

# iMoD-Inventory of Moral Distress

Final Project Report

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## 1. Introduction

Jameston (1984) defines “moral distress” as the stress that occurs “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action”. Our team was first introduced to the term of moral distress by Dr. Lucia Wocial, Nurse Ethicist at Fairbanks Health Center and Indiana University Health. Dr. Wocial has an active ongoing research program regarding the ethics and distress in the nursing community. She shared with us her research and vision to weave in technology to monitor and provide interventions for nurse’s moral distress. She has designed a paper tool for recording the moral distress level of nurses and helps them to select factors that contribute to the particular level of distress. The paper tool is named as the moral distress thermometer tool shown in the figure below.

**Moral Distress Thermometer**

Many things can contribute to feelings of moral distress. Please put a check in the box to indicate factors that contribute to your current feelings of moral distress. If other things not on the list are contributing to your moral distress, please provide information where there is an “other” option.

Moral distress occurs when an individual's moral integrity is seriously compromised, either because one feels unable to act in accordance with core values and obligations, or attempted actions fail to achieve the desired outcome.

Please draw a line on the thermometer that best describes how much moral distress you have been experiencing related to work in the past week including today.

**Clinical Triggers**

- Current treatment
  - o unnecessary
  - o causes undue harm
  - o non-beneficial
  - o prolongs dying
  - o hastens death
  - o not in patient's best interest
  - o Disregards patient preferences
    - o Based on surrogate demands
    - o Due to provider preferences
  - Inadequate symptom relief (e.g. pain, dyspnea)
  - Unclear goals of care (lack of treatment plan)
  - Lack of consensus regarding treatment plan
  - Lack of continuity/treatment plan/providers
- Other \_\_\_\_\_

**Internal factors**

- Feeling powerless
- Difficulty stating the ethical issues or ethical concerns
- Lack of assertiveness
- Self-doubt, Clinical inexperience
- Socialization to follow orders
- Personal values compromised
- Professional values compromised
- Other \_\_\_\_\_

**Institutional/Environmental factors**

- Lack of involvement in decision-making
- Inadequate staffing
  - o not enough
  - o not right mix
- Lack of administrative support
- Policies that conflict with care needs
- Tolerance of disruptive/abusive behavior from staff
- Tolerance of disruptive/abusive behavior from patients/families
- Issues of unequal power within healthcare system
- Inadequate resources to meet patients' needs
- Excessive documentation requirements
- Preferential treatment of some patients/families (VIPs)
- Compromised care to marginalized populations
- Safety concerns
- Other \_\_\_\_\_

**Communication and Interpersonal Issues**

- Information withheld
- Incorrect information
- Feeling “in the middle” between key stakeholders
  - o Between physicians and patients
  - o Between family members and patients
- Providers giving false hope
- Inadequate team communication
- Intra-professional conflict (e.g. RN to RN)
- Inter-professional conflict (e.g. RN to MD)
- Work with clinically unsafe staff
- Fear of retribution if I speak up
- Feeling disrespected by those in authority
- Other \_\_\_\_\_

**Legal and Regulatory Factors**

- Treatment plan focused on risk avoidance
- Compromised care due to cost containment
- Tension between ethical and legal perspectives
- Other \_\_\_\_\_

Are you thinking about leaving your current job due to moral distress? YES NO

Please comment on anything you believe is relevant to your level of moral distress (e.g. a particular patient assignment, attendance at educational offering or contact with an ethics resource)

\_\_\_\_\_

\_\_\_\_\_

**Figure: Thermometer scale and parameters for recording moral distress for nurses**

Healthcare is a sensitive field taking into consideration the well-being of the patients. Nurses and other hospital staff remains neglected on all fronts and need attention to assure the mental and physical well-being of the patient. Dr. Wocial, with an attempt to digitize the paper tool holds a vision to provide treatment in the form of interventions to the nurses.

The report describes our project to design and develop a prototype of a mobile application that allows nurses and other health care professionals to record their level of moral distress.

## 2. Business requirements

Dr. Wocial helped us understand the current scenario for nurses, nurse managers, physicians, and other staff in the hospital setting. She introduced us to her research in the field of moral distress and made us aware of the various triggers that contribute to the moral distress of nurses. The following requirements were determined in the initial stakeholder meeting.

- **Authentication**

Provide the user with the authenticated entry to the system by sign-in. This feature will ensure secured access to the application for the nurses and Nursing Managers.

Authenticated access to the application will ensure the privacy of user's data.

- **Record the level of distress**

This section of the application is mainly for the Nurses to record the moral distress parameters. This feature will have two more sub categories:

1. Record Moral Distress Level using Thermometer Analogy

Nurses will select the level of their Moral distress with a Thermometer analogy

2. Select all possible causes for the Moral Distress

Nurses can select possible causes of the moral distress level with multiple options.

- **Aggregate Moral Distress Level**

A Nursing Manager should be able to view and print an aggregate level of Moral Distress in a particular Nursing Unit. The access to this page will also be secured by providing authentication to the Nursing Managers.

### **3. Literature Review**

A literature review was conducted to validate and understand the problem space and existing interventions for moral distress.

#### **3.1 Validating the Problem of Moral Distress**

Every nurse is an advocate of the well-being of every patient; this forms a central part of their schooling as a nurse practitioner (International Council of Nurses, 2012). Moral distress occurs when the nurses want to advocate for the user but fail to do so, due to several hindrances (Jameston, 1984). A recent study on moral distress in nurses suggests that the highest level of moral distress is found in critical care nurses as compared to non-critical care specialties (Whitehead et al., 2015). Moral distress is a very prevalent phenomenon among nurses and other health care practitioners and is associated with job dissatisfaction (De Veer et al., 2013), burnout (Whitehead et al., 2015), emotional exhaustion on the job (Meltzer et al., 2004) (Oh et al., 2015), and staff turnover (Burston et al., 2013; Corley, 2002). Another recent multi-site study of 323 healthcare professionals, including nurses, suggests that professionals who look to leave the healthcare profession or who have already left the profession rate moral distress as the prime cause of this decision (Allen et al., 2013).

#### **3.2 Research in the Area of Measuring Mental Health**

There have been attempts to develop scales to measure emotional well-being of a person. One example is the Maslasch Burnout Inventory scale, which assesses different types of “burnout”. In this scale, the three important measures of burnout are emotional exhaustion, depersonalization and reduced personal accomplishment (Maslasch et al, 1997). Another attempt to measure the

psychological behavior of general users is called the Cancer Coping Questionnaire (CCQ) (Moorey et al., 2003). A scale that was developed to measure moral distress is the Moral Distress Scale (MDS), which is a 38-item instrument that has different clinical conditions that lead to ethical issues and moral distress among nurses (Corley et al., 2005). (Dyo et al., 2016) state that the clinical conditions leading to moral distress among nurses include “several categories: individual responsibilities (physician practice, nursing practice and institutional factors), care not in the patient’s best interest (futile care), deception and euthanasia.”

### **3.3 Technology and Healthcare**

There have been attempts to use technology in nursing care to improve the lives of nurses, who are constantly thriving to help improve patient care. Technologies that facilitate non-invasive and less invasive use of treatment and diagnostics will help nurses provide stress-free care to the patient (Carol 2013). Health care providers, which include nurses, handle a large amount of patient records 24 hours a day and 7 days a week. These records provide coordinated care to the patients and facilitate accountability (Carol 2013). Electronic Health Records (HER) are of great help not only to the nurses but also to the other health care practitioners. Many federal programs currently exist to support EHR adoption, including those around meaningful use (capturing the right data that can improve patient outcomes); the implementation of electronic information exchange; consumer e-health; and workforce training (Centers for Medicare and Medicaid Services, 2010; Take 5 with a Nurse Leader, 2012).

Judy Murphy, deputy national coordinator for Programs and Policy at the Office of the National Coordinator (ONC) for Health Information Technology, Department of Health and Human Services, in Washington, DC stated that “I used to think we [nurses] provide health care first, and that the need for health information was secondary” (Take 5 with a Nurse, 2012, para. 8). Murphy suggests that in this age of information we cannot separate information technology and healthcare. The nurses need the right information at the right time to make decisions that help them improve patient care and act ethically. She also suggests seeing the nursing profession as an information based profession and technology plays a part of taking

this information to the point of care (Carol, 2013). A significant amount of research has been conducted on moral distress in nurses. Researchers have explored factors that have caused moral distress to the nurses and nurse managers. We have not, however, found significant research that has combined moral distress with technology.

## 4. User Research

In our user interviews sessions, we attempted to validate the problem space that was defined by stakeholder inputs and also focused on identifying user needs. These sessions also helped us get an idea about nurse's work hours and work environment. The interviews exposed us to a day in nurse's life and helped us understand their emotions and needs when working in a highly critical and sensitive environment.

### 4.1 Introduction of User Sessions

We conducted three interviews at the IU Health Hospital coffee room. The unit that we covered was the Intensive Care Unit (ICU), where most of the critical care nurses work. The patients in this unit are generally more critical than patients in other units. This brings us to the hypothesis that the nurses are a lot more distressed in the ICU, than in other units, because the rate of deaths is higher in the ICU. Nurses were asked to participate in the sessions in their break times. The following is the procedure that we followed:

- 1. Introduction:** We made them aware that we were working with Dr. Wocial
- 2. Welcome and Project Brief:** We read the Interview Script to each of the nurses.
- 3. Consent:** We asked them for their consent for recording audio
- 4. Survey:** We provided them a questionnaire.
- 5. Interview:** We asked them a few open ended questions to get their insights.

### 4.2 Participants Response Summary

The three interviews conducted not only validated problem space for us but also made us aware of the diverse factors contributing to moral distress. Participant responses were unified in terms of undergoing moral distress and also showcased

that it differs with the type of unit a particular nurse works in. The critical care unit nurses often experienced moral distress. Below is the summary of responses gathered from the interviews with nurses.

1. Lack of staffing is a reason for moral distress.
2. Work schedules restrict nurse availability to meet the required counselors or consultants arranged by the hospital administration.
3. The ethics class of “Stress and Coping with the Stress” helps nurses cope with stress.
4. Nurses enjoy spending time with family and sharing stress-related issues with family.
5. Nurses are aware of certain scales that help measure mental health, such as the Maslach burnout scale and the cancer patients tool.
6. Nurses prefer sharing information with a small set of close peers who are considered as friends.

## 5. Project Scope

At this stage of the project, our initial project proposal included that the solution should consist of the following theme or areas:

**1. Data Collection Module:** This module will help us explore the ways technology can intervene to improve the collection of data from the nurses. The constraints here would be to identify most simplistic ways to capture data and at the most appropriate timing.

**2. Therapy Recommendations:** Based on the data captured and the state of the nurse's distress level, the solution will give them immediate feedback and therapy recommendation based on their preferences, severity level and other parameters that we learn about them.

**A. Follow up on the progress:** This would be the sub module that would ideally help us follow up with the nurses by giving them extra care based or therapy reminders based on their consent.

**3. Data Visualization Module:** This module will visualize the data that the individual nurse captures and the individual nurse data would be aggregated to nurse managers without disclosing the identities of the nurses.

**A. Aggregate Individual Nurse Data:** This sub module will focus on the visualizing the individual nurse's data.

**B. Aggregate Nurses Data for Nurse Manager:** This module will focus on visualizing the aggregate nurses' data to the nurse managers in order to take appropriate decisions. The visualizations could be printed to showcase daily status of the nurses in the unit.

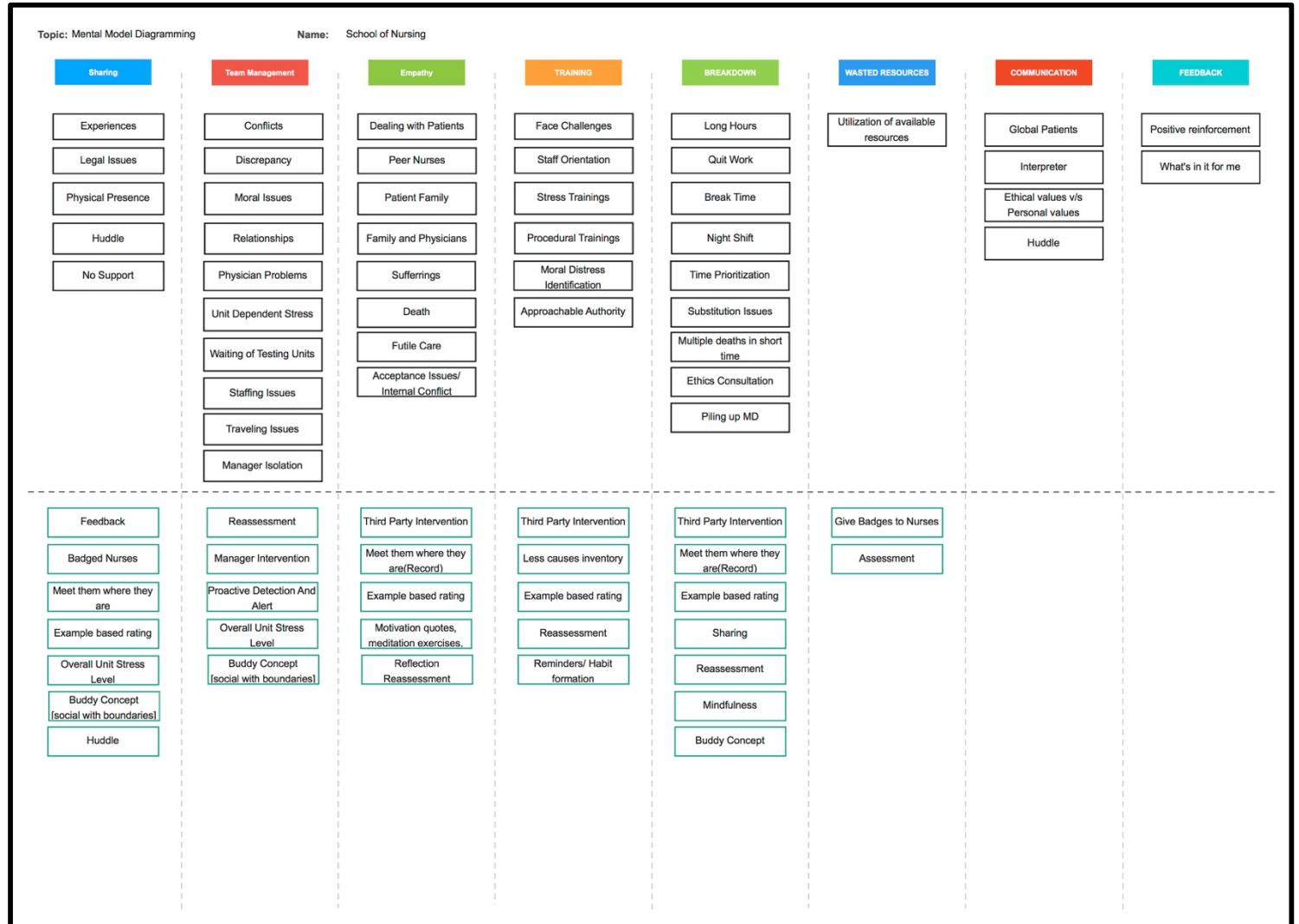
## 6. Making Sense of Data

From the interviews and surveys we were able to collect data from nurses regarding their levels of moral distress and their concerns about moral distress. The next step for us was to derive insights from the raw data collected and categorize it into buckets that would allow us to make sense about the data and derive models for further conceptual design. For categorizing the interview data, we decided to create an affinity diagram as a data modelling technique. We also attempted to characterize the nurses' and nurse managers' mental models regarding their concerns and the remedial measures they take to address those concerns.



**Figure: Affinity Diagram for nurses to categorize the inputs gathered through one-on-one interviews.**

## IMOD – INVENTORY OF MORAL DISTRESS



**Figure: Mental Model Diagram to understand the problems and possible solutions from the nurse's point of view.**

## 7. Conceptual Design

After the data modelling exercise, we conducted individual brainstorming session taking into consideration the insights derived from the previous techniques. We each came up with five concepts, which was further refined by conducting group brainstorming sessions to derive three concepts.

Three broad categories of solution are as follows:

**1. Only strategic solution:** The idea behind having an “only strategic solution” was to cater to the needs of nurses who are not willing to use technology to a large extent. Many nurses mentioned using their cell phones for calling and texting purposes only.

**3. Only technological solution:** This conceptual design category is based on a complete technology solution such as wearables and a mobile application. This concept catered to the young nurses who are tech-savvy and frequently use their mobile phones for social media and internet browsing.

**2. Combined strategic and technological solution:** This concept was derived keeping in mind the current advancement in technology and also addressing the needs of nurses and nurse managers. With this solution, we hoped to target an innovative and out-of-the-box solution that would use sensory signals to detect moral distress and communicate with nurses using interactive intelligent technology.

The concept selected to implement in a low-fidelity prototype was the “only technological concept”, although some ideas from the “only strategic concept” were identified to be included in the prototype. Our low-fidelity was developed using Balsamiq. The concept is a mobile app for nurses used to record moral distress, along with a social platform with boundaries within the hospital to maintain the privacy and adhere to the legal regulations of the hospital.

The final concept chosen catered to the needs of the nurses mentioned during the interviews. The nurses mentioned to be subjected to research and collect moral

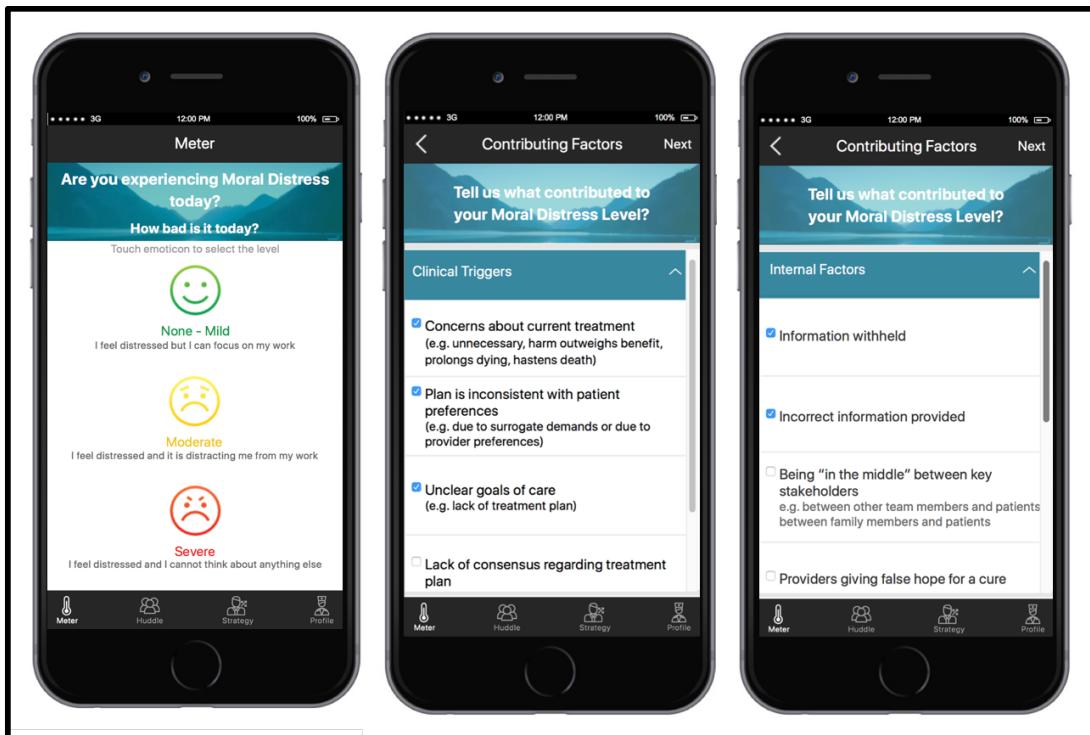
distress data but no action taken further. We proposed a mobile application taking into consideration our users (the nurses) technology use and also proposed to keep the recommended interventions for a short time interval understanding the limited amount of time nurses get to spent during their busy day.

While experiencing moral distress, subjecting nurses immediately to recommended strategy would benefit them less versus asking them to take a step back and relax before performing the recommended intervention. Following are the main functions of the final concept:

- 1. Meter:** Allows nurses to record their level of moral distress from the three levels “mild”, “moderate”, “severe” and select the factors contributing to a particular level of distress.
- 2. Strategy:** Suggests interventions such as “mindfulness”, “coloring”, “physical activities” and also tracks the level of moral distress after performing a certain strategy.
- 3. Huddle:** Social platform within the hospital boundaries for nurses to chat with their peers, charge nurses, nurse managers and nurse ethicist. It also allows the nurses to create groups for discussing a pressing situation or share some important information with a set of people.
- 4. Profile:** Allows nurses to update their personal information and track progress of the strategies performed in the past to benefit from them in the future.

### **High-Fidelity Prototype**

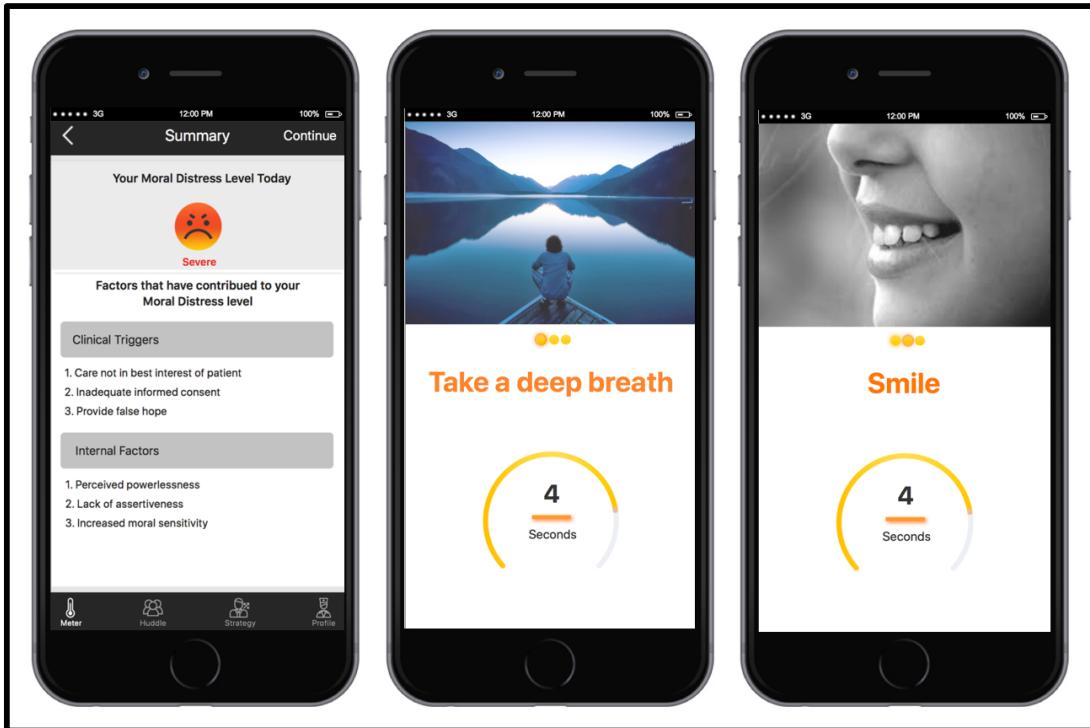
After evaluating the low fidelity prototype with our users we developed a high-fidelity prototype using the Axure RP tool.



**Figure: Meter recording screen, Clinical Trigger screen and Internal Factors screen**

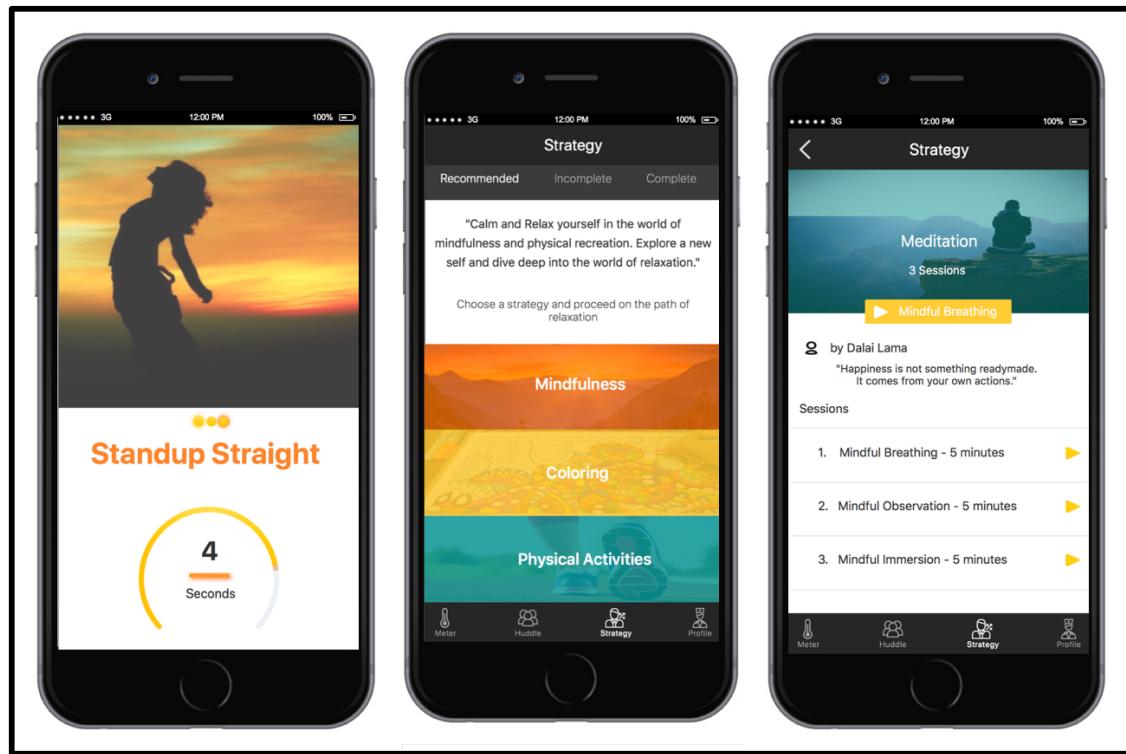
The screens above belong to the meter functionality which allows the nurses to record their level of moral distress. After Sign in, nurses select one of the three level which are “Mild”, “Moderate” and “Severe” shown by the three colored smileys. The recording scale was deduced from the extensive 10-point scale introduced in the moral distress thermometer concept to keep it aligned with the mobile design specification and not overwhelming the nurses with choices in the initial process itself.

After selection of a certain level, the nurses are asked to choose from a list of contributing factors. Every high level contributing factor consists of sub-factors that explain in detail about what exactly contributed for the moral distress of nurses. The contributing factors help the nurses to understand and map their level to triggers for the nurse managers or nurse ethicist to understand in order to help nurses to cope up with their distress.



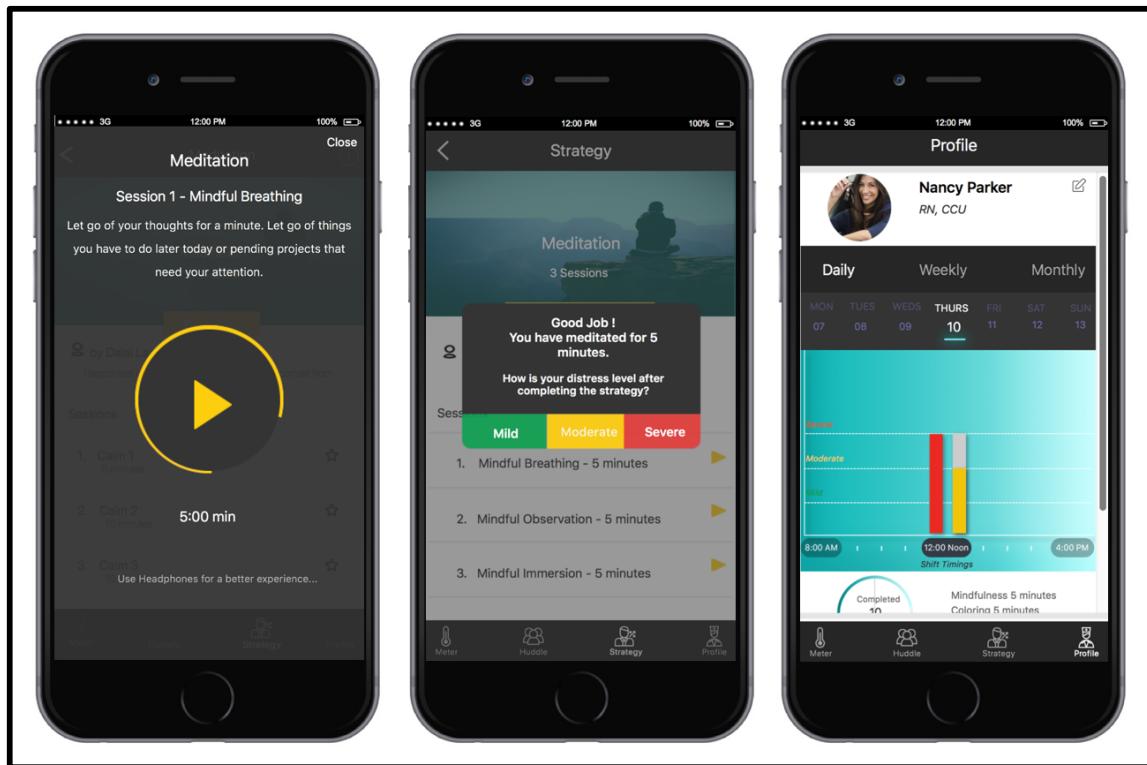
**Figure: Summary screen, Crisis management step 1 screen, Crisis management step 2 screen**

The nurses are presented with a summary in case they have to go back and rethink on their selection of contributing factors. After recording the moral distress level, the nurses are subjected to crisis management sessions with each screen lasting up to 4 seconds. The reason behind this design decision was to allow the nurses to take a step back and relax before going ahead with the recommended strategy. Subjecting person immediately to a coping strategy reduces the benefits reaped from the strategy. Introducing crisis management steps allows the nurses to calm down and take up the strategy to get the maximum benefit out of it.



**Figure: Crisis management step 3 screen, Strategy screen, Mindfulness activity screen**

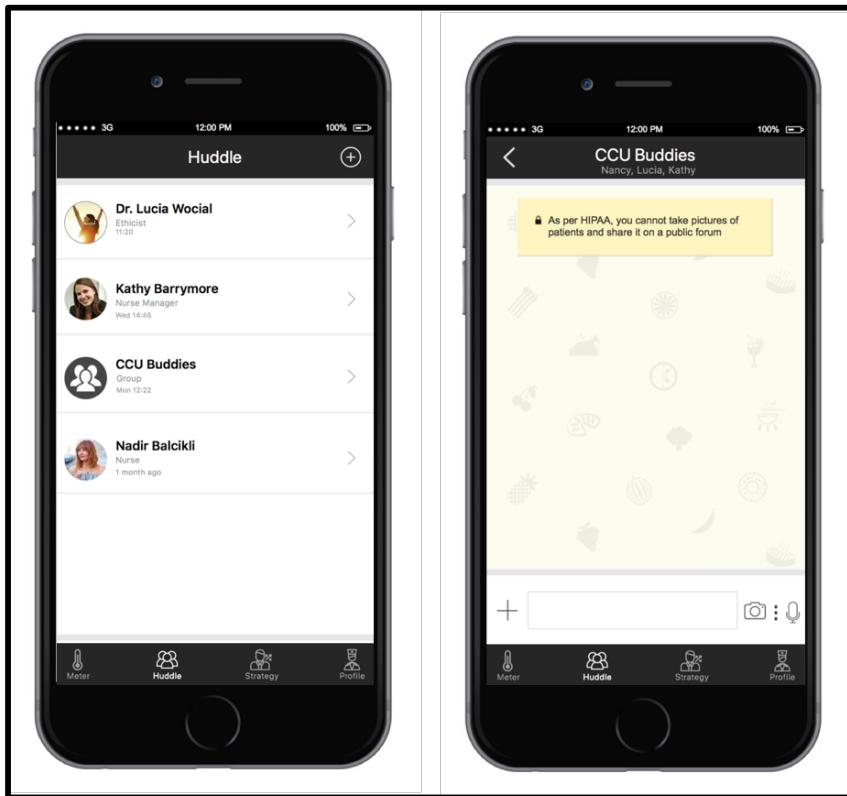
Once completing the crisis management steps, nurses are recommended few strategies to choose from. The strategies are divided into three sections namely “Mindfulness”, “Coloring” and “Physical Activities”. Each strategy contains 5 minutes’ activities. The activities are designed keeping in mind the time nurses are able to devote using the app. The app is designed with the intention of utilizing least amount of time of the nurses and to be used in the small breaks at work. The activities in the strategies align with this design consideration. The nurses perform selected activity from the recommended strategies. Any incomplete activities would reflect in the incomplete tab of the strategies.



**Figure: meditation activity 1 screen, feedback screen, profile screen**

After taking up a 5 min activity, the nurses are asked to rate their moral distress again. The reason for taking feedback in the form of moral distress level is to reiterate over the level after performing a certain activity to see if the activity benefited the nurse. It also provides the nurse with their progress to revisit and perform an activity at a later point in time. The nurses are suggested to take up another activity after providing a feedback. Guiding them through the further steps helps them to decide rather than leaving them in the middle of the situation. Due to frustration of moral distress the nurses sometimes are unable to decide what is beneficial for them and might overlook the coping measures. The activity suggestion interaction aids the nurses to do the decision making in the situation of distress. Eventually the nurses are asked if they would like to share their causes of moral distress with their peers, nurse manager, nurse ethicist or charge nurse. The idea of the app along with recording the moral distress and providing interventions is also helping the nurses to vent out. We want the nurses to share moral distress for them to understand why did they undergo distress at the first place. Making the

nurses aware of the moral distress will help to train to handle similar situations of distress with more ease and without affecting self.



**Figure: Huddle home screen, Group chat window screen**

For venting we have provided the nurses with huddle functionality which is an inbound chat platform. Nurses can use this platform to create groups for sharing their moral distress. They can also select particular peers to chat with. The profile section helps them edit personal information and also track the progress of the activities performed.

## 8. Usability Evaluation and Results

We conducted six usability test sessions with nurses and nurse coordinators with varied experience level and age groups at University Hospital and Riley Hospital. Each of the six sessions lasted for 40-50 minutes each. We used a “think-aloud” method for our user testing. The think-aloud method involves asking participants to verbalize their thoughts while performing a set of tasks. We audio recorded each

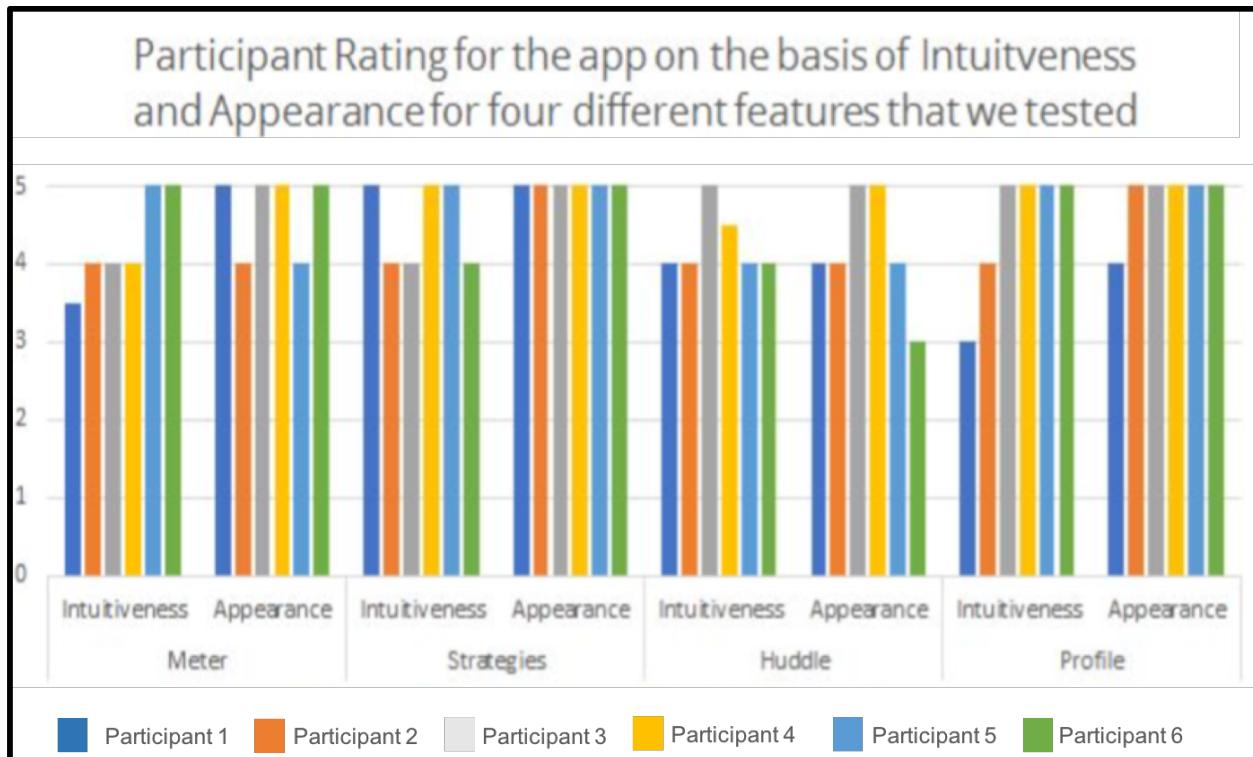
of the sessions along with taking notes. Our usability testing was designed around four scenarios where the nurses were recited the scenario first and then asked to perform a set of tasks. Each scenario targeted a particular function of the app. After performing each task, we asked the nurses to rate the app based on the intuitiveness and appearance of the screens. Questions asked to the nurses after performing the task were as follows:

1. On a scale of 1 to 5, how intuitive was the screen navigation and flow?
2. On a scale of 1 to 5, how pleasant was the appearance of the screens you just saw?

The ratings were charted to display the comparisons between the different functions based on intuitiveness and appearance.

Following are some of the comments from the usability evaluation sessions:

1. One of the participant mentioned the graphical representation of the smileys for recording moral distress levels to be visually appealing and meaningful.
2. Nurses appreciated the crisis management steps and were able to relate to situations that frustrated them due to which they could not concentrate on any of their tasks at hand.
3. The recommended strategies were the ones that they desired performing in their free/break time.
4. Revisiting their level of moral distress after taking up a strategy was a very well accepted design decision.
5. “I would suggest changing the text on the crisis management steps, because I won’t be able to smile when I have witnessed a child’s death”.
6. “Can I talk to people only from first shift?”



**Figure: Participants ratings for intuitiveness and appearance of the app.**

The figure above represents the ratings of six participants based on the intuitiveness and appearance of the app. Participants rated the strategy function high in intuitiveness and appearance and also expressed to see journal writing as one of the recommended strategies. Meter and profile screens were also rated above average however; the users were confused with the contributing factors selection interaction. The data visualization chart on the profile screen was not very clear to the users. Huddle function was appreciated a lot by the nurses. They were happy to find a space where they can vent out their feelings of distress with their peers specially the night shift nurses. The nurses were pleased with the simplicity of interactions and the color scheme of the application. They were very excited to see the kind of solution proposed to record and cope with their moral distress. Nurses were able to understand and navigate through all the functions seamlessly with less effort. They also mentioned the strategies to be engaging and relaxing for the amount of time they are asked to spent on performing those strategies. Overall there were also few suggestions made with respect to the huddle functionality.

Nurses wanted to filter their peers based on their shift timings. They also desired to network with nurses from other units and see how other units are fairing with their moral distress levels through huddle.

## 9. Future Work

IMOD application has great potential to assist nurses to navigate the emotional components of the experience of moral distress. The app will help the nurses to be heard in times of distress and take-up short treatment strategies recommended for their well-being. With minimum exposure to use of technology during their entire day the app allows nurses to utilize the time they could take off from work and indulge in the activities that helps to relax. Currently the app requires few refinements that were suggested during the usability evaluation sessions by the nurses to make it more effective. Further work is needed to develop the app to assist with navigating the ethical challenges that led to the feelings of distress. Nurse Managers profile and aggregating the moral distress data in the form of data visualization for them is also one of the potential areas of future development. Website for nurse managers would leverage the effectiveness of the iMoD app and both together would helps the nurse and the nurse managers to deal with the problem of moral distress efficiently.

## 10. Appendix

### 1. Low-Fidelity Prototype

The screens include profile, meter, huddle, strategy for moral distress.

Low fidelity Screens link

[https://docs.google.com/a/umail.iu.edu/document/d/1192q6NnmpO9E4WZCfFtH2yNCpphwUldukOV-ouvKyGg/edit?usp=sharing.](https://docs.google.com/a/umail.iu.edu/document/d/1192q6NnmpO9E4WZCfFtH2yNCpphwUldukOV-ouvKyGg/edit?usp=sharing)