

2013 Special Topics Conference: Peaks and pitfalls in longitudinal studies of symptom outcome data

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ABSTRACT

Symptom science is inherent in nursing care, with symptoms being guideposts for practice. The occurrence of symptoms has the potential to impact multiple health outcomes. In order to identify the natural history of a symptom, longitudinal data related to the occurrence and severity of symptoms over the disease/treatment epoch are essential and should include the collection of potential biologic correlates. One of the primary limitations with longitudinal studies is the problem of data missingness. This can then impact the analysis and interpretation of findings. Additionally, there are a variety of approaches to the analysis of the data. As part of the American Academy of Nursing Special Topics Conference this year, issues related to the planning and analysis of longitudinal data analysis were discussed. This article provides a summary of the presented content at that meeting.

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Introduction

Symptom science is inherent in nursing care, with symptoms being guideposts for practice (Armstrong, 2003). Each symptom is recognized to be a multidimensional experience (Armstrong, 2003; Lenz, Pugh, Milligan, Gift, & Suppe, 1997) that seldom occurs in isolation (Brant, Beck, & Miaskowski, 2010). Symptoms can occur concurrently or be multiplicative in nature, with several researchers suggesting that symptoms can occur in clusters and have a shared biologic mechanism (Cleeland, 2007; Miaskowski, 2006; Miaskowski, Aouizerat, Dodd, & Cooper, 2007). The occurrence of symptoms has the potential to impact multiple health outcomes as seen in the symptom experience model (Figure 1).

Symptoms may only be known and meaning established by the person experiencing the symptoms and their reports (Rhodes & Watson, 1987). As such, patient-reported outcomes (PROs) are often used as a method to collect self-reported occurrence of symptoms. Symptoms are often reported in terms of their quality, intensity, and timing as well as the potential distress or associated burden. There is a multitude of PROs available for self-report, including those capturing individual symptoms and those that include multiple symptoms reported concurrently.

Traditionally, symptom management has primarily consisted of treating the symptom once it has occurred or reached a certain level of severity, as shown in the lower portion of Figure 2. If the symptom occurs frequently in a population (e.g., if a chemotherapeutic agent is considered highly emetogenic), there may be an attempt at prophylaxis, but this is often given to

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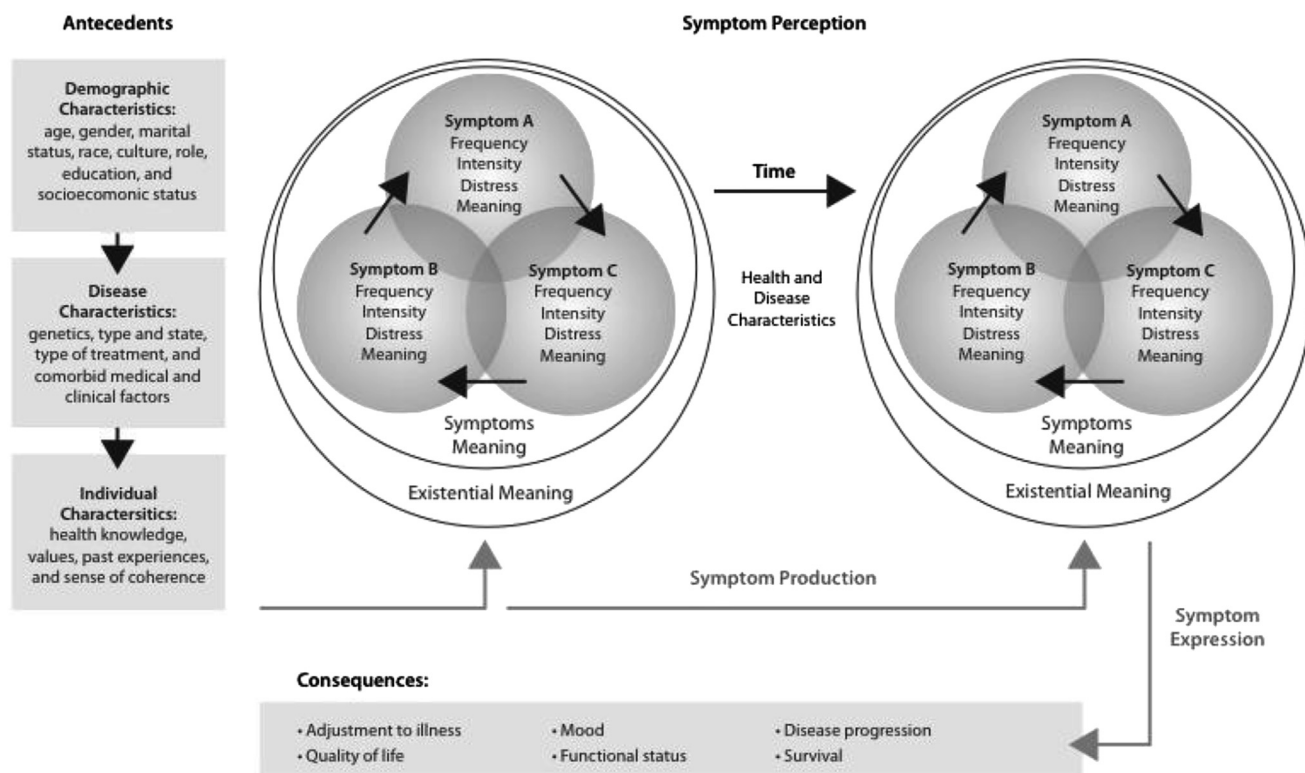


Figure 1 – Symptoms experience model.

the entire affected population. Conversely, if the symptom is related to a particular disease or treatment and prophylaxis is either unavailable or ineffective, the offending agent can be removed or the dose can be reduced. This action may have additional consequences, and at its most extreme, reduced survival time is a potential outcome.

In order to identify the natural history of a symptom, longitudinal data related to the occurrence and severity of symptoms over the disease/treatment epoch are essential and should include the collection of potential biologic correlates. Data can then be used to develop clinical and genomic prediction models and identify pathways and therapeutic targets, which have the potential for amelioration of the associated symptom. For example, as shown in Figure 3, both the collection of symptoms over time and the measurement of potential biologic correlates or pathways may allow for modeling of the symptom occurrence and severity over time and uncover potential pathways that can then be targeted before the symptom occurring or attenuating the peak severity of the symptom. If the biologic target is identified, treatment can occur before the onset of the symptoms or before it becomes severe, potentially altering the course of symptoms over time and representing a new approach to the management of symptoms (Figure 2).

Longitudinal collection of data is integral to understanding this trajectory and the advancement of symptom science. As part of the American Association

of Nursing Special Topics Conference this year, select issues related to the planning and use of longitudinal data in symptom science were discussed. This article provides further summary of the presented content at that meeting.

Longitudinal Data

When conducting a study exploring the symptom experience over time, an investigator is often interested in an index episode of the symptom, such as the prevalence or severity of a symptom in relation to a disease or treatment and any prodromal event associated with the symptom (Adamis, 2009). Depending on the research question, data collection may include PROs administered before the index episode and the time surrounding the index episode and after the index episode. This can include follow-up assessments of how the symptom interacts with other symptoms or outcomes. Figure 4 provides a depiction of the potential study epoch for longitudinal data related to a specific index episode.

The importance of longitudinal data collection to the development of knowledge related to the biologic underpinning of symptoms cannot be overstated. However, several authors have outlined potential advantages and disadvantages of longitudinal data collection (Adamis, 2009; Zeger & Liang, 1986, 1992). One of the prime advantages is that longitudinal data are more informative about the symptom of interest. In

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