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Strengths and resources used by Australian and Danish adult patients and their family caregivers during treatment for cancer

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ABSTRACT

Purpose: Family plays an essential role in supporting the patient with cancer, however, relatively little attention has been given to understanding the strengths and resources of the family unit across different settings and countries. This study aims to investigate the strengths and resources of patients and family members in Australia and Denmark.
Methods: Using a descriptive, cross-sectional design, 232 patient and family participants from inpatient and outpatient oncology services in Australia and Denmark completed paper based surveys that included the Family Hardiness Index (FHI) and Family Crisis Orientated Personal Evaluation Scales (F-COPES), together with demographic and health information.
Results: The family's appraisal of the cancer and ways the family worked together predicted the level of external resources used to manage their circumstances.
Conclusion: After a cancer diagnosis patients and family respond in different ways related to their family functioning. There is a need for nurses to work closely with the family to understand their strengths and resources, and tailor support and information for family to promote optimal patient outcomes.

1. Introduction

Cancer is one of the leading causes of morbidity and mortality, with approximately 14 million new cases of cancer worldwide every year (WHO, 2015). The treatment for cancer is complex and often involves intermittent hospitalisation. Symptom treatment and management create considerable distress for adult patients and families (Milbury et al., 2013; Williams et al., 2013). Family based interventions are reported to be effective in providing support to patients but less attention has been given to the concurrent needs of family caregivers (Deek et al., 2016). Understanding family strengths and resources can assist health professionals to assess family caregiver needs and implement tailored support (Griffin et al., 2014; Tang et al., 2013).

Recent research has investigated the role and experiences of the family as a unit highlighting a high level of unmet needs and distress experienced by family members (Coyne et al., 2012; Senden et al., 2015). Family have been identified as the 'silent carers' of patients, and are often invisible in the treatment plan of the patient (Blum and Sherman, 2010; Coyne et al., 2012; Williams et al., 2013). Furthermore, the family often bear the hidden costs of cancer care related to unpaid time, loss of productivity, as well as out-of-pocket expenses of, which can be up to $27,000 for breast cancer treatment (Cancer, 2017; Kang et al., 2016). Increasingly family caregivers are responsible for providing supportive care to patients at home, which requires an understanding of treatment schedules and pain management. The stability and functioning of the family unit not only influence quality of care in the home but also the patient's emotional and physical outcomes (Northouse

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et al., 2012). However, family caregivers often have little preparation or possess the necessary skills for caregiver tasks related to cancer (Northouse, 2012; Yates et al., 2004). Reviews of the literature around family caregiving have highlighted the stress experienced by family caregivers, but also the lack of understanding about the family role by health professionals and strategies to best support families (Deek et al., 2016; Northouse et al., 2012).

The family is a group of individuals who bring a combination of strengths and resources into the care of their family member with cancer (E. Coyne, 2013a). A Family Systems approach focuses on the strengths and resources of the family in relation to phase of life and connectedness to each other (Wright and Leahey, 2013). It is the flexible combination of strengths and resources that allows some families to mobilise and manage adversity while other families are ineffectual in similar circumstances (McCubbin et al., 1998; Wright and Leahey, 2013). As families adjust to health adversity they draw upon internal strengths, both individually and as a family unit to assist the patient. These strengths include commitment to the family, communication skills, personal appraisal of the health adversity, and characteristics such as sense of control (Walsh, 2006). Strengths are defined as protective attributes that enable the family to better adjust to health adversity (McCubbin et al., 1998). Family resources refer to the capacity to access assistance outside the family to manage the situation with minimal disruption to their functioning (McCubbin et al., 1998). One Australian mixed method study on resilience when a family member suffered chronic pain found that family coherence and social support assisted the family to maintain functioning (West et al., 2012). Communication within the family also influenced their ability to work together and maintain a positive approach to managing pain (West et al., 2012).

The role of nurses in supporting families is also receiving attention. A descriptive exploratory survey study with 242 family caregivers and 356 nurses in Germany compared what families valued compared to what nurses thought families valued in the provision of care (Pinkert et al., 2013). Family caregivers most valued information followed by the need for partnership with nurses to help work through problems (Pinkert et al., 2013). Conversely, nurses overestimated the family's need for emotional support, and had limited awareness of the desire of families to be involved in the care of the patient (Pinkert et al., 2013).

International collaborative research can provide opportunities to build research capacity and develop strong links for future interventional research (Priest et al., 2007). Australia and Denmark are developed countries with high quality publically-funded health care. However, we do not fully understand the impact of possible differences between countries related to the impact of geographic distance between home and hospital, paid carer leave; and how the supportive role of nurses in different health systems may influence the coping of family members. In order to better understand family experiences and needs, family researchers have recommended collaborative international research to build knowledge around families' adjustment during cancer (Bell, 2014; Ganong, 2011; International Family Nursing Association (IFNA), 2015). Ostergaard and Wagner (2014) described the evolution of family research in Denmark and highlighted the importance of shifting the focus to the patient and family as a unit of care. In Australia, research is beginning to include family caregivers (Coyne et al., 2012; Kean and Mitchell, 2014; Mitchell et al., 2009); however a focused understanding of the strengths and resources of family is still lacking.

2. Conceptual framework

Family Systems Nursing, which emphasizes the family as a unit of care, informed our conceptual framework (McCubbin et al., 1998; Wright and Leahey, 2013). Investigating the family as a group of individuals who influence each other allows for exploration of family and patient strengths, particularly communication, connection, and functioning (Walsh, 2006; Wright and Leahey, 2013). For the purpose of the current research, family is defined as a group of individuals who are bound by strong emotional ties, a sense of belonging, a commitment to being involved in one another's lives, and who call themselves 'family' (Wright and Leahey, 2013).

The current study aimed to investigate the strengths and resources of adult patients and family caregivers during treatment for cancer in Australia and Denmark. An earlier qualitative study by Coyne and Dieperink (2016) revealed similar health delivery systems, nursing care roles, and standards of living across Australia and Denmark providing a baseline for the current study.

3. Method

A descriptive, cross-sectional design was used to investigate the strengths and resources of adult patients and family caregivers during treatment for cancer in Australia and Denmark. The Family Systems Nursing Theory informed the recruitment strategy, survey content and approach to analysis to determine how the patient and family work together as a unit during treatment for cancer.

3.1. Sample and setting

A convenience sample of adult patients was recruited from two metropolitan oncology units in Denmark and Australia. Recruited patients then identified family members who could be approached. Inclusion criteria were adults receiving active cancer treatment as inpatients or attending the oncology outpatient clinic and their nominated family members. Exclusion criteria were inadequate ability to speak the country's native language or complex medical needs as decided by supervising registered nurse.

Approximately 2000 new patients attended the two oncology units during the three month recruitment period. However, recruitment was influenced by clinical staff decisions, reducing the potential pool to approximately 1000. A sample of 214 patients was required to achieve a small/medium effect size with a 90% Confidence Interval and <0.05 probability.

4. Measures

Demographic data included age, gender, educational level, occupation and ethnic origin. Respondents indicated if they were in a committed spousal relationship or not; and if they had dependent children or not, and if so, if the children were less than ten years or over. Demographic subgroups were country, patient, gender, age, family, cancer groups. These subgroups allowed for comparison across the standardized measures.

4.1. Family strengths

Family Hardiness Index (FHI) is a validated scale, designed to measure overall strengths and durability of the family unit by combining patient and family responses (E. Coyne, 2013a; Jeong et al., 2016). The FHI has 20-items reflecting three interrelated subscales: Commitment, Challenge and Control. 'Commitment' relates to an individual's loyalty to the family and sense of how the family works together. 'Challenge' relates to how the individual views adversity and their efforts to be active and innovative in response. 'Control' relates to the individual's sense of control over the situation. Participants rate their response using a 4 point Likert scale (0 false - 3 true) to indicate the degree to which each