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Burden of Treatment in Chronic Heart Failure: Does symptom burden play a role?

Faulty of Health Sciences. Rosalynn C Austin, University of Southampton, University Rd, Southampton, SO17 1BJ, *BN, MSc, BSc.*

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Background

In the past twelve years Chronic Heart Failure (CHF) prevalence has increased by 23%, responsible for a growing demand on health systems, hospitals, patients and their support networks (1). A fundamental component of CHF care provision is empowering patients to self-manage their CHF with regular input from health care providers (2), including Heart Failure Specialist Nurses (HFSN). Self-management is an important adjunct strategy to CHF management (3) and a powerful treatment strategy that may delay progression of illness (4, 5). It is widely known that CHF patients’ struggle to successfully complete self-management regimes guided by HFSN. The resultant effect on mortality and morbidity thought to be substantial (2, 4). The Burden of Treatment Theory (BoT) helps us to identify, characterise, and understand the work of self-care. BoT proposes that adherence to self-care regimens is shaped by interactions between the workload of self-care and patient capacity to meet the demands of that workload (6). Consequently, if BoT can be modified in the patient’s favour then adherence to self-care regimens should improve along with clinical outcomes. BoT might provide HFSN with information that could be used to help patients engage more successfully with their self-care regimes.

Burden of Treatment Theory

BoT is an emerging theory, thought to be comprised of dynamic states of workload (time and energy required to manage a condition), impact (effect of the workload on the patient), and individual capacity (factors altering ability to handle the work) (6-9) (Table 1). Sav et.al. (10) suggest that BoT attributes are a dynamic multidimensional process that is comprised of; objective elements (total workload and complexity) and patient specific subjective elements (feelings of guilt, hopelessness and fear). They state, BoT will be influenced by predisposing factors: age, gender, relational networks, comorbidities, polypharmacy, treatment requirements, and healthcare relationships. Despite the acknowledgement of these antecedents, they agree with May et.al. (6) in the belief that BoT is theoretically distinct concept from symptom burden. Sav et.al. (10), propose a cyclic interaction between disease progression and increased symptom burden resulting in more treatments with a concurrent rise in BoT. However, for patient the relationship between symptom burden and BoT may be more entangled in their lived experience of managing CHF.

Influence of Burden of Treatment

Evidence is mounting that BoT likely influences patient engagement. Eton et.al. (11), in examining disease specific measures of burden, state burden appears to have influence on self-care, clinical outcomes, number of hospitalizations, and health related quality of life (HRQoL). Shippee et.al. (9), argue that if the components of BoT become unbalanced then the patient is less likely to adhere, resulting in higher burden of illness and poorer outcomes. May et.al. (6) purport that overwhelming burden leads to non-compliance and under-utilization of health services likely leading to worsening illness and more treatments. Sav e.al. (10), in a systematic literature review, determined that the consequences of BoT included poor health and well-being, lack of compliance to treatment strategies, ineffective resource use, and increased reliance on others. Understanding modifiable factors of BoT is crucial. It appears that BoT negatively influences patients’ engagement with self-care strategies resulting in poor outcomes, increasing treatments.

Symptom Burden

Patients experience symptoms due to illness or treatments. Symptoms can be associated with objective clinical measurements, but also exist without a concurrent clinical observation. Symptom burden is thought to be the lived experience of these cumulative symptoms (12) and goes beyond scoring symptom severity or prevalence, as it encompasses the impact of the experience that the symptoms bring to the individual (13). CHF symptom burden appears to influence Quality of Life (QoL). Zambroski et.al. (14) and Blinderman et.al. (15) both examined symptom burden in CHF patients. They both found that CHF patients had a high level of symptom burden that negatively affected QoL. Their findings suggest that improvements in symptoms will have a positive impact of QoL. While the complete elimination of symptoms is unlikely, there are treatment options that may help to reduce the symptom burden of the most prevalent symptoms. Further lower symptom burden is associated with improved functional ability, and better self-care engagement (4). Implicit in this is that with more adequate self-care patients BoT would be lower, but this has yet to be explored.

Proposed Interaction between Symptom Burden and Burden of Treatment

Clinical observation of CHF patients’ suggests that symptoms may be central to a patient’s experience. Their perceived BoT could be intrinsically linked with their symptom burden. Symptoms may interact with individual capacity, but may also alter workload and its impact; thus changing their overall BoT. If this relationship exists then if may be possible to increase CHF patients’ engagement with their self-management through altering their overall symptom burden.

Implications for Practice

The idea that symptom burden may directly influence individuals perceived BoT could be particularly relevant to CHF patients’ where specific symptoms are thought to influence a patient’s individual capabilities. Two examples are cognitive dysfunction and iron deficiency. Deficits in memory and attention impair patients’ ability to apply preventative behaviour (16) and impaired executive function impairs perception and evaluation of symptoms leading to delayed treatment seeking (17). Iron deficient CHF patients have associated poorer outcomes, impaired exercise capacity, and quality of life (18, 19).

Understanding the interaction between symptom burden and BoT that CHF patients’ experience, could be important in helping increase their engagement with self-management. The authors are conducting a mixed methods study with the intention of understanding any interaction that may exist as well as identifying modifiable factors. This study, “SYMPACT: How do symptoms and management tasks in chronic heart failure impact on a person’s life?” will measure and explore symptom burden and BoT in CHF patients’. Until more is known, it could be worth considering what work as health care professionals we are asking CHF patients’ to do.

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| Table 1: What Burden of Treatment means to patients and clinicians | | |
| BoT | Patient Implications | Clinical considerations |
| Workload | Work of managing illness (e.g. take medications, attend appointments, learn about illness and treatments, enact lifestyle changes, monitor illness, etc…)  Recruit others to assist with care, use tools and strategies to help with care  Manage factors that intensify burden (e.g. navigate healthcare system, side-effects of treatment, etc…) | How much work am I asking the patient to do? |
| Impact | Changes to self  Changes to relationships  Changes to activity (work and recreation) | Will this treatment suggestion negatively disrupt the patient’s life, decreasing their motivation to adhere to the treatment? |
| Individual Capacity | Physical ability  Cognitive function  Emotional status  Socioeconomic resources  Social networks  Health literacy  Culture and spirituality | Does this patient have the capacity and resources to successfully engage with the treatment plan? |

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Conflict of Interest

The authors declare that there are no conflicts of interest.

Declarations

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List of Abbreviations

BoT Burden of Treatment

CHF Chronic Heart Failure

HRQoL Health Related Quality of Life

NHS National Health Service

NPT Normalization Process Theory

NYHA New York Heart Association

QoL Quality of Life

UK United Kingdom

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