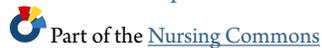

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Effect of a nurse-led lymphoma survivorship model of care: A pragmatic phase II pilot randomised controlled trial

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Publication Details

Taylor, K. (2018). Effect of a nurse-led lymphoma survivorship model of care: A pragmatic phase II pilot randomised controlled trial (Doctor of Philosophy (College of Nursing)). University of Notre Dame Australia. <https://researchonline.nd.edu.au/theses/206>

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Chapter Three — Conceptual Framework

“Being able to put my thoughts and feelings into words, being able to just say it out loud to someone was quite therapeutic and then discussing some solutions was really really helpful” Female_HL

3.0 Conceptual Framework

The purpose of this chapter is to outline the conceptual framework that guided the development and/or pilot testing of essential elements of the nurse-led lymphoma survivorship model of care. These included the unique survivorship care plan and treatment summary, choice of assessment measures and development of a resource pack. These essential elements will be further detailed in Chapter Four. Included in the discussion of the conceptual framework is a description of motivational interviewing, a technique that was used with participants randomised to the intervention of the pragmatic RCT.

Conceptual Framework

This study is guided by Bandura's theory of self-efficacy; defined as one's ability to succeed in a specific situation or achieve a specified skill, such as making a difficult decision or, within the context of this study, communicating with a health care professional (Bandura, 1977). Within the area of health, self-efficacy is identified as an affirmative personal resource that can contribute to managing one's health generally and how an individual manages a crisis (Schumacher, Sauerland, Silling, Berdel, & Stelljes, 2014). In this instance a lymphoma diagnosis, treatment and life thereafter. An individual's sense of self-efficacy can have a major influence on how challenges, tasks and goals are approached (Bandura, 1977). This is the principal concept underpinning self-management education, which teaches patients to identify their problems and provides skills in decision making and developing an appropriate action plan (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Philip, Merluzzi, Zhang, & Heitzmann, 2013).

Empowering patients to become responsible for the management of their health and well-being can contribute to the influence and control patients (self-efficacy) ultimately have over their health. Positive effects of empowerment in patients who are managing the consequences of a cancer diagnosis and treatment can lead to improved quality of life and survival through improved health outcomes including physical and emotional well-being (Bodenheimer et al., 2002; Foster et al., 2015; Kuijpers, Groen, & Aaronson, 2013). It has been reported that encouraging self-efficacy and assisting patients to become self-empowered may help lymphoma survivors adjust to the challenges of their lives during and after treatment and assist in the resumption of “normal” life activities (Schumacher et al., 2014).

Notwithstanding the positive influences of individual or self-empowerment and self-efficacy, previous life experiences held by the patient can impact upon how he/she will cope and function from diagnosis, throughout treatment and in the post-treatment phase of life (Richardson, 2002). Perceived self-efficacy has a direct influence on the choices that individuals make and how they cope once they have initiated a course of action (Bandura, 1977). Self-efficacy, as mentioned previously, is task-specific and therefore an individual can learn in a specific setting, regardless of previous failure in other contexts. Similarly, motivation can be influenced by self-efficacy. Individuals with high self-efficacy are more likely to actively persist and complete a task. Individuals with low self-efficacy may sometimes be motivated to learn more about a subject or situation they are unfamiliar with. However it may also lead to a state of learned helplessness and lack of motivation (Bandura, 1977). Consequences of inadequate support may include lower levels of self-management, reduced utilisation of appropriate support services and worsening health (Foster et al., 2015; Hoffman, Lent, & Raque-Bogdan, 2013). It is therefore imperative that a patient’s life

experiences be explored and considered when developing a model of survivorship care in order to provide an appropriate level of support that is tailored to the individual.

Working with individuals (i.e. cancer survivors in the context of this study) to develop a personalised patient action plan (i.e. survivorship care plan) that includes tailored healthy lifestyle resources will likely result in a reduction in the perceived need for support from the health care system by patients (Bodenheimer et al., 2002; Foster & Fenlon, 2011). Maintaining patients' motivation to enact healthy lifestyle changes and "follow through" is important particularly for those individuals who may have lower levels of empowerment and/or self-efficacy (Foster et al., 2015), since it is known that people who give up a task before completion will retain their self-debilitating and/or limiting expectations (Bandura, 1977).

In keeping with the concepts underpinning self-empowerment and self-efficacy, it was recognised that a nurse-led model of survivorship care developed specifically for this study needed to incorporate self-reported assessment measures to accurately identify an individual survivor's ability to self-manage his/her health and well-being (Philip et al., 2013). Further, it was anticipated there would be variations across domains measured (i.e. survivorship needs; depression, anxiety and stress; mental adjustment to cancer; self-empowerment). Patient self-assessment can facilitate targeted support that will allow lymphoma survivors to improve self-efficacy and management of the effects of a lymphoma diagnosis and treatment (Foster et al., 2015). The conceptual framework guiding this study's nurse-led lymphoma survivorship model of care is outlined in Figure 3.1.1.

Motivational interviewing was explored as a credible technique to use in the nurse-led lymphoma survivorship model of care. This form of interviewing is defined as a directive, patient-centred counselling style for prompting behaviour change by facilitating patients to explore and resolve uncertainty (Litt, 2006). The researcher was guided by the four principles of motivational interviewing when developing the study intervention: resisting the urge to fix participant problems; gaining understanding of the participant's motivations; listening with empathy; and empowering the participant to have hope for the future and be positive they could make changes if desired (Rollnick, Miller, & Butler, 2008).

To assist intervention participants with the process of making changes to unhealthy lifestyle behaviours such as cigarette smoking and excessive alcohol consumption, the researcher customised a motivational chart based on work by Rollnick et al. (2008) to provide to these participants (Appendix J.2). During a motivational interview, questions can be posed to the interviewee as he/she works with the researcher through the process of change to help guide thoughts and motivations. Questions such as: 'why do you want to make a change?'; 'what important benefits do you anticipate will come from the change?'; 'how will you make the change?'; 'what are you already doing towards making the change?

Once a motivational chart has been completed, the role of the interviewer is to summarise the benefits and barriers posed by the interviewee and reflect all the positive change behaviours the interviewee has committed to undertake. Interviewees who are not ready to make changes at the first nurse-led lymphoma survivorship clinic (NLSC) appointment will be encouraged to address these issues at subsequent NLSC appointments. The success of this approach requires interviewees to feel in control of these

changes since permanent behaviour changes can only be made by individuals who are motivated (Rollnick et al., 2008). Bandura's theory of self-efficacy (Bandura, 1977) is also a principal concept in self-management education, which teaches patients to identify their problems and provides skills in decision making and developing an appropriate action plan (Bodenheimer et al., 2002). Empowering patients to become more responsible for the management of their health and well-being can contribute to the influence and control patients have over their health which has the advantage of improving quality of life (Bodenheimer et al., 2002; Kuijpers et al., 2013). It is anticipated that increasing a patient's empowerment and providing healthy lifestyle resources will result in a reduction in the perceived need for support from the health care system by patients (Bodenheimer et al., 2002).

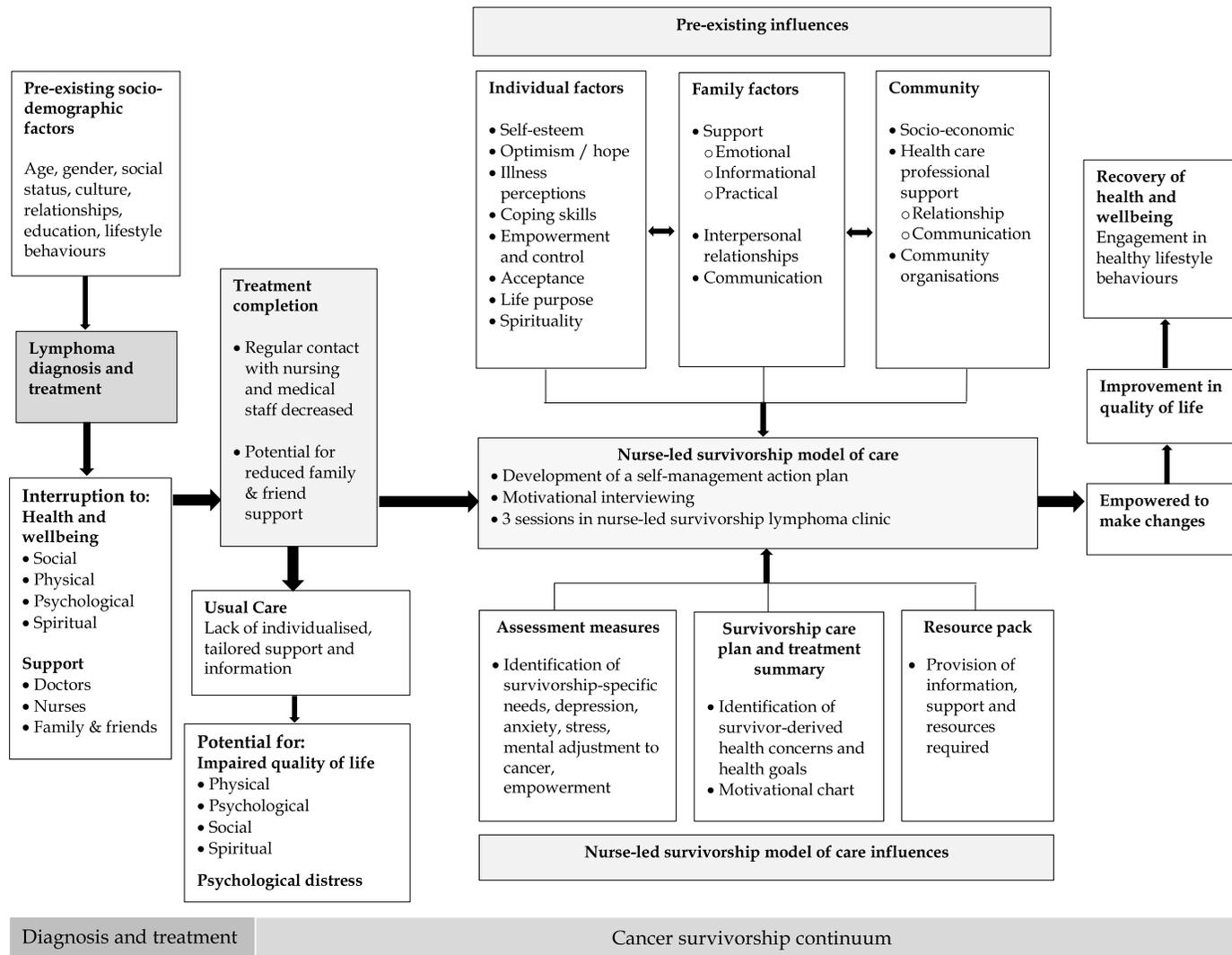


Figure 3.1.1. Conceptual diagram of the nurse-led lymphoma survivorship model of care

Chapter Summary

In summary, the nurse-led model of survivorship care utilised a conceptual model based on self-efficacy and the development of a self-management plan with actions to assist lymphoma survivors to recover their health and well-being and to engage in healthy lifestyle behaviours.

Development of a survivor-centred SCPTS, the identification of assessment measures that would allow survivors to self-report issues and concerns and the assembly of appropriate and targeted resources facilitated lymphoma survivors to transition into the survivorship phase with support. An important element of the conceptual framework of this model of care was to understand the life experiences and factors that were important to the individual before they were diagnosed with lymphoma and how these experiences and factors may have influenced their motivation for self-efficacy and empowerment.

The following chapter of this thesis details the development of the essential elements of the survivorship model of care which were used in the pragmatic RCT.