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## HONOURING THY SELF: DISENFRANCHISED GRIEF AND THE PROFESSIONAL CAREGIVER

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Much has been written that highlights that fact that the profession of nursing is stressful and taxing both physically and emotionally on nurses. Most recently, the field of end of life (EOL) and palliative care has been acknowledged as a stressful occupation and that burnout, attrition, and a nurse's personal involvement is unique to this particular field of health care (Huggard & Nichols 2001; Lobb et al, 2010; Rollings, 2008). Caring for the nursing staff working within the field of EOL and palliative care has not kept pace with the advances in self-care that is acknowledge for other health care professionals. According to Gerow et al, 2010, the impact of death on a family and its members has been well documented throughout the literature including the grief response and process, yet the grieving process and self-care of registered nurses during and following the death of a patient has not been researched extensively as a result.

The purpose of this presentation is to demonstrate identify gaps that exist in EOL and palliative nursing for registered nurses in terms of self-care. Secondly, evidence will be presented in support of models that exist for registered nurses and policy makers to implement self-care within their organizations and into the EOL or palliative care setting. Implications of the lack of consideration of self-care in the profession will be discussed throughout the paper. Additionally, the concept of disenfranchised grief will be deliberated in terms of how this phenomenon has an additional negative affect and its consequences for health care professionals.

## SUBJECTIVE QUALITY OF LIFE/SYMPTOM MEASUREMENT OVER TWO DECADES

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The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) is a phenomenological approach to the measurement of quality of life (QoL), in which the terms- of-reference are determined by the individual. Little is known about the impact of symptoms on patients' quality of life. The degree to which the symptoms are actually bothersome to the patient is a missing area in symptom assessments. Waldron et al, demonstrated that symptom 'bother' is a separate entity from both symptom frequency and intensity. Quality of life is a dynamic construct. Over the course of time, areas of life meaningful to the patient to shift through a process of adaptation. There appears to a process of psychological adaptation that enables patients cope and maintain good quality of life, even in the face of adversity. This is a concept known as 'intra subject construct dynamism' or 'response shift'. Using an outcome measure as a clinical tool, especially in the area of quality of life (QoL) is uncommon. We hypothesized that individual QoL information may help improve patient's QoL outcome over time when shared with the multidisciplinary team.

**Results:** Results of seven Higher Theses are explored to reflect on all above views with both published and presented, Nationally and Internationally papers reviewed.

**Conclusion:** Subjective QoL can be measured in Advanced Cancer patients and incorporation of Symptoms, Symptom Bother/ Symptom interference with QoL and Response Shift as well as 'Using the Outcome as a Clinical tool' can really help this very vulnerable patient group.