

# Empowerment for people with end stage renal disease: A literature review

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## Abstract

**Aim:** This review of the literature aimed to establish current understandings of empowerment and how they may relate to the care of people living with ESRD.

**Methods:** A search, selection, analysis and review of nursing, medical, social work and psychological literature was performed. Six concept analyses and fourteen primary research articles met the selection criteria.

**Results:** Seven major elements of the concept of empowerment were found: self-determination, partnership, effective communication, goal setting, socio-political awareness, a caring environment and construction of knowledge. Empowerment in nursing and nursing education requires nurses and nursing students to have an increased understanding of the socio-political framework from which they operate on a daily basis. Empowerment of patients in non-renal settings focuses mainly on self-determination and the patient's ultimate right to decision making in their own care. Empowerment of patients with ESRD has also focussed on self-determination. No study incorporated all seven proposed elements of the concept of empowerment.

**Conclusion:** Future research studies on the role of empowerment in the care of people with ESRD should investigate all elements of the concept of empowerment to provide a total picture of their views on this aspect of care to inform nursing practice.

## Key Words

Empowerment, nursing, haemodialysis, end stage renal disease, concept analyses

Empowerment has been viewed from various perspectives, having been defined in political, health, feminist and educational terms (Hokanson Hawks, 1992; Ryles, 1999) This complexity required an attempt to define the key elements of the concept of empowerment so as to provide a thorough exploration of empowerment related to those receiving dialysis care. Thus, the purpose of this paper is to investigate the literature relating to the empowerment of people with ESRD undergoing haemodialysis in a hospital setting.

The goals of this review are: to develop an understanding of the elements of the concept of empowerment from the literature; to examine the literature on empowerment of nurses; to analyse the research related to empowerment for patients in the non-renal setting which has relevance to the dialysis setting; to examine the research found on ESRD and empowerment and finally to discuss the findings, drawing similarities and conclusions, with recommendations for future research.

## Introduction

People with end stage renal disease (ESRD) are portrayed as feeling helpless, powerless, lacking control and lacking compliance and in a complex setting, such as a haemodialysis unit, they are put at risk of being dehumanised (Molzahn, 1996) The concept of empowerment is relatively new (Murray, 1989) and complicated by a claim that there is 'no hard data on the factors that create

empowerment' (Rondeau, 2000; p. 220). Empowerment is appealing, but there is very little in the nursing literature which addresses the concept of empowerment and maybe is better understood by its absence (Gibson, 1991). Authors have attempted to define empowerment and its ideological underpinnings, yet the concept still lacks coherence and clarity (Lewis, 2000) resulting in ambiguity of the term (Hokanson Hawks, 1992; Rissel, 1994; Rodwell, 1996).

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## Methods

### Sampling process

The key words used to find relevant articles included empowerment, patient empowerment, empowerment of nurses, power, power in health care, Foucault empowerment in mental health and community nursing, empowerment in social work and psychology, concept analyses, self advocacy, self care, self-determination, self efficacy, patient preference, nursing, renal, ESRD, decision making, psychological factors in ESRD, and the relationship between nurse and patient. In order to locate research articles for this literature review, a range of databases were searched. These included: Medline, Ovid, CINAHL, Proquest, Blackwell Science, and Web of Science. Reference lists from retrieved articles were also hand searched for relevance. Only concept analyses and published research articles written in English from 1970 to 2005 were retrieved. Research articles and concept analyses were sought through electronic databases and journal texts.

### Selection Process

A total of 114 articles were identified and retrieved. At first, all the articles appeared to be relevant to this review. Many were excluded for the following reasons:

1. The article was about empowerment and haemodialysis, but did not clarify how the concept of empowerment was used in the study.
2. The article discussed self-care during dialysis treatment but 'self care' pertained to dietary regime or other types of care not indicative of empowerment or any similar psychosocial issue.
3. The article was about haemodialysis but was specific to paediatric care.
4. The article was not a concept analysis or a research study.

The results of this selection process revealed 6 concept analyses on empowerment, 5 research studies on empowerment in nursing and 9 research studies on empowerment and patients (two of which were specific to ESRD patients).

## Results

### Framework

The papers were reviewed and the following themes were identified:

1. The elements of the concept of empowerment
2. Empowerment in nursing and nursing education
3. Empowerment of patients in non-renal settings
4. Empowerment of patients with ESRD

The research studies reported in the 14 reviewed articles were conducted in the United Kingdom (UK), United States, Europe, Canada, Australia and Taiwan, and represented several different fields of nursing (mental health, community health, aged care and renal). The majority of the studies used qualitative methods and analyses, had small sample sizes, and involved one type of setting.

### Elements of the concept of empowerment

In general, the term empowerment was used but was not clearly defined. Therefore, it was initially necessary to explore concept analyses to establish the key elements of empowerment. Six papers were identified as undertaking analysis of the concept of empowerment. They all used the framework of Walker and Avant (1988) for concept analysis and included aspects of other concept analysis approaches (Meleis, 1991; Morse, Mitcham, Hupcey, & Tason, 1996; Rogers, 1997; Schwartz-Barcott & Kim, 1986) (Table 1). Seven key elements of the

concept of empowerment were identified in this review because they were central in all six concept analyses. The elements have been grouped according to the emerging and consistent themes, which arose from the concept analyses.

Essentially the process was to read thoroughly and analyse each of the concept analyses including the antecedents and consequences of empowerment. Through these six analyses, emergent themes arose to the researchers in terms of elements that are central to the concept of empowerment. Each concept analysis did not necessarily use exactly the same language. For example, one element of the concept was goal setting; a term used by 4 of the concept analyses authors. Hokanson Hawks (1992) called this an ability to set and reach goals, while Finfgeld (2004) called it making goals and achieving them.

The review identified 7 major elements of empowerment as: self-determination, partnership, effective communication, goal setting, socio-political awareness, a caring environment and construction of knowledge. No specific definition has been given to the elements, but rather an effort has been made to describe the nature of each of the elements. These have been ordered according to the prominence of the element within the concept analyses. Table 2 details the themes and their source. These themes were identified as core to defining the elements of the empowerment and were subsequently used to analyse the research literature and to determine if the author(s) of a study was researching empowerment or perhaps some other related concept.

Figure 1 illustrates the number of studies that addressed each of the elements of empowerment and clearly demonstrates that no single study incorporated

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all the seven identified elements of empowerment. The element of self-determination was used in all but one study, while the elements of construction of knowledge and goal setting were not used at all.

### Empowerment, nursing and nursing education

Five studies met the criteria for this literature review pertained to empowerment in nursing and nurse education (Campbell, 2003; Fulton, 1997; Jones, 1996; Faulk-Rafael et al 2004; Laschinger & Finegan, 2005). From these studies it was clear that empowerment is an issue for educators, nursing undergraduates and those already practicing in the field.

Fulton (1997), in her study of nurses in focus groups found that empowerment involves making the right decisions and having choice and authority. The nurses in her study conceptualised empowerment in terms of having freedom. Laschinger and Finegan (2005) surveyed 273 medical, surgical and critical care nurses concluding that structural empowerment had a direct effect on organisational trust and respect, job satisfaction and commitment. Their results are linked with the elements of effective communication, caring environment and to an extent, partnership. These findings also highlighted interpersonal factors, which are important for nursing practice. This is central to a conceptual understanding of empowerment. In a related finding, Jones (1996) concluded from an ethnographic study of 14 participants, that nurses have a perceived lack of clinical empowerment related to their notion that management was viewing them as simple labourers. In addition if nurses remain disempowered their interest and ability to empower others through any process felt inappropriate and unavailable to them.

Focus on the concept analysis	Author(year)
Empowerment in Nursing Education	Hokanson Hawks (1992)
Empowerment in Nursing	Gibson (1991) Rodwell (1996)
The process of empowerment	Ellis-Stoll and Popkess –Vawter (1998)
Empowerment and its relationship to mental health nursing	Ryles (1999)
Empowerment of individuals with enduring mental health problems	Fingfield (2004)

Table 1. Concept analyses of empowerment

The experience of empowerment was found to be dependent on the individual nurse, the environment, the individual's past experiences and current interactions with others (Campbell, 2003). These findings from a study using grounded theory methodology emphasised a circular process, which values self and others, and are related to the elements of the concept of effective communication, partnership and caring environment.

An important addition to the understanding of empowerment in nursing education was the finding that empowerment increased in students where feminist pedagogical principles were taught, and was likely to also extend beyond the classroom (Falk-Raphael, Chinn, Anderson, Laschinger, & Rubotzky, 2004). The authors used an empowerment data collection tool, Barrett's Power as Knowing Participation in Change Tool (PKPCT), to measure student empowerment that has also been used by Murray (1989) to explore empowerment for sufferers of ESRD. This study grasped one of the fundamental elements of empowerment, that of socio-political awareness and they used it to educate nursing students.

In summary, the research studies in relation to empowerment in nursing and nursing education were found to incorporate elements of the concept

of empowerment related to self-determination, effective communication, caring environment and the importance of socio-political awareness. No studies covered the elements of goal setting and construction of knowledge.

### Empowerment and patients in non-renal settings

Seven studies meeting the criteria for this literature review pertained to empowerment of patients in non-renal settings. Most of these research studies focussed on the elements of self-determination and partnership, with one study, focussing on socio-political awareness. The focus was placed on an individual's ability to self empower.

An Australian study using grounded theory methodology found that many nurses were not prepared to share their knowledge and decision-making powers with patients (Henderson, 2003). Henderson (2003) identified that partnerships and self-determination are essential, however, the use of power to control patients still appears to occur. Similarly, a UK study found that the National Health Service was fundamentally paternalistic. Key findings were that poor communication was central to patients not feeling empowered, and only one interviewee who chose an active role in her care

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Elements of the concept of empowerment	Author (Year)
<b>Self Determination.</b> The motivation to change behaviour. Synthesis/ autonomy/ freedom to make choices. Self efficacy and self confidence.	Hokanson Hawks (1992), Gibson (1991), Ryles (1999), Fingfield (2004), Rodwell (1996), Ellis-Stoll, Popkess-Vawter (1998)
<b>Partnership.</b> Power sharing. Participatory decision making. Collaboration and negotiation. Mutual exchange of ideas. A partnership which values self and others. Interactions are mutually beneficial.	Fingfield (2004), Rodwell (1996), Gibson(1991), Hokanson Hawks (1992), Ellis-Stoll, Popkess-Vawter (1998)
<b>Effective Communication.</b> Active listening. Openness and authenticity. Nurturing environment.	Gibson (1991), Hokanson Hawks (1992), Rodwell (1996), Fingfield (2004) Ellis-Stoll, Popkess-Vawter (1998)
<b>Goal Setting.</b> Mutual establishment of goals and the means to achieve these goals. Ability to set and reach goals.	Gibson (1991), Rodwell (1996), Hokanson Hawks (1992), Ellis-Stoll, Popkess-Vawter (1998)
<b>A Caring Environment.</b> Caring nurturing environment that encourages open communication, honesty and genuineness accepting people as they are valuing others.	Hokanson Hawks (1992)
Socio-political Awareness.	
Understanding of the complex social, political and economic forces which shape people's lives. Critical comprehension of the socio-political realities of one's environment.	Ryles (1999), Fingfield (2004)
<b>Construction of knowledge</b> Knowledge is gained from the collective sharing of experiences and understanding of the social influences.	Gibson (1991), Fingfield (2004), Ellis-Stoll, Popkess-Vawter (1998)

**Table 2. Identifying elements of the concept of empowerment**

was able to describe active participation in her decision-making (Doherty & Doherty, 2005). Conversely, Lammers (2002) argued that attitudes from service providers may be improving toward the mentally ill although resistance remains from providers in terms of accepting consumers as contributors in their care.

There have been attempts to measure empowerment quantitatively. For example the 'Patient Empowerment Scale' (PES) was tested in the UK with 102 patients and 38 registered nurses, where elderly care in a rehabilitation ward had the lowest score (Faulkner, 2001). The PES was developed as a valid and reliable measure of patient

empowerment and disempowerment in hospitals catering for older people and therefore may not be transferable to different age populations. In another quantitative study, empowerment was shown to have significant positive correlations with psychosocial functioning, social network and subjective quality of life (Hansson & Bjorkman, 2005). This work suggests that nurses should consider socio-demographic factors and socio-political awareness in terms of supporting empowerment of patients.

Paterson (2001) aimed to identify the element of self-determination with 22 Caucasian Canadians aged between 24-81. She found that practitioners discounted the experiential knowledge of people who had lived with a disease for years, and that the same practitioners did not provide the resources necessary for someone with chronic illness to make informed decisions. This study showed that despite some practitioners reporting that they were partners with people with chronic illness, the notion of empowerment may be more rhetoric than reality.

In an effort to increase patient empowerment Fleury (1989) found a process of empowering in a cardiac rehabilitation population consisted of three stages: appraising, readiness and integrating change. The study provides a framework for the nursing theory of empowering potential, and the conceptualisation of individual motivation as a pathway to initiating and sustaining cardiovascular health behaviours. Application of Fleury's study to ESRD may be limited given its specificity to empowerment for patients with cardiac disease.

In summary, the major elements of empowerment in relation to patients in non-renal settings investigated in these

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studies involved self-determination, effective communication, partnership and socio-political awareness. Absent from the research were the elements of goal setting, construction of knowledge, and a caring environment.

### Empowerment and patients with ESRD

The literature search pertaining to empowerment and sufferers of ESRD found two research papers specific to this topic. According to these studies patients with ESRD require self-determination for empowerment. This reflects the similarities with the literature pertaining to patients in general.

A qualitative approach by Murray (1989) employed Barrett's Tool (Barrett, 1985) to interview 7 women and 4 men undergoing different forms of dialysis treatment while living in the community in various parts of Alabama. Murray identified 2 themes; *Assets*; purpose for life, realistic view, positive outlook, support system and hope, and *Actions*; accepts responsibility, makes lifestyle choices, changes life pattern. The study revealed factors that hindered participants' empowerment, including decreased physical endurance, financial constraints, and decreased mobility. Significant to this study, were the empowered individuals who had the capacity to bring about change, to direct a portion of their environment, and to move toward self-determination. Murray creates the impression that empowerment is solely up to the individual, which is contrary to other published work that identified a more complex conceptualisation. Importantly, Murray defined empowerment as a 'process of enabling individuals to discover within themselves...their capacity to gain direction over some portion of their environment and proceed toward self-

determination' (Murray, 1989 p.15).

Tsay and Hung (2004) used a randomised controlled trial (RCT) with a pre test post test design with 50 people in two major hospitals in Taiwan (n=25 empowerment group, and n=25 control group). Their overall purpose was to 'investigate the differences in empowerment, self care, self efficacy and depression among those ESRD patients receiving usual care plus empowerment intervention and those receiving usual care' (Tsay & Hung, 2004; p.59). This study showed significant statistical differences in improvement of empowerment, self-care, self-efficacy, and depression in patients who were in the intervention group than with the control group. However, their findings need to be given cautious consideration given the limitations of a small sample size for a quantitative study, and that the participants did not have mental health co-morbidities. The results of this study were statistically significant for this group, and highlight the complexities in attempting to quantify the concept of empowerment.

The two studies directly related to empowerment for people undergoing dialysis only addressed the element of self-determination, and did not overtly consider the other elements of partnership, effective communication, goal setting, a caring environment, socio-political awareness or construction of knowledge. Thus, the use of the term empowerment may require further complex analysis in subsequent studies.

### Recommendations

To assist future researchers and clinicians the elements of empowerment in terms of practical examples for renal care require some discussion. Researchers

and clinicians will benefit from exploring their own understanding of the following elements related to empowerment. Each element is discussed below:

- *Self-determination* is a term used to describe respect for a patient as an individual and that patients should have some control of the dialysis process in which the patient and clinician share. This means that the patient is an integral part of their own care and the decision-making required. Self-determination in a dialysis unit recognises who owns the "body" and therefore who has the right to make choices. If clinicians are uncomfortable with this, they may conceptualise how they would feel if someone made health decisions for them without consultation.
- *Partnership* in ESRD care requires true collaboration and negotiation between clinician and patient. This involves shared decision making, and both patient and nurse being equally involved. To avoid tokenistic versions of partnership, nurses, for example should be consulting and giving rights to patients on how much weight is taken off per session, where the machine is placed, where the needles are inserted, and the speed of the machine.
- *Effective communication* is the sharing of ideas, thoughts, knowledge and experience, and there is always more than one person involved. Although this definition may appear obvious to some, the 'take home' message for renal clinicians is that in order to effectively communicate with patients, one must remember that it is a two way process, and this means actively listening to one's patient, for example, when they state why they

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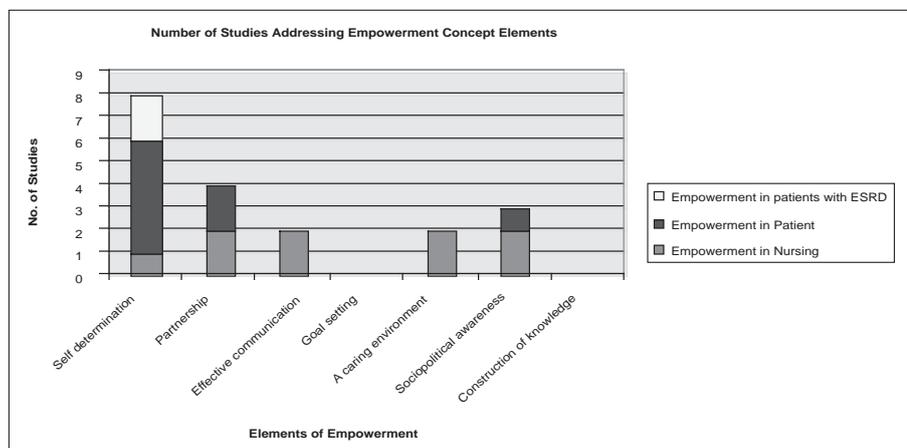


Figure 1. Comparison of Studies using elements of the concept of Empowerment

have consumed too much potassium or why they are unable to insert their own needles.

- *Goal setting* requires a form of collaboration between nurse and patient and the means to achieve these goals. For example, the goal to remove an amount of fluid per dialysis session needs to be achievable and agreed upon by clinician and patient. Effective goal setting incorporates effective communication and self-determination.
- *A caring environment* in a renal setting where patients have long-term relationships with clinicians requires that patients be heard in terms of what they require for this element to be satisfied. One example is that phone calls are made to individuals post treatment to check on their health/ emotional status. Another example is for the clinician to be sensitive to the differing needs of patients, especially if they want the curtains drawn around them during the treatment.
- *Socio-political awareness* requires the clinicians to be aware of the

cultural, personal and political issues a patient may be facing. For example, a female patient, living in poverty and domestic violence has a complex social reality, which may interfere with this woman being able to arrive on time or adhere to diet requirements for example. Just as renal clinicians have complex social and personal lives, their patients are acknowledged with the same entitlement.

- The final element termed *construction of knowledge* encapsulates the ontology and epistemology of the dialysis unit. Ontology understands what it means to exist as a dialysis patient in the dialysis unit and epistemology means the theory of knowledge embedded in the dialysis unit. Collectively they represent the term “construction of knowledge” and ask whether the meaning of dialysis is beyond clinician-patient interaction or if there is one truth in the dialysis unit. The researchers of this paper advocate that regardless, the patient’s own construction of this knowledge must be understood for empowerment to be possible.

## Conclusion

Empowerment is not unlike a new glossy product on the supermarket shelf, attractive and interesting. The question is “Is there any substance within the packaging”? Only two papers were found to have researched empowerment of people living with ESRD, and as they both stated, the concept of empowerment is ambiguous and the related research is very limited (Murray, 1989; Tsay & Hung, 2004). Consequently, it was useful and appropriate before reviewing the research to analyse the concept analyses on empowerment and discern their thematic elements. From these concepts, seven elements arose which became the launch pad for the analysis of the literature including nursing, nursing education, patients in non-renal settings and patients in renal settings.

The concept analyses within the literature gave a solid theoretical grounding to a concept holding multiple meanings and affecting numerous health professions (eg. social work, nursing, psychology). The main elements emerging from the analyses were self-determination, effective communication, goal setting, caring environment, partnership, socio-political awareness and construction of knowledge. The five studies, which met the criteria in terms of empowerment and nurses and nursing education, emphasised socio-political awareness and for nursing students and practitioners to understand the socio-political framework from which they operate on a daily basis. The research studies pertaining to patient empowerment focussed mainly on self-determination and the patient’s ultimate right to decision making in their own care. The only two studies found on empowerment and ESRD also focussed on self-determination, and did not incorporate the other concepts of

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empowerment into their study.

In summary, this literature review has identified that there are seven elements of the concept of empowerment, which can be identified in any further research on empowerment. Thus the challenge for researchers is to incorporate the elements of empowerment into future studies and subsequent clinical practice. We propose that future research on empowerment in relation to caring for patients living with ESRD should be guided by the elements to provide a thorough exploration of patient care.

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