

FAMILY-CENTRED APPROACHES TO HEALTH CARE INTERVENTIONS IN CHRONIC DISEASES: A REVIEW.

Running Head: Family-centred care in chronic conditions

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FAMILY-CENTRED APPROACHES TO HEALTH CARE INTERVENTIONS IN CHRONIC DISEASES: A QUANTITATIVE SYSTEMATIC REVIEW.

Abstract

Background: Increasingly there is a focus on self-care strategies for both malignant and non-malignant conditions. Models of self-care interventions have traditionally focussed on the individual and less on the broader context of family and society. In many societies, decision-making and as a consequence health seeking behaviours, involve family members.

Objective: To identify elements of effective family-centred self-care interventions that are likely to improve outcomes of individuals living with chronic conditions.

Design: Review paper.

Data Sources: MEDLINE (Ovid), CINAHL, Academic Search Complete, PsychInfo, and Scopus between 2000 and 2014.

Review Methods: Quantitative studies targeting patient outcomes through family-centred interventions were retrieved using systematic methods in January, 2015. Search terms used were: “family”, “spouse”, “carer”, “caregiver”, “chronic”, “chronic disease”, “self-care”, self-management”, and “self-efficacy”. Reference lists of related articles were further reviewed for studies.

Study appraisal: Risk of bias assessment was performed using the Cochrane Collaboration’s tool.

Synthesis methods: Data were reported using a narrative summary approach.

Results: Ten studies using quantitative approaches were identified. Improvements were noted in readmission rates, emergency department presentations, and anxiety levels using family-centred interventions compared to controls. Elements of effective interventions used were a family-centred approach, active learning strategy and transitional care with appropriate follow-up.

Conclusions: Involving the family in self-care has shown some positive results for patients with chronic conditions. The benefits of family-centred care may be more likely in specific socio-cultural contexts.

Limitations: The review has year limits and further research needs to identify support for both the patients and family caregivers.

Keywords: Literature review, nursing, caregiver, chronic disease, family, self-care and self-management, spouse.

Impact statements:
• Patient outcomes can be improved when the types of support; informational, instrumental and emotional are tailored to the patients’ needs and health conditions.
• Family-centred approaches maybe more suited to Non-Western, collectivist cultures while patient-centred approaches may be more suited in Western cultures.
• The duration of the response may be more related to the type of outcomes targeted through the intervention rather than the dose of the intervention.
• No pooled evidence is available in the literature. There is a need for further intervention studies addressing the effectiveness of family-centred care in managing patients with chronic conditions.

Introduction

Chronic conditions are a major source of burden to individuals and society (Beaglehole et al., 2008), they account for 60% of global mortality and are expected to increase to 80% by 2020 (World Health Organization, 2002). The increasing prevalence of these conditions is due to a range of factors including urbanisation, ageing population and changes in dietary and lifestyle patterns (Yach et al., 2004).

Most chronic conditions involve changes in lifestyle (including diet, activity, and medication adherence) and so management occurs mainly in the community setting (Ory et al., 2013). An increasing focus on chronic and complex conditions has magnified the focus on self-care which is defined as an individual's decision to maintain wellbeing and an approach enacted to do so (Riegel and Dickson, 2008). Self-care can be more broadly envisioned through a theoretical lens that represents the patient, with complex health conditions, as an agent needing care by another (Denyes et al., 2001) but this approach has been challenged by the need for self-agency. The burden imposed by chronic conditions, the severity and complexity of their regimens has necessitated novel approaches to providing care for chronic lifelong health conditions, such as thoughtfully and intentionally involving the family in health care (Chesla, 2010). Filling medication prescriptions and assisting with administration, shopping for healthier food and encouraging the sick family member to do physical activity are approaches a family caregiver can be involved in to improve outcomes (Rosland and Piette, 2010). Often this involvement is implicit but less explicitly defined. These are among the health, family, individual and environmental resources identified by Grey et al. (2006) to be factors affecting the delivery of self-care and self-management. Grey and colleagues proposed the Self and Family Management Framework highlighting the risk and protective factors affecting patient outcomes. These factors can be targeted through either individual or family approaches to improve patient outcomes. This framework was proposed due to the shift of care from tertiary to primary with the increasing burden of chronic conditions (Grey et al., 2006). This approach has also gained traction across the world with many health care systems placing an increased emphasis on care in the community (Islam et al., 2015).

As hospitalisation, quality of life, self-care and medication adherence are frequently used by policy makers as markers of both patient outcomes and organisational efficiency this review focussed on these constructs. This paper is timely as many governmental and funding agencies are interested in the role of family in health care (Davidson and DiGiacomo, 2015).

Background

Definition and background of self-care

Self-care is essential in the management of chronic conditions and failing to engage in self-care practices is likely to contribute to adverse health outcomes (Riegel and Dickson, 2015). The increasing burden of chronic conditions has fuelled scholarly debate and discussion on self-care approaches and its application in different settings and cultures (Davidson et al., 2013). Self-care is defined differently across disciplines. In nursing, which is our focus, self-care is based on outlining the treatment goals and assessing the patient's capability of carrying out activities to reach these goals (Gantz, 1990). Riegel and Dickson (2008) defined self-care based on two major concepts, maintenance and management, where one decides to act as a response to physiologic instability to maintain wellbeing. The word self-management emerged to mean the ability to manage one's health condition, symptoms, and lifestyle changes and maintain physical and psychosocial wellbeing (Coster and Norman, 2009). These terms; self-care and self-management, are sometimes used to reflect the same meaning and so are used interchangeably (Riegel and Dickson, 2008, Moser and Watkins, 2008).

How are social support & self-care addressed in the literature?

To date, discussion and debate on health care interventions have focussed on the individual with a lesser focus on the broader socio-cultural context of that person and this is attributable to the dominance of Western perspectives. This is true despite that a change in one family member's health condition can negatively affect the whole family (Ryan and Sawin, 2009). Social support can be provided from family members, partners, friends, healthcare professionals and others (Pressler et al., 2013). It can be provided in different forms that are all necessary for optimal patient outcomes. These forms are emotional, informational and instrumental support (Kalichman et al., 1996). Emotional support is the provision of comfort, empathy, and understanding to the chronically ill patient. Informational support is the delivery of appropriate knowledge specific to the patient's current condition. Instrumental support is aiding the patient with activities of daily living when needed (Linn et al., 1993, Cohen, 1998, Meyerowitz, 1980).

Types of care provided from different support groups

The impact of social relationships on health has long been established in the literature; those who are socially isolated have more risk factors, poorer health outcomes and are less flexible to lifestyle changes (Hawton et al., 2011). Conceptually, there are potential links between qualities of relationships and improved tangible assistance in self-care behaviours (Salyer et al., 2012). Different support people (i.e. spouse vs. son/daughter vs. other (friend or relative)), are thought to provide varying levels of care. For example, patients having a friend's support were found to have more self-care confidence which was lacking with those having spouse support (Sayers et al., 2008). This could be explained by the patients' dependence on the spouse. However, with the spouses' support, patients with heart failure had better lifestyle adaptation and medication adherence (Molloy et al., 2005,

Martire et al., 2010). Moreover, married patients had significantly longer event-free survival than non-married patients, and those with a “high quality marriage” had significantly better survival after four years of follow-up than their counterparts (Rohrbaugh et al., 2004).

The concept of family involvement in care

Family-focussed care has its foundation in caring for children. This form of care is the tenet of nursing care for sick children globally (Coyne et al., 2011). The concept was introduced almost 60 years ago and has received considerable attention in the literature focussing on the theoretical basis and underpinning nursing constructs (Shelton, 1987). Family-centred care has been analysed through two approaches, either parents viewed as equal partners of care for their children or being supervised by the nurse in a hospital setting (Hutchfield, 1999). Family involvement evolved to include the adult population when treatment goals shifted from curative to palliative with chronic conditions (Pressler et al., 2013). This increasing burden of hospitalisation and increasing fiscal constraints have pushed the family to become partners of care in the community (Kaakinen et al., 2014). This is especially true in low and middle income countries where families play an important role in health care (Tolle, 2009). This along with the natural family connectedness especially in non-western cultures (Beitin and Aprahamian, 2014), make family involvement vital in the care of patients. Although starting as a resolution for shortage of resources and cost, family-centred approaches have been shown to be associated with improved caregiver satisfaction and quality of care in hospital settings (Tandberg et al., 2014). This was also highlighted in a number of studies using qualitative approaches where patients with stroke and aphasia emphasised the importance of family connectedness and support on their outcomes (Brown et al., 2012). Furthermore, an established positive relationship between healthcare workers and the family can lead to better understanding of the disease condition, coping and adherence to self-care instructions (Foster et al., 2010, Driscoll et al., 2009).

Application of self-care in chronic conditions has improved outcomes such as readmission rates (Carr et al., 2014), mortality rates (Laxy et al., 2014), and quality of life (DeWalt et al., 2012) and reduced healthcare cost (Mejía et al., 2014). However, interventions aimed at improving outcomes were described in the literature mainly without identifying the elements that led to their success.

Aim

As presented, the type and source of support needed by patients with chronic diseases differ according to their health conditions; so what elements of family-centred self-care interventions, that are likely to improve outcome of patients with chronic conditions, can be identified from quantitative studies?

Design

This review focussed on quantitative studies on family-centred interventions in chronically-ill adult patients. Studies included randomised and non-randomised experimental designs (level II, III-1 and III-2 studies according to NHMRC level of evidence scheme (Coleman et al., 2009) addressing the involvement of family members in the management of patients with any chronic condition. This design also conforms to the EPOC (Effective Practice and Organisation of Care) review guidelines which states the pertinence of including a wider range of quantitative studies in the absence of enough randomised trials to address questions on health care delivery and implementation strategies (EPOC Resources for review authors, 2013). The EPOC guidelines were followed without deviations although an integrative approach, including both experimental and non-experimental studies, was considered to provide a greater understanding of the role of family caregivers.

Search methods

Databases searched were MEDLINE (Ovid), CINAHL, Academic Search Complete, PsychInfo, and Scopus (Elsevier). References of relevant articles were also searched for articles meeting the inclusion criteria. Search terms used were combinations of “family”, “spouse”, “carer”, “caregiver”, “chronic”, “chronic disease*”, “self-efficacy”, “self-care”, and “self-management”. These terms were searched for in titles, abstracts and keywords. Since self-care and self-management maybe used interchangeably in the literature, both terms were used in our search; but for this review we were interested in self-care defined as outlining treatment goals and adopting strategies to reach these goals. A family was defined as two or more persons, one of whom is at least 15 years of age, who are related by blood, marriage (registered or de facto), adoption, step or fostering, and who are usually resident in the same household (Australian Bureau of Statistics, 2012). Family-centred interventions were defined as educational interventions on self-care that included sessions, handouts or prescheduled visits provided to the patient and the family caregivers. These sessions were about the health condition which had caused a hospitalisation or health decline. The search was limited to include only intervention studies on adult human beings of papers published in English, in peer-reviewed journals between 2000 and 2014. The search was last done in January, 2015.

Search outcomes

The primary outcomes of interest were readmission rates, self-care, quality of life and medication adherence. Secondary outcomes were cost, mortality, and satisfaction with no limit to the follow-up period under study. Studies were excluded if they were not intervention studies, caregiver-focused outcome interventions, had no family involvement, centred on paediatric and adolescent populations, review papers, pilot studies, protocols, or concerned non-chronic conditions. Papers having more than one exclusion criteria were categorized as irrelevant. Table 1 presents the search

strategy used in the three databases; MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Academic Search Complete and the online. Table 5 presents the full online version of the search strategy.

Quality appraisal

The quality of the studies reviewed was appraised by two independent reviewers (HD & NB). Risk of bias assessment is presented in Table 2 (online version) using the Cochrane Collaboration's tool for assessing the risk of bias (Higgins et al., 2011). Risk of bias assessment was summarised for the review as a whole (EPOC Resources for review authors, 2013).

Data abstraction

After removing the duplicates, screening for relevance and abstraction (title and abstract) was performed by two people (HD and PJN) using pre-set search criteria that were devised with the assistance of a health librarian. Any disagreements were resolved by the involvement of the principal author of this paper (PMD) and there was no need to contact any of the paper authors for additional data.

Synthesis

Data were reported using a narrative summary approach due to heterogeneity across the studies of the outcomes reported.

Results

The primary search of the databases yielded 1265 articles. Articles extracted from the databases were as follows: MEDLINE (69), CINAHL (153), Academic Search Complete (546), PsychInfo (317), Scopus (Elsevier) (180). Additional articles were retrieved through hand searching of the reference lists of the relevant articles to yield an additional 7 articles. Duplicates were removed leaving 677 records to be screened. After screening the titles, 656 records were excluded leaving the remaining 23 papers for a full-text eligibility assessment. Ten articles met the search criteria. Figure 1 outlines the search strategy based on the PRISMA flowchart. Characteristics of the selected studies are presented in Table 3. Number of excluded articles and reasons for exclusions are presented in Table 4.

Following analysis of the retrieved studies, the following themes emerged: caregiver identification; identified studies and study types; interventions used across the studies, operationalization of the interventions, and outcomes achieved in the studies. These themes are addressed below:

Caregiver Identification

There was no consensus on a definition for a family caregiver across the studies. A caregiver was defined as the person helping with daily living activities and advocating on the patient's behalf (Kalra et al., 2004), a person living with the patient (Smith et al., 2004), or a family member/significant other/spouse or partner classified by the patient as their primary source of physical and emotional support (Northouse et al., 2005) or the spouse who provided emotional or physical care (Northouse et al., 2013, Northouse et al., 2007). Couples were recruited if they identified themselves as in a committed relationship which they perceived as viable for at least another year (Remien et al., 2005). Smith et al. (2004) and Ågren et al. (2012) identified the carer as someone living in the same household as the patient while Shahriari et al. (2013) added an age and a literacy factor where caregivers had to be aged more than 18 years and literate. No definition was provided by Coleman et al. (2004).

Identified studies and study types

We have used the American Heart Association disease management taxonomy that standardises and facilitates reporting and comparison of health care interventions (Krumholz et al., 2002). This taxonomy was used here to provide a summarised description of each individual study presented in Table 3. A total of 1,823 patients along with their family caregivers, which were all dyads, were recruited to test the impact of educational sessions on their chronic diseases. The identified chronic conditions were heart failure (Shahriari et al., 2013, Ågren et al., 2012), chronic obstructive pulmonary disease, coronary artery disease, diabetes, stroke, medical or surgical back conditions, hip fracture, peripheral vascular diseases, arrhythmias (Coleman et al., 2004), stroke (Kalra et al., 2004, Smith et al., 2004), persistent knee pain (Keefe et al., 2004), recurrent breast cancer (Northouse et al., 2005), prostatic cancer (Northouse et al., 2007), advanced cancer (Northouse et al., 2013), and HIV (Remien et al., 2005). All studies but one (Coleman et al., 2004) randomized their participants to intervention or control groups. All studies had either a control or an intervention group except for Keefe et al. (2004) who divided his participants into 3 intervention groups vs. usual care group and Northouse et al. (2013) who divided his participants into a brief intervention, extensive intervention or the control groups. The usual care group or the control group was not defined in some studies (Keefe et al., 2004, Northouse et al., 2005, Coleman et al., 2004), while others defined usual care as conventional care (Shahriari et al., 2013, Ågren et al., 2012, Northouse et al., 2013, Northouse et al., 2007), counselling provided to the patients and/or their caregivers on medication adherence (Remien et al., 2005), community services, encouragement to attend nursing activities and involvement in discharge planning (Kalra et al., 2004), or having a reader manual about the patient's health status available for the patient when needed (Smith et al., 2004). Participants were stratified by couple type (Remien et al., 2005), treatment type (Northouse et al., 2005), study site, phase of illness

(Northouse et al., 2007, Northouse et al., 2013) and cancer type (Northouse et al., 2013) or Barthel Index scores (activities of daily living) and aphasia in stroke patients (Smith et al., 2004).

Interventions used across the studies

All studies involved face to face educational sessions with the patients and their caregivers. However, the type of sessions and the follow-up varied across the studies. These details are presented in Table 3 and briefly summarized below. Three categories of interventions were identified: self-care strategies, coping skills and education and support.

Improving patient self-care and carer support (Ågren et al., 2012, Coleman et al., 2004, Keefe et al., 2004, Remien et al., 2005, Shahriari et al., 2013)

Coleman et al. (2004) assigned a transition coach to the patients and their caregivers and arranged for a home visit within 72 hours of discharge from the hospital (Coleman et al., 2004). The coach's role was to encourage communication between the patients, their caregivers, and the healthcare professionals. The coach emphasised medication adherence, identified warning signs, provided more education about the condition and its treatment, and provided support to the caregivers in having an active role in their patients' treatment. This educational visit was followed by a series of telephone calls to the patient to enhance the provided education. The coach was involved in any hospital or clinic visit of the patient for 24 days after discharge (Coleman et al., 2004). Similarly, Ågren et al. (2012) administered psychosocial support intervention to both the patients and their caregivers to strengthen their physical and mental function and improve their perceived control over their health condition and consequently their self-care. Other interventions included 12 weekly, 2-hour sessions on spouse-assisted pain coping skills training (SA-CST), 60 min 3 times weekly exercise training (ET) or both to the caregivers comparing them to a control group (Keefe et al., 2004). HIV patients and their partners were invited to four discussion sessions over 5 weeks. These 45 to 60 min sessions included education on viral resistance, medication adherence and partner support (Remien et al., 2005) and caregivers of patients with heart failure were invited to 3 weekly educational sessions on the related health condition and self-care skills (Shahriari et al., 2013).

Increasing patient and carer coping skills (Northouse et al., 2005, Northouse et al., 2013, Northouse et al., 2007)

Northouse et al. (2005, 2007 & 2013) divided the FOCUS intervention into 2 phases: phase one comprised 2-4 monthly educational home visits involving both the patients and their caregivers and phase two was one or two 30 min phone calls identified as the booster phase. The latter phase included emphasis on the provided information and assessment of the patients' wellbeing. The FOCUS intervention involved education on Family involvement, Optimistic attitude, Coping

effectiveness, Uncertainty reduction, and Symptom management (Northouse et al., 2005, Northouse et al., 2013, Northouse et al., 2007).

Patient and carer education and support (Kalra et al., 2004, Smith et al., 2004)

A multidisciplinary approach was adopted by Smith et al. (2004) where stroke patients and their caregivers were invited to fortnightly, 20 minute educational meetings in the stroke wards (Smith et al., 2004). On the other hand, Kalra et al. (2004) provided three to five educational sessions to caregivers of stroke patients. These sessions provided education on management of incontinence, nutrition, prevention of ulcers and positioning. These sessions also included hands on training on transferring, positioning and assisting their patients in their daily living activities (Kalra et al., 2004).

Operationalization of the interventions

Most educational sessions were conducted by trained post-baccalaureate clinicians with clinical experience. Clinicians included a PhD prepared psychologist (Keefe et al., 2004), a Masters prepared geriatric nurse practitioner certified in chronic disease self-management (Coleman et al., 2004), a Masters prepared nurse (Northouse et al., 2005, Northouse et al., 2013, Northouse et al., 2007), and a nurse practitioner (Remien et al., 2005). The multidisciplinary approach (Smith et al., 2004) included a rehabilitation team of doctors, nurses, physiotherapists and occupational therapists. There was no mention of who provided the educational sessions and the training in the studies conducted by Kalra et al. (2004) and Shahriari et al. (2013) while Ågren et al. (2012) mentioned that his interventions were nurse-led without identifying their qualifications.

Coleman et al. (2004) used a quasi-experimental approach to evaluate the effect of transitional care on readmission. Therefore outcomes such as level of confidence in care were only reported in the intervention group. The implementation of a randomized trial allows for control of confounding variables in both arms of the study. This was interpreted by Northouse et al. (2005) who found baseline difference between the control and the intervention group with less negative appraisal of illness and hopelessness in the former group. These differences were controlled for statistically when analysing the difference in outcomes between groups. Similarly, Remien et al. (2005) found a significantly different baseline variable between the groups where the control group had higher income than the intervention group. These baseline differences may have had an impact on the findings of these studies in producing less favourable results of the intervention. Other studies (Kalra et al., 2004, Keefe et al., 2004, Shahriari et al., 2013, Smith et al., 2004) found no significant differences between the groups at baseline.

Outcomes achieved in the studies

The main outcomes that were sought in this review were readmission rates, quality of life, self-care and medication adherence. Significant reductions in the readmission rates at 30, 90 and 180 days: adjusted odds ratios 0.52 at 30 days (95% CI, 0.28, 0.96, $p = 0.04$), 0.43 at 90 days (95% CI, 0.25, 0.72, $p = 0.002$), 0.57 at 180 days (95% CI 0.36, 0.92, $p = 0.02$) and a significant prolongation in time to rehospitalisation (Intervention 225.5 days, control 217.0 days. HR=0.59 (95% C.I.0.41, 0.83, $p = 0.003$) were noted after Coleman's intervention (Coleman et al., 2004). Patients' quality of life showed varied improvement across the studies at 3, 6 and 12 months (Ågren et al., 2012, Kalra et al., 2004, Northouse et al., 2005, Northouse et al., 2013, Northouse et al., 2007). Medication adherence with the HIV patients significantly improved (change score $b = -22.38$; $p < .001$) when involving the caregiver (Remien et al., 2005). Also, self-care behaviours were significantly improved after the intervention (28 vs. 47 in the control group and the intervention group respectively, $p < 0.001$) in patients with heart failure (Shahriari et al., 2013).

The lack of consistency across the studies limits providing a clear set of elements that could improve patients' outcomes. However, identifying specific patient needs and identifying specific caregiver roles were shown to be vital in improving these outcomes. Some elements of interventions pinpointed in these studies included hands on training to caregivers of patients with stroke. This specific training on prevention of bedsores, optimal nutrition, and positioning reduced the cost of hospitalisation and treatment of complications. Other elements of interventions that improved outcomes in terms of readmission were the provision of long term educational sessions on self-care with active learning strategies, identification of the warning signs, family-centred approaches, self-care tools such as diaries, transitional care and proper follow-up. These elements provided empowerment to the patients and their caregivers while caring for the identified chronic health condition.

Risk of bias assessment

Risk of bias was assessed using the Cochrane Collaboration's tool (Higgins et al., 2011) based on the seven criteria. For each criteria, each study was classified as low, unclear or high risk of bias. Sources of bias were identified with the absence of random number generator and blinding of participants and outcomes assessment leading to possible overestimation of the studies. Selection bias was carefully avoided in four studies only (Kalra et al., 2004, Remien et al., 2005, Shahriari et al., 2013, Smith et al., 2004). The remaining studies either did not randomise (Coleman et al. 2004) or did not mention the randomisation process (unclear risk). Concealment of allocation or blinding of participants was not appropriate in any of the studies but one (Smith et al. 2004) when measuring medication adherence. Detection bias was violated in all studies but one (Northouse et al. 2007) with either no mention of blinding the outcome assessors or the absence of randomisation (Coleman et al. 2004). Furthermore, GRADE was used for grading the certainty of evidence of the outcomes of

interest, readmission, self-care, quality of life and medication adherence. The grading was based on the design, risk of bias, inconsistency, indirectness, and imprecision where scores (-1 or +1) are then summed to yield an overall scores (4=high, 3=moderate, 2=low and 1=very low)(EPOC Resources for review authors, 2013). The certainty of evidence was rated moderate for the outcomes of interest. In brief, in addition to the moderate rating of the evidence, most information came from studies at low or unclear risk of bias. Therefore, despite effective intervention, results should be interpreted with caution.

Discussion

The importance of family involvement in the care of patients with chronic conditions has been outlined in the literature using experimental and qualitative approaches (Shilling et al., 2013, Knafl et al., 2013). In spite of this importance, only ten studies examining family/partner interventions were identified. The aim of the review was to present elements of family caregiver interventions likely to improve outcomes of patients with chronic conditions. The limited number of studies conducted, heterogeneous populations (i.e. patients with different chronic conditions) and the different clinical outcomes interventions studied, make it difficult to identify the elements that make family-centred interventions effective. However, outcomes varied depending on the type of support provided for each patient and how the roles of their caregivers were defined by the authors. When activities of daily living were the primary caregiver's role i.e. instrumental support, quality of life improved significantly after the intervention (Kalra et al., 2004). This finding was supported by a study undertaken with patients with COPD where instrumental support was identified as one of the relevant domains affecting patients' quality of life (Paap et al., 2014). Conversely, quality of life did not improve (Northouse et al., 2005, Northouse et al., 2013, Northouse et al., 2007) when the carer was a source of emotional support.

Similarly, readmission was not reduced when solely assistance in activities of daily living was provided (Kalra et al., 2004) while it improved significantly up to 180 days with empowering educational interventions to the dyads (Coleman et al., 2004). The latter finding was greatly supported by more recent literature (Wahba et al., 2015, Peter et al., 2015). These findings suggest that outcomes can be better targeted for improvement when specific and subjective patient needs are met.

While there were significant differences between the intervention and control groups in outcomes at the short term follow up, these differences waned with longer follow-up periods (Ågren et al., 2012, Northouse et al., 2005, Northouse et al., 2013, Northouse et al., 2007, Remien et al., 2005). This trend was a consistent finding with intervention studies targeting health outcomes (Karinkanta et al., 2015), although the dosage of the intervention or the characteristics of the participants (Sheffet et al., 2015) may explain it. On the other hand, interventions targeting coping produced sustained improvements (Northouse et al., 2013) suggesting that the duration of the

response may be more related to the type of outcome targeted through the intervention rather than the dose of the intervention (Northouse et al., 2013).

Multidisciplinary approaches

Pooled data have shown the significant effect of multidisciplinary approaches in improving outcomes of patients with severe chronic conditions, such as heart failure (McAlister et al., 2004). Systematic reviews demonstrate the effect of such approaches in reducing mortality, condition specific readmission and all-cause readmission (McAlister et al., 2004). The key to this success is the follow-up of these patients with a multidisciplinary team or in a multidisciplinary clinic. It was recommended in the review that caregivers be partners in care. They need to be provided information about the health condition, lifestyle management and medication adherence, be involved in the management plan and accompany their patients to follow-up appointments. In the current review, Smith et al. (2004) reported the effect of a multidisciplinary approach in reducing anxiety levels in stroke patients, but no readmission rates were reported. Within these complex interventions there is a need to carefully describe unique components and to date there has been a limited focus on family caregivers.

Informal caregiving in western vs. non-western societies

The importance of family unity is often more pronounced in non-western countries (Tseng and Verklan, 2008). Family ties and the perception of society as a group of related individuals rather than individuals, a concept known as collectivism, is reflected in many minority groups, such as the African American (Kreuter et al., 2003). However, only one study from non-Western countries was identified in our search (Shahriari et al., 2013). In fact, all other nine studies were conducted in Sweden, the United Kingdom and the United States of America.

This review has some limitations. First, limiting the years of the search to the last 14 years and to the English language only may have excluded some important studies conducted within non-western cultures and before that time frame. However, we wanted to identify the most recent literature and the exhaustive database search was likely to cover the available studies. The other limitation was the exclusion of qualitative studies and the grey literature which could have enriched our findings and understanding of the concept of family-focused care. This exclusion however, was based on the aim of the study to identify the elements of effective interventions in chronic conditions and self-care. Furthermore, addition of search terms such as “parents” and naming the chronic condition such as diabetes and heart failure could have provided a richer input on other possible pathways of family models. Yet the paucity of studies using search terms and a strategy supported by a health librarian signal that there has been a limited focus of specifically involving the caregiver in interventions, although their involvement is often implicit (Davidson et al., 2013). It is worth noting that seven of

the ten studies identified were between 2004 and 2007, one in 2012 and two in 2013. Finally, although a systematic search strategy was followed for this review, a meta-analysis was not suitable due to heterogeneity across the included studies in outcomes and interventions.

Conclusion

Involving the family in self-care has shown improved outcomes in patients with chronic conditions. Coping with a chronic illness may be facilitated when a family caregiver is involved but prospective, systematic and accountable processes are lacking. The distilled elements presented above need to be further studied across different settings with varying patient population. The benefit of family-centred care may be more likely in certain cultures that are collectivists like Asian populations, whereas, individual person-centred approaches may be more suited to Western cultures whereby individualism is prevalent. Support methods for these patients should be targeted to the needs of these patients based on the demands of the health condition. Caregiver needs should also be addressed in future research.

Relevance to clinical practice

Although nurses implicitly engage family members in interventions, tailored, focussed and structured processes are warranted that focus on the needs of both the individual patient and the family unit. Family caregivers should be aware of patients' needs and appropriate education and support should be provided by health care professionals. Increasing the focus on family involvement in interventions, both conceptually and in the evaluation of interventions, is critical to address the global burden of chronic illness.

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