cared For, and General Communication, plots demonstrated that the intervention group populated higher scoring areas, consistent with greater success in narrative intervention. For Emotional Wellbeing, plots demonstrated that the control group populated a lower scoring area, indicative of greater success in the control group receiving no narrative intervention. Linear mixed model results indicate that those who underwent treatment reported improvement in General Communication and Feeling Cared For while control groups experienced a decline. For Emotional Wellbeing, both groups experienced improvement, with the control groups reflecting a greater change in score. Overall, across the first two themes, the intervention group yielded higher scoring results than the control group, demonstrating that narrative intervention was effective in positively impacting a patient’s perceived sense of Feeling Cared For, and General Communication. Intervention was not more effective for a patient’s emotional wellbeing than standard treatment. This lack of efficacy could be attributed to the patient’s condition and other factors outside of narrative-based treatment.

This study and its results lend way to numerous avenues of future research. An adjusted linear mixed model approach could be implemented to have a more accurate reflection of trends in patient-reported scores. With the numerous variables playing a role in a patients score; it could also be valuable to incorporate a factor analysis to scale down the large number of variables to a smaller set of factors. Within this study, specific columns were combined into broader themes to achieve a general overview of how intervention impacts patient experience. A future study could focus on the subsets of one broader
theme to determine the effect of intervention on more specific columns, such as “how effective was your provider at answering all your questions about your illness and treatment?”, “how good is your provider at including your loved ones in decisions about your illness and treatment?”, etc. A future study using the same approach could implement a larger sample which would prove to be effective at not only increasing reliability, but also assist in the data collection process. With more survey responses, from nurses in particular, the feasibility of narrative intervention and its role in the EHR could be assessed. A larger study size would also provide ample data to conduct an analysis on patient demographics and their potential role in satisfaction. Results of this study will enable further efficacy trials and establish a foundation for application testing within a future R01 phase.
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