The Journey of the Purple Butterfly: A Quality Improvement Initiative

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Abstract

Introduction: Dying in the hospital is not always a good experience for patients and their families. To be more in line with evidence-based practices for healthcare workers to effectively support high quality end of life care, the project team implemented a standardized communication tool to alert interdisciplinary team members of patients on comfort care measures. **Methods:** Purple Butterfly was a quality improvement project that was implemented at a diverse community hospital in the urban setting. Clinical and non-clinical interdisciplinary team members participated in a pre- and post- implementation survey to assess the need for a standardized communication tool that would alert them of patients who transitioned to comfort care. **Results:** Pre-implementation, 37% of survey respondents (n = 60) reported they were always aware of the presence of a patient on comfort care measures prior to entering the room. After implementation of a standardized communication tool, 100% (n = 43) of respondents at 9 months, reported that they were always aware of the presence of a patient on comfort care measures prior to entering the room. Additionally, 9 months post-intervention 100% of respondents reported that knowing this contextual information supported them in performing their job duties in a compassionate, patient-centered fashion. **Conclusion:** Implementation of a standardized communication tool increased awareness for team members, about the presence of patients on comfort care measures prior to entering the room and supported team members to perform their job duties in a compassionate, patient-centered fashion supportive of this patient population.

Keywords

comfort care, palliative care, end-of-life, communication, purple butterfly, compassionate care, patient-centered

Introduction

Globally, it is estimated that about 20.4 million people are in need of high quality end-of-life care.[1] Similarly, by the year 2040, approximately 75-88% of patients at the end stages of life could benefit from high-quality palliative care.[1] Palliative care focuses not only on providing patients with symptom and stress relief, but also embracing the care of the patient at the end of his/her life.[2] Caring for the dying patient is complex; it encompasses symptom management, holistic, culturally sensitive practices and assisting patients and families with grieving, the dying process, and ultimately, the death of their loved one.[3]

The terms "end-of-life care" (EOL care) or "comfort care" are commonly used in the healthcare setting to describe care measures provided to patients who are imminently facing death. Comfort care measures aim to provide symptom relief and other therapeutic interventions for patients close to death including physical, emotional, and psychosocial needs for both the patient and family.[4] Moreover, while there is a large focus on death itself, implying a single event, the way a person dies, including the delivery of care, is of a particular importance to the family and friends of the person who passed on.[5] That said, healthcare providers play an influential part in the dying process by ensuring death transpires in an environment fostering

patient and family centered care, support, dignity, and autonomy.[5]

Care providers who impact the dying journey, irrespective of professional roles, can both positively and negatively affect the dying experience regardless of the number of patient and family interactions.[5] High quality EOL care is so important to the patient's family and support system and could aid in decreasing psychological symptoms after the loss of a loved one when high quality EOL care is provided.[8] That said, despite the high proportion of patients who could benefit from palliative care and evidence-based recommendations to ensuring high quality end of life care, there are little to no strategies for how healthcare settings should communicate to interdisciplinary teams when patients are on comfort measures and at the end of life.[9] Prior to improvement initiatives, verbal handoff report about

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Table 1.

Pre- and post-implementation survey participation by clinical and non-clinical teams [a]

Pre-purple butterfly implementation survey

	Clinical Healthcare Teams	Non-Clinical Healthcare Teams
Total pre-survey participants (n = 60)	30 participants (50%)	30 participants (50%)

Post-purple butterfly implementation surveys

	Clinical healthcare teams	Non-clinical healthcare teams
Total post-implementation survey participants 3 months post (n = 60) 6 months post (n = 41) 9 months post (n = 43)	30 participants (50%) 20 participants (48.8%) 23 participants (53.5%)	30 participants (50%) 21 participants (51.2%) 20 participants (46.5%)

[a]Percentages reflect proportions of respondents from clinical and non-clinical teams

patients on comfort care measures was the common practice for the primary healthcare teams at the intervention hospital, however, this specific patient information was rarely shared with disciplines outside of the primary care team. This gap in information between direct and indirect healthcare team members had the potential to affect how we managed all aspects of patient care at the end of life.

Problem/Purpose

In 2018, 15% of the patients referred to Palliative Care Services at the intervention hospital transitioned to comfort care measures and passed away during hospitalization. Prior to improvements, there was no standardized communication tool to alert all team members of the presence of patients on comfort care measures and at the end of life prior to entering the patient's room. The purpose of this quality improvement project was to:

> **Aim 1:** Implement a tool to communicate to both clinical and non-clinical team members of the presence of patients on comfort care measures prior to entering a room or engaging with the patient/family and their environment.
>
> **Aim 2:** Create a stronger foundation for all care team members to perform their job duties in a more compassionate, patient-centered fashion that is particularly supportive of patients at the end of life.

Methods

This quality improvement project was conducted from January 2019 to December 2019 at a small, urban, culturally diverse community hospital that is a subset of a multi-campus acute-care healthcare system. The intervention units included 3 medical-surgical units and one medical intensive care unit (MICU). There were 4 primary specialties on both the medical-surgical and MICU patients including medicine, surgery, orthopedics, and primary care. Institutional review board approval was not needed for this quality improvement project.

In order to capture an interdisciplinary group of healthcare workers, both clinical and non-clinical team members participated in a 3 question pre- and post-survey. The surveys were designed de novo and underwent peer review from the Director of Nursing, a registered nurse, and a food and nutrition ambassador for content reliability and validity. Peer reviewers recommended no changes to the proposed survey. Surveys from both pre and post intervention assessments were conducted in person. Participants were randomly selected from the intervention units based off availability at the time of survey collection and they verbally consented to participating prior to completing the survey. Demographics were limited to participant identification of which interdisciplinary group they were in, clinical or non-clinical. Clinical teams are described as licensed or certified professionals that provide direct patient care. Clinical team members could include registered nurses, patient care technicians, physicians, physician assistants, physical therapists, and social workers. Non-clinical team members describes professionals that do not provide any medical treatment or testing but who directly interact with patients. Non-clinical team members could include unit clerks, environmental housekeepers, food and nutrition ambassadors, and patient transporters. Table 1 describes the proportions of respondents for each survey interval. The survey was designed to help understand whether clinical and non-clinical team members, outside of the primary care team, were always aware of patients on comfort care measures prior to entering a patient's room or engaging with a patient and/or family. Similarly, we aimed to learn if communicating this contextual information to team members would support them in performing their job duties in a more compassionate, patient-centered fashion that is tailored and individualized to this patient population.

In February 2019, a 3 question pre-survey was conducted amongst clinical (n = 30) and non-clinical (n = 30) team members. Respondents answered the following questions using a Likert scale of strongly disagree, disagree, neither agree or disagree, agree and strongly agree:

Figure 1. Purple Butterfly door sign.

1. You ALWAYS know if there is a dying patient (who transitioned to comfort oriented measures) in the room you are about to enter?
2. You would feel better prepared to perform your job duties in a more compassionate patient-centered fashion if you ALWAYS knew that there is a dying patient on comfort oriented measures in the room you are about to enter?
3. Knowing there is a dying patient on comfort oriented measures before you enter the room will make a difference of how you would approach the patient and/or family.

Post intervention survey questions 2 and 3 were modified to assess improvements retrospectively. Post implementation questions 2 and 3 were as follows: 2) After implementation of the Purple Butterfly door sign, you feel better prepared to perform your job duties in a more compassionate patient-centered fashion knowing that there is a dying patient on comfort oriented measures in the room you are about to enter? 3) Knowing there is a dying patient on comfort oriented measures before you enter the room makes a difference in how you approach the patient and/or family.

In March 2019, a lavender-colored sign pictured with a butterfly, also known as the Purple Butterfly sign (Figure 1), a symbol of transition, was displayed at the entry of rooms to alert all team members of a patient on comfort care measures. The sign was designed to provide contextual communication for all interdisciplinary team members prior to entering a patient's room or engaging with the patient and/or family. To ensure cultural and spiritual neutrality amongst a diverse patient population, the Purple Butterfly sign was vetted through Pastoral Care, Patient Services Administration, and the Palliative Care committee. No spiritual, religious, or cultural concerns were noted. The following criteria needed to be met for the Purple Butterfly Sign to be displayed:

1. The patient is actively dying and a goals of care discussion took place
2. Patient and/or family opted for comfort care measures
3. Do Not Resuscitate (DNR) is in effect and comfort measures are ordered by the primary team

It is important to note that while DNR patients were included as part of the criteria for the Purple Butterfly sign to be displayed, Do Not Intubate (DNI) patients were not. The logic behind this was that patients could already be intubated when the goals of care discussions took place and comfort care measures were ordered.

The Clinical Nurse Specialist and Palliative Care Nurse Practitioner provided education about the communication tool to all interdisciplinary departments via team huddles, email, flyers, and at a large interdisciplinary leadership team meeting the full month prior to intervention. Team huddles were held in clinical settings (i.e. nursing stations) and included both clinical and non-clinical team members. Additional huddles were held to specifically target larger groups of non-clinical team members during their designated morning and afternoon change of shift team huddles. Educational flyers including information with the project purpose, an image of the Purple Butterfly communication tool and the targeted patient population were posted throughout the intervention hospital to capture all interdisciplinary team members who may not have been available at the time of in-person education. Additional supplemental education was provided as needed by department leadership for new hires and team members who didn't participate in in-person sessions.

Starting in June 2019, 3 months post-intervention, a 3 question post-survey was conducted to determine whether the implementation of a standardized communication tool, the Purple Butterfly sign, provided clinical and non-clinical team members, outside of the primary care team, with the contextual information that a patient was on comfort care measures prior to entering the patient's room. Post-surveys also captured if implementation of a standardized communication tool would provide interdisciplinary team members with the contextual information needed for them to provide tailored patient-centered, compassionate care specific to patients on comfort care measures. Additional post-implementation surveys were conducted at 6 months post intervention, in September 2019 and 9 months post intervention, in December 2019.

Results

Prior to implementing the Purple Butterfly communication tool, 37% of survey respondents (Figure 2) (n = 60) agreed (n = 11) or strongly agreed (n = 11) that they were always aware of the presence of a patient on comfort care measures prior to entering the room. To assess the value of the proposed intervention, participants were asked if a comfort care communication tool would be impactful to their care delivery and/or interactions with patients at the end of life. 83% (n = 60) of both clinical and non-clinical respondents either agreed
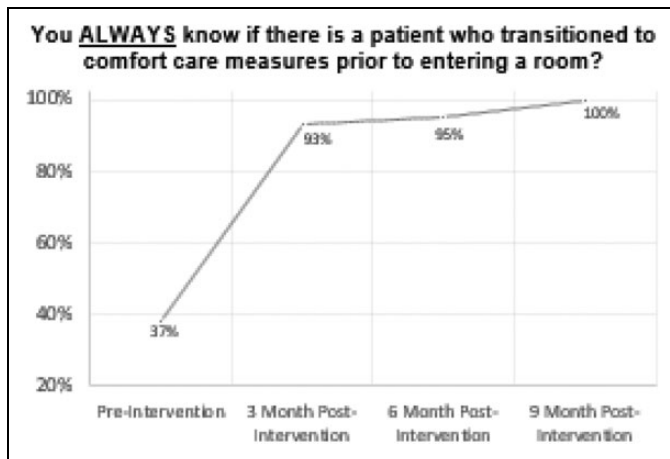
Figure 2. Pre- and post-survey question number one. Respondants answered using a five point likert scale (1) strongly disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) strongly agree. Participants who responded "agree" or "strongly agree" were included in this data. Survey question two was designed to learn if there was a gap in awareness about patients on comfort care measures.

(n = 12) or strongly agreed (n = 38) that knowing patients are on comfort care measures would better prepare them to perform their job duties in a more compassionate, patient-centered fashion specific to this population. Furthermore, 82% (n = 60) agreed (n = 15) or strongly agreed (n = 34) that having the knowledge of patients on comfort care measures prior to entering a patient's room would make a difference in how they approach the patient and/or family.

Post implementation surveys were collected at 3, 6, and 9 months. 3 months post-implementation 93% (n = 60) of respondents agreed (n = 8) or strongly agreed (n = 48) that after the implementation of a standardized communication tool, they were always aware of the presence of a patient on comfort care measures prior to entering the room. At 6 month post implementation, 95% (n = 41) agreed (n = 0) or strongly agreed (n = 39) and 9 months post, 100% (n = 43) agreed (n = 8) or strongly agreed (n = 35) they had awareness of patients on comfort care measures prior to entering a patients room. (Figure 2; Table 1).

Additionally, respondents were asked if knowing the contextual information that a patient was on comfort oriented measures would support them in performing their job duties in a compassionate, patient-centered fashion. 3 months post implementation of the Purple Butterfly communication tool, 93% (n = 60) of surveyed respondents agreed (n = 7) or strongly agreed (n = 47) that knowing this information assisted them in performing their job duties compassionately and fashioned for this population of patients. 6 months post intervention 98% (n = 41) agreed (n = 5) or strongly agreed (n = 35) and 9 months post, 100% (n = 43) agreed (n = 6) or strongly agreed (n = 37) that the Purple Butterfly communication tool supported them in providing care to comfort care patients (Figure 3).

Lastly, participants were asked if knowing there was a patient on comfort oriented measures prior to entering the room
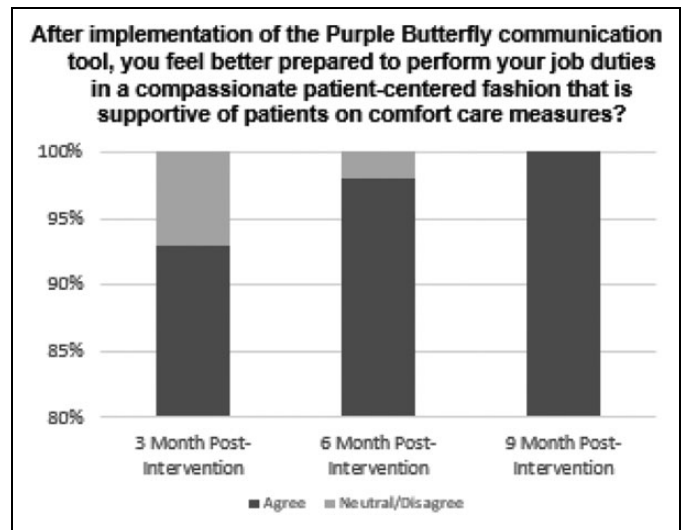

Figure 3. Pre- and post-survey question number two. Respondants answered using a five point likert scale (1) strongly disgaree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) strongly agree. Survey question two was designed to learn if the implementation of the Purple Butterfly communication tool was impactful on self-reported care delivery.
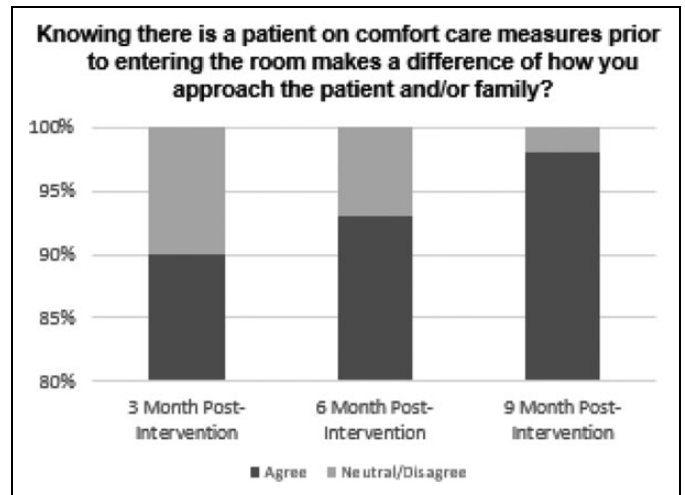

Figure 4. Pre- and post-survey question three. Respondants answered using a five point likert scale, (1) strongly disgree, (2) disagree, (3) neither agree nor disgree, (4) agree, (5) strongly agree. Survey question three was designed to learn if the implementation of the Purple Butterfly communication tool was impactful on self-reported care delivery.

made a difference in how they approached the patient and/or family. 3 months post implementation, 93% (n = 60) agreed (n = 7) or strongly agreed (n = 49), 6 months post implementation, 93% (n = 41) agreed (n = 1) or strongly agreed (n = 37) and 9 month post implementation, 98% (n = 43) agreed (n = 6) or strongly agree (n = 36) that knowing there was a patient on comfort oriented measures made a difference in how they approached the patient and/ or family (Figure 4).

Anecdotes from the Healthcare team

"As the unit clerk the Purple Butterfly allows me to be included in understanding our patients. It reminds me to be mindful before I enter the patient's room and to show a different level of sympathetic compassion towards the patient and family during this time". -Unit Clerk

"I'm always sure to keep my eyes out for the purple sign on the patient's doors. It makes me aware that I need to be a little more sensitive when in that patient's room". -Environmental Services Housekeeper

"The Purple Butterfly Project has empowered me with the knowledge, skills, and confidence to be able to easily identify patients (and their loved ones) who are nearing the end of their lives. This allows me to enter those rooms and treat those individuals with the compassion, dignity, and respect they so deserve . . . As healthcare workers, we are always striving to provide personalized, empathetic care. This project supports us in being able to do just that." -Registered Nurse

Discussion

The number of patients who wish to die at home is growing, however there is still a significantly high percentage of patients who die in the hospital, with approximately one-third of the deaths in the United States occurring in hospitals.[6] While some patients and/or their families choose aggressive, life-sustaining interventions, others decide to transition to comfort care measures and to avoid aggressive care at the end of life. For patients who transition to less aggressive measures at the end of life, hospitals remain a major site for end-of-life care with the average terminal admission lasting 7.9 days.[4] Although hospitals remain a common location for patient's final days of life, evidence suggests that dying in the hospital is not always a good experience for the patient and/or family.[7]

All healthcare team members, regardless of discipline, play a critically important role influencing the patient experience. Many influencing factors expand beyond elements that seem the most obvious such as providing medication when a patient is experiencing pain or a drink of water when they are thirsty. For patients who are at the end of their life, death can be supported through actions, words, and respect. Actions such as knocking before entering a patients room to notify them you are arriving in their space, consciously providing a quiet, stress-free environment when cleaning a room and emptying the trash, or acknowledging that the patients food tray may no longer be needed on the bedside table, but rather offering a box of tissues for grieving loved ones. The things that may mean the most to a patient and/or family during those final moments of life could be as simple as consciously speaking in a softer, supportive tone, rather than the jovial, encouraging manner many healthcare workers are accustom to communicating in. Question is; how can one show patient-centered compassion if there is no awareness of the situation in the room?

While many healthcare team members are aware of therapeutic ways we can communicate and interact with this specific patient population, it is imperative that healthcare team members are aware of this unique patient experience prior to engaging with the patient and/or family. Prior to the implementation of the Purple Butterfly communication tool, clinical and non-clinical team members often felt unaware when there was a patient on comfort care measures, leaving opportunities for gaps in therapeutic communication or care. The primary goal of this quality improvement project was to implement a tool that easily communicates to all team members when there is a patient on comfort care measures prior to entering a room or engaging with the patient/family and their environment. In creating this awareness, we created a stronger foundation for teams to perform their job duties in a compassionate, patient-centered fashion that is especially supportive of this patient population.

Traditionally, research has focused on patient and family perceptions about the care that was provided at the end of life and recommendations for how care can be improved when dealing with this patient population. Evidence-based recommendations for high-quality EOL care are crucial to the patient and family experience and it is essential that all members of the healthcare team can actively participate in a supportive, personalized patient experience. A multitude of disciplines directly and indirectly interact with patients and families throughout their hospital stay and often times, team members who are not directly taking care of a patient have a lack of awareness about what a patient and family are experiencing. The examples of housekeeping noisily exchanging trash bins, a nurse on the unit not addressing the alarming IV pump while passing the room, or food and nutrition leaving a food tray for a patient who can no longer swallow, all contribute to the necessity of this intervention. Without being acutely aware of a patient and families sensitive situation, intentional and deliberate supportive measures cannot be taken. The project team felt it was important to bridge the gap in awareness about when interactions with patients on comfort care measures were occurring to ensure evidence-based best practices can be provided. Future studies may look to delve deeper into the impacts of a standardized comfort care communication tool on patient and families perspectives of their care delivery, specifically from members outside of their primary clinical care team.

Limitations

There were several limitations apparent to the project. First, the project was developed to fit the criteria for a small community hospital, which is a part of a larger hospital network. While we were able to implement the project across all inpatient units at the same time in the small hospital, we understand that implementation might need to take place in several steps in a larger setting. Secondly, neither the pre-implementation nor the post-implementation surveys were blinded. This decision was made because many non-clinical healthcare workers do not have access to computers during their shift and the project team was not confident we would capture the numbers

of non-clinical team members we aimed to if we used electronic, anonymous platforms. Instead, the project team conducted the surveys in-person, on paper, and randomly chose a healthcare team member to complete it, which has the potential to skew the results. Thirdly, for sustainability we needed to provide continuing education to newly on-boarded staff on a regular basis. While we provided education to the healthcare team prior to implementation of the project, now frontline teams primarily do education during the orientation process. Lastly, although the symbolism of the communication tool can be appropriate for any patient population at the end of life, the intervention only took place on adult patients and may need further vetting to assess for neutrality prior to implementation with pediatric populations.

Conclusions

Implementation of a standardized communication tool increased awareness for both clinical and non-clinical team members, about the presence of patients on comfort care measures who are at the end of life prior to entering the patient's room. Similarly, implementation of a standardized tool communicating rooms with patients on comfort care measures supported healthcare team members to perform their job duties in a compassionate, patient-centered fashion that is supportive of this patient population. Further work is needed to examine the effect of this intervention on patient and families perception of the quality of care delivered at the end of life.

Authors' Note

This quality improvement project was conducted at NewYork-Presbyterian Lower Manhattan Hospital in New York, New York.

Brief Presenting Author Bios

Jessica O'Brien Gufarotti is a Clinical Nurse Specialist for Medical-Surgical services with 10 years experience at NewYork-Presbyterian Hospital. In this role, she focuses on 3 domains, patient and family, nurses, and the system. Furthermore, she provides support to nurses caring for patients at the bedside, ensures the use of best practices and evidence-based care, and drives practice change throughout the organization to help ensure optimal patient and organizational outcomes. She received her master's of science from the Hunter-Bellevue School of Nursing and her bachelor's in nursing at SUNY Plattsburgh. Ms. O'Brien Gufarotti is currently involved in multiple projects to help advance nursing practice and improve patient outcomes.

Anna Krakowski is a Palliative Care NP and has more than 10 years' experience in palliative care. She co-leads palliative care services at New York Presbyterian/Lower Manhattan Hospital. Anna is a Graduate from a Master Program at Hunter-Bellevue School of Nursing, Board Certified as an Adult/ Geriatric Primary Health Care Nurse Practitioner, Certified Hospice and Palliative Registered Nurse and certified Advanced Hospice and Palliative Nurse. She is ELNEC (End of Life Nursing Education Consortium) Certified Trainer. In 2011 she completed the Bioethics and Medical Humanities Certificate Program at Albert Einstein College of Medicine and is certified bio-ethics consultant. She is now enrolled in a Master of Science in Palliative Care with a Post-Graduate Certificate in Clinical Leadership and Administration In Hospice and Palliative Care.

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