A Dying Wish: End-of-Life Care With Intent

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The World Trade Center Health Program (WTCHP) is a limited-benefit federal health program that is administered by the National Institute for Occupational Safety and Health (NIOSH), a division of the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services. The program, authorized through 2090, provides no-cost medical monitoring and treatment for certified World Trade Center-related health conditions to those directly affected by the 9/11 attacks in New York, the Pentagon, and Shanksville, Pennsylvania (CDC, 2023). The WTCHP acts as both a provider and payer of services. In the years since the 9/11 attacks, the members of the WTCHP have aged, and many have become increasingly ill as their conditions have worsened. As some members face terminal illnesses, End-of-Life (EOL) care has become a focus of program administrators. Unless members and their families are prepared for EOL, unavailing or futile treatment may increase patient suffering and the overall cost of care. Due to these factors, the WTCHP has identified the lack of EOL care planning and ongoing utilization of futile treatment to be problematic. The purpose of this study was to identify ways to address these WTCHP concerns.

Significance and Purpose of the Study
Healthcare professionals are often unprepared to talk about EOL with their patients (Wyatt et al., 2021). Most are trained to extend life, not guide patients to its end. Due to this, it is vital to train healthcare professionals in providing EOL care and assisting with EOL care planning. Many providers, especially general and family practitioners, lack confidence in providing EOL care and find it challenging to communicate and prescribe these services (Wyatt et al., 2021).

The aim of this project was to identify best practices utilized by other payers and providers in planning EOL care and implement strategies that the WTCHP might use to guide their members in preparing for EOL. Additionally, a significant consideration in this project included researching methods other payers use to prevent unnecessary, unavailing, or futile care so as to promote good stewardship of government funds.

Research Question
Healthcare professionals are not given adequate training in providing information or assisting in decision-making regarding choices in EOL care (Woo et al., 2006). The lack of knowledge often results in continuing with futile care, causing unnecessary physical and emotional distress and unneeded expense to patients, families, and healthcare payers (Huynh et al., 2014). Often, palliative treatment is introduced too late in the dying process to benefit the patient (WHO, 2020), and only 14% of people who could benefit from palliative care receive it (WHO, 2020). With the goal of helping the WTCHP assist its members in planning for EOL and reducing futile care, the following research question served as a guide:

> How can EOL care be anticipated, planned, and provided to WTCHP members to improve their quality of life and decrease the cost of futile care to the program?

The researcher developed 10 guiding questions to assist in exploring this topic, focusing on responsibility, best practices, and regulations regarding EOL care and planning. In addition, current practices at the WTCHP were also reviewed.

Data Collection and Methodology
A comprehensive review of the available literature presented information on frameworks, best practices, benchmarks, and gap analysis. WTCHP internal and external reports, processes, and documents were reviewed to gain insight into the program's current status.

A customized methodology framework was developed to analyze the data comprehensively, answer the research question, and evaluate potential solutions. The researcher used the human performance technology model to evaluate the gap analysis and multiple perspective solutions and identify the best solution for the WTCHP. A TOWS matrix showed the actual and desired state for EOL Care Planning at the WTCHP. A gap analysis revealed several potential solutions. Each solution was carefully assessed for risk to the program and measured using the McKinsey 7-S framework, based on its impact on the program's social capital.

Recommended and Selected Solution
Grounded in the described methodology, a comprehensive solution that combined five of the potential solutions was selected. Implementation of a comprehensive EOL Care Planning Program includes:

- Addition of an EOL Status Assessment to the Benefits Eligibility Assessment Tool (BEAST)
- Development of an EOL Needs Assessment for Case Managers
- Development of an EOL Care Planning Tool for Case Managers
- Development of EOL educational materials for members and families

Commander Hannah Dupont of the WTCHP agreed that this comprehensive solution fully addressed the concerns of the program. The multifaceted solution helps the program address EOL assessment, planning, implementation, and education while also working to reduce futile care. The researcher conducted a force field analysis to evaluate the forces for and against the change and to assist in developing the change management plan.

Limitations and Generalizability
While some of these solutions may be adapted for use by other payers or healthcare entities, they are targeted directly at the WTCHP. Due to this, the results and solutions may not be easily generalized to larger organizations.

One of the weaknesses of the findings is the limited benefit nature of the WTCHP. Because the program only covers health conditions related to the members' exposure to the 9/11 attacks, the cause of death for some members may be something other than those conditions. In that case, the program may not be aware of other illnesses or conditions of the member or be notified if the member is facing EOL. Therefore, the program may be unable to support the member with case management or assist the member with EOL care planning.

Change Management Plan

A comprehensive change management plan was created to execute the selected solution. Following the ADKAR change management model, the primary focus areas are awareness of the need for change, desire to support the change, knowledge of how to change, ability to execute new skills and activities, and reinforcement to maintain the change. The detailed action plan includes a list of actions and activities, the responsible parties, and a flexible timeline for the WTCHP to initiate the plan when it best suits the program based on program needs. The start date may be adjusted to accommodate the large number of changes currently taking place. However, the timeline can be adjusted once implemented to support a systematic and successful implementation.

<div align="center">References</div>

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