The concepts of patient-centred care, patients’ involvement in knowledge co-creation and empowerment have been introduced as a way to move away from the current health-care system in which the physician-centred model of care remains dominant. This model was found to be insufficient for improving patients’ quality of life due to its strong focus on medical–technical aspects of care. A more collaborative approach in which patients’ needs are taken into account is thought to be helpful in incorporating social and psychological factors, leading to enhanced quality of care and subsequently improved health outcomes and patient satisfaction. Chapter 1 described the need to obtain more insights into strategies to strengthen knowledge co-creation and empowerment processes to enhance a patient-centred approach. This chapter presents the theoretical background from which this topic is studied. First, the concept of patient-centred care will be described. Next, patient involvement – and specifically the involvement of patients in knowledge co-creation processes – will be discussed, followed by an elaboration on how empowerment of both patients and health professionals has been conceptualized. Finally, the chapter reflects on the relations between the different concepts and presents the conceptual framework used for this research.

2.1 | PATIENT-CENTRED CARE

Over the past two decades, the need to adopt a more patient-centred approach to improve current care services has been increasingly recognized around the world (IOM, 2001; IAPO, 2007; Britain, 2005; WHO, 2000). Various authors have explored the concept of patient-centred care (Lusk and Fater, 2013; Mead and Bower, 2000; Robinson et al., 2008; Bensing, 2000). Following the review of Robinson et al. (2008) four sources of definitions of patient-centred care could be distinguished: (1) policy, (2) economic, (3) clinical and (4) patient-based definitions (Robinson et al., 2008). The focus of these definitions varies (Robinson, 2005; Stewart, 2001; IOM, 2001). Where the Institute of Medicine defines patient-centred care as “a partnership to ensure that decisions include patients’ preferences and needs and support patients in becoming involved in their own care” (IOM, 2001: p.7), Robinson’s consumerist view framed patient-centred care as “patients’ ability to make choices that, in turn, generate pressures for increased quality and efficiency among providers and insurers” (Robinson, 2005: p.1479). An example of a clinical-focused definition is: “taking into account the patient’s desire for information and for shared decision-making and responding appropriately” (Stewart, 2001: p.445). Robinson et al. (2008) further notes that various studies have identified patients’ preferences in order to define patient-centred care. To demonstrate this, Robinson cites Jennings et al. (2005), whose work showed that in order for care to be patient-centred, patients should be treated respectfully and with competence and receive sufficient information. In this thesis, patient-centred care will be defined as: “a partnership to ensure that health-related decisions include patients’ preferences and needs” based on the definition of IOM mentioned earlier. Regarding the conceptualization of patient-centred care, Kitson et al. (2013) indicated that the seven dimensions of patient-centred care identified by Gerteis (1993) were most frequently referenced. The Institute of Medicine (IOM) adopted these dimensions of patient-centred care as part of a framework for health care improvements published in the report ‘Crossing the Quality Chasm’ (IOM, 2001). Following these dimensions, care should (1) respect patients’ values, preferences, and expressed needs; (2)
be coordinated and integrated; (3) provide information, communication, and education; (4) ensure physical comfort; (5) provide emotional support; and (6) involve family and friends. More insights into the conceptualization of patient-centred care are addressed in Chapter 5.

A patient-centred approach has been applied in various ways, ranging from including patients' values in the mission statement of health-care organizations and policy documents (e.g. Britain, 2005; IOM, 2001), enhancing the value for patients by including their needs in health-care decision-making (e.g. Poochikian-Sarkissian et al., 2010; Gillespie et al., 2004), and restructuring care services around the patient by care pathway management (e.g. Schrijvers et al., 2012; Vanhaecht et al., 2010). In addition, groups often adopt only certain elements of the concept depending on their specific interests and needs (Gillespie et al., 2004; Kitson et al., 2013). For instance, some focus on the information and communication process dimension of the IOM framework, others on the dimension of individualization of care (Rathert et al., 2013). As a result, the concept of patient-centred care has been pursued differently in various contexts (Rathert et al., 2013; Kitson et al., 2013).

Patient-centred care is expected to enhance patients' health outcomes and quality of life (Stewart, 1995; Oates et al., 2000) by improving self-care and self-efficacy (Ulin et al., 2015; Roumie et al., 2011), the quality of health-care services (Bertakis and Azari, 2011; Ekman et al., 2011; Oates et al., 2000) and subsequently patients' satisfaction (Rathert et al., 2013). Bertakis and Azari (2011) demonstrated that adopting a patient-centred approach led to reduced hospitalization and less use of specialized care. Patients' rather than health professionals' perspectives on patient-centred care were found to be an important predictor for patients’ outcomes, ultimately stressing the importance of patient-centred care (Stewart, 2003).

However, the success of attempts to incorporate patient-centred care in practice has been variable (Kitson et al., 2013; Wilkins et al., 2001). Patient-centred care is often used as a buzzword without actually applying its values in practice (Davies, 2007). For example, patients are frequently not involved in patient-centred care initiatives (Leplege et al., 2007). To shift towards patient-centred care, a participatory process in collaboration with patients and their families and carers is recommended (Wilkins et al., 2001).

2.2 | PATIENT INVOLVEMENT

Patient-centred care means placing patients' needs and preferences at the centre of care services (Laine and Davidoff, 1996; IOM, 2001). In addition, Little et al. (2001: p.1) state that “it makes little sense to try to implement each component of the patient-centered approach unless they are consonant with patients' perspectives.” Patients’ perspectives on the extent to which care services are patient-centred, were found to be a clear predictor of health outcomes (IOM, 2001; Stewart, 2001). As a result, the inclusion of patients’ perspectives in health-care decision-making has been presented as a way to ensure patient-centred care (Leplege et al., 2007; Kitson et al., 2013; Scholl et al., 2014; Lusk and Fater, 2013; Pelzang, 2010). For a true understanding of patients' preferences and needs, their involvement is crucial (Titter and McCallum, 2006).
CHAPTER 2

**Conceptualization of patient involvement**

Regarding the first part of the term ‘patient involvement’ – relating to the person receiving care – various terms have been used. Historically, the term ‘patient’ – traditionally used in health care – was increasingly seen as passive and disempowering within the movement towards patient-centred care (Christmas and Sweeney, 2016). Alternative terms, were introduced such as ‘consumer’, ‘customer’, ‘client’ or ‘service user’, which were thought to be more empowering. These terms attributed a more equal and active role to the care recipient (Neuberger and Tallis, 1999). A review by Costa et al. (2019) revealed, however, that the term ‘patient’, is still preferred in most studies for discussing the person receiving care. Reasons mentioned for this preference were ‘familiarity’ and ‘social identity’ (Costa et al., 2019). As van den Hooff (2012: p.8) states: “the term patient does justice to the fact that the care recipient is a human being. By using the term ‘patient’, the situation of an ill care recipient and the feelings that come along – a dependent situation with limited choice options – is taken into account.” In addition, empirical studies also indicate that people receiving care prefer to be called patients (Ritchie et al., 2000; Wittich et al., 2003; Deber et al., 2005). This preference does not necessarily apply to all care recipients: notable exceptions include mental health, maternal health, occupational therapy and social work (Simmons et al., 2010; Mcguire-Snieckus et al., 2003).

Based on this reasoning, the term ‘patient’ will be used in this thesis, – with the exception of the use of the term ‘client’ in Chapter 5, which focuses on the maternity care context. The term ‘patient representative’ will be used in cases where a patient represents a patient group, exceeding their own experiences and formulating a ‘we’-story (Pittens, 2013).

Regarding the second part of the term – relating to the active role of the care recipient – the terms ‘involvement’, ‘engagement’, ‘participation’, ‘collaboration’ and ‘partnership’ have been applied (Ocloo and Matthews, 2016; Gallivan et al., 2012), and are often used interchangeably. Yet, some authors use specific terms to imply involvement in varying degrees. For example, Ocloo and Matthews (2016) describe the involvement process as a form of engagement in which a partnership is formed between patients, the public and health professionals. Other literature, however, does not attribute different meanings to ‘involvement’ and ‘engagement’ (Fumagalli et al., 2015; Gallivan et al., 2012). ‘Participation’ has also been used to indicate a specific degree of involvement, consisting of two-way communication in which both preferences and opinions are integrated (Thompson, 2007; Fumagalli et al., 2015). Gallivan et al. (2012) specifically describes participation as meaningful involvement in decision-making about health policy and planning, care and treatment and the wellbeing of themselves and the community. Collaboration and partnership have also been related to a specific form of involvement that attributes a more equal partnership role to the patient. From an ideological perspective, the terms collaboration or partnership would be most appropriate, but owing to a lack of consensus on the terminology (Gibson et al., 2012), pragmatic reasons – the use of the term in the relevant literature – guided the decision to use the term ‘involvement’ in this thesis. Regarding patient involvement, we use the definition of Ocloo and Matthews (2016: p.627): “an activity that is done ‘with’ or ‘by’ patients rather than ‘to’, ‘about’ or ‘for’ them.” Other definitions of patient involvement specifically focus on involvement in decision-making processes (Higgins et al., 2017), thereby overlooking the diverse aspects of care in which patients can be involved outside the decision-making context (Coulter and Ellins, 2006; Longtin et al., 2010).
Involvement initiatives differ in the extent to which power is handed to the patient. The ‘participation ladder’ of Arnstein (1969) has often been used as a guide to distinguish the different levels of involvement, depending on the extent to which citizens can influence the decision-making process and its outcomes. The higher the level, the more decision-making power is given to the ‘citizen’ – or in the case of this thesis, the ‘patient’. Following Arnstein this ladder shows the distinction between genuine involvement and having no or limited power to influence decision-making. Where the first five levels refer to non-involvement (manipulation and therapy) or tokenistic forms of involvement (informing, consultation and placation), initiatives relating to the last three levels (partnership, delegated power and citizen [patient] control) genuinely hand over power to the patient. Other authors emphasize that the appropriate level of patient involvement depends on a specific situation: ‘higher is not necessarily better’ (Titter and McCallum, 2006; Gallivan et al., 2012). Tritter and McCallum (2006) indicate that Arnstein’s ladder fails to recognize the complexity and diversity of aims, knowledge sources and participation opportunities within health care. These authors present a mosaic model, giving space to a more complex relationship in which patient involvement could be discussed (Titter and McCallum, 2006).

A distinction has also been made in the literature between individual and collective patient involvement (Andersson and Olheden, 2012; Jones et al., 2004; Wiig et al., 2013; Tritter, 2009). Where ‘individual involvement’ is focused on patients’ own care (Thompson, 2007), ‘collective involvement’ focuses on care services in general (Wiig et al., 2013). In addition, Tritter and McCallum (2006) made a four-level division of collective involvement, distinguishing: (1) service development; (2) evaluation of services; (3) professionals’ education and training; and (4) research activities. This division arises from the different topics in health care decision-making. The categorization ‘evaluation of services’, for instance, consists of all initiatives in which knowledge is co-created on how current practices can be improved by evaluating current experiences from different stakeholders. In this thesis, involvement will be studied both at an individual and collective level relating to service development and evaluation of services.

Until now, most of the patient involvement literature focused on patients’ individual involvement (Andersson and Olheden, 2012). Much is written on the process of shared decision-making, which has been presented as a model for two-way communication in which patients are involved in the decision-making regarding their own care. According to Stiggelbout et al. (2015), this process consists of four phases: (1) mention that a decision has to be made; (2) address the options and their pros and cons; (3) discuss the preferences; and (4) discuss role preferences regarding decisions, the decision itself and the follow-up. Various initiatives have been set up to build capacity and initiate a change in knowledge, attitudes and behaviour towards shared decision-making (Légaré et al., 2008a). Other applications of patient involvement at an individual level, differ from a way

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1 Arnstein’s ladder of Citizen Participation has been set up as a guide for different levels of involvement in decision-making, depending on the extent to which power has been shared. The ladder consists of eight steps: (1) manipulation, (2) therapy, (3) informing, (4) consultation, (5) placation, (6) partnership, (7) delegation and (8) citizen control.
to foster self-management skills (e.g. McCarley, 2009; Jordan et al., 2008), stimulating awareness about physical and emotional needs enabling shared decision-making, to ensure opportunities for patients to manage their own care by treatment alliance (e.g. Barello et al., 2014). In addition, patients’ individual involvement has been found helpful for reaching a correct diagnosis, ensuring treatment adherence and identifying side effects (Coulter and Ellins, 2007). As a result, patients’ needs are placed more centrally in health services, having a positive impact on patient outcomes.

At a collective level, patients have been involved in activities like guideline development (Serrano-Aguilar et al., 2015; Pittens et al., 2015; van der Ham et al., 2014; Boivin and Légaré, 2007), quality improvement (e.g. Andersson and Olheden, 2012; Wiig et al., 2013; Armstrong et al., 2013; Gustavsson, 2016; Millett and Adams, 1999), patient safety (e.g. Bishop et al., 2015; Davis et al., 2007), health policy (e.g. van der Meide et al., 2015; Hoogerwerf et al., 2004), care logistics (e.g. Beedholm and Frederiksen, 2019; Crawford et al., 2002; Faber et al., 2014; Gagliardi et al., 2008), and professional education (McCutcheon and Gormley, 2014). Involving patients at a collective level is expected to improve care services, lowering health-care costs and positively affecting patient outcomes (Brett et al., 2014; Mockford et al., 2011). Involving patients in giving advice and revising drafts, for example, led to the development of clinical guidelines that are more applicable in daily practice (Pittens et al., 2015; Loudon et al., 2014).

**Barriers to patient involvement**

Progress towards achieving patients’ more successful involvement in health care has been variable (Ocloo and Fulop, 2012; Ward and Armitage, 2012). On an individual level, the principles of shared decision-making have for instance been limited implemented in practice (Couët et al., 2015). Support varies regarding the clinical context, treatment decision and patients’ characteristics (Pollard et al., 2015; Stiggelbout et al., 2015). The attention in recent years of patient involvement at a collective level, has been mainly focused on health research and to a lesser extent on involving patients in health care. This difference could be explained by the fact that their involvement in health care seems to be more self-evident. As a result, involvement opportunities have not yet been fully exploited (Andersson and Olheden, 2012). Patients are often involved only once and initiatives focus on mostly lower levels of involvement – such as informing and consultation (Tritter, 2009). Even when patients are heard, they lack the power to make sure their perspectives are actually heard which could result in tokenistic involvement (Arnstein, 1969).

Current literature also shows that patient involvement is frequently tokenistic, becoming an obligatory ‘box-ticking exercise (Supple et al., 2015; Andersson and Olheden, 2012; Ocloo and Matthews, 2016). Involving patients in decision-making challenges health professionals’ dominance, and could therefore be experienced as threatening by health professionals and organizations (Andersson, 2015). Issues such as the lack of resources (Angel and Frederiksen, 2015), patients’ lack of medical knowledge and confidence (Longtin et al., 2010) and devaluing patients’ perspectives, were found to be barriers to patient involvement (Ocloo and Matthews, 2016). Furthermore, limited studies have been conducted to assess the impact of patient involvement (Mockford et al., 2011) because of the absence of reliable and valid tools for measuring it (Phillips et al., 2016), and the resources required for further improvement (Légaré et al., 2011). The limited impact of involvement
activities on decision-making (Boivin, 2012; Staniszewska et al., 2008) further reinforce tokenism.

2.3 | KNOWLEDGE CO-CREATION

To address the above-mentioned barriers to patient involvement, more continuous patient involvement in the provision of care has been put forward (Titter and McCallum, 2006). In continuous involvement, the level of inclusiveness could differ over time and according to the situation, depending on patients' preferences (Titter and McCallum, 2006). To involve patients in health care at the structural level, previous literature stressed the need to involve patients as partners in a knowledge co-creation process (van Veen et al., 2013; Pittens, 2013; Batalden et al., 2016). Although the concept of knowledge co-creation was originally developed in the context of collective involvement of patients to improve health care innovations, it can also be used on an individual level to improve treatment decision-making. By involving patients in knowledge co-creation processes, the idea is that patients' needs will become more central in health-care services. Knowledge co-creation – also known as knowledge co-production – has been proposed as a way to equally include different stakeholders' knowledge and to stimulate learning processes (Jasanoff, 2004), which is necessary for overcoming current barriers to patient involvement (Collins and Ison, 2006). In this thesis, the term knowledge co-creation will be used as it is the one most widely accepted. Knowledge co-creation has been defined by Regeer and Bunders (2009: p.63) as “a communicative process which takes place within a shared practice.” This is not a linear but a complex co-evolutionary process that proceeds iteratively and is action-oriented (Regeer and Bunders, 2009).

Steps in knowledge co-creation

The process of knowledge co-creation consists of three iterative steps (see Figure 1). First, knowledge is articulated (knowledge articulation), meaning that implicit or tacit knowledge – which is used unconsciously – is made explicit (Pittens, 2013). Making implicit knowledge explicit is especially crucial for patients because they are often not aware of their experiential knowledge. This experiential knowledge that patients have obtained by experiencing the illness and care process complements explicit expert knowledge. These two types of knowledge – experiential and expert knowledge - are closely intertwined, meaning that patients and health professionals can have both types of knowledge (Caron-Flinterman et al., 2005). In addition to their experiential knowledge, patients can obtain expert knowledge by discussions with health professionals, attending conferences or reading information about their condition. This is called proto-professionalism (Caron-Flinterman et al., 2005). Health professionals also acquire experiential knowledge through the experience of practicing medicine, as well as by experiencing illness and care themselves. The extent to which a certain type of knowledge is present in each actor group, however, differs. By articulating their knowledge, patients become more aware of their own perspectives and needs, and are therefore better equipped to interact with other stakeholders (Abma and Broerse, 2010). This process – also known as 'enclave deliberation' – is seen as an important condition for reaching a dialogue between equals, which is needed for knowledge integration (Karpowitz et al., 2009). This second step of knowledge co-creation can be seen as the joint construction of the different types of articulated knowledge, such as expert and experiential knowledge. This process is not just a matter
of adding different parts of knowledge together (Regeer and Bunders, 2003), but is a complex iterative communicative process in which understandings are developed, shared and deepened (Regeer and Bunders, 2009). Within this process, learning takes place, and stakeholders develop new ideas because they obtain insight into each other’s perspectives and underlying assumptions (Abma and Broerse, 2010; Collins and Ison, 2006). Learning can take place on three interconnected levels: (1) single-loop, (2) double-loop, and (3) triple-loop (Argyris and Schön, 1978). In single-loop learning, substantial and procedural learning on a topic takes place. Double-loop learning is more reflexive and concerns stakeholders’ underlying norms and values. Triple-loop learning focuses on a meta level by reflecting on the learning process itself. To initiate double- and triple-loop learning, a dialogue should take place consisting of critical listening to and reflecting on each other’s perspectives and assumptions (Caron-Flinterman et al., 2007) and developing new insights and ways of working (Isaacs, 1999). Reflection on the processes of knowledge co-creation are found to be essential of to initiate incremental change (Peschl, 2007). However, such reflection rarely takes place (Healy and Braithwaite, 2006; Pittens et al., 2013). As a result, learning is usually restricted to single-loop learning, and double-loop learning to a certain extent. Where learning is seen as a direct outcome of the knowledge co-creation process on a collective level, knowledge co-creation

![Diagram of the process of knowledge co-creation](Image)

**Figure 1:** The process of knowledge co-creation, based on (Regeer and Bunders, 2009) and (Pittens, 2013)
on an individual level focuses on improving decision-making processes in which learning takes place. The last step of knowledge co-creation, *knowledge embedding*, involves the sustainable implementation of the process and outcomes of knowledge co-creation processes. Embedding of the process and outcomes of knowledge co-creation entails implementing the integrated knowledge in practice and structurally involving patients in knowledge co-creation in the long term (Ward *et al.*, 2010; Abma *et al.*, 2009).

**Barriers to knowledge co-creation**

Patients’ experiential knowledge is increasingly acknowledged as a legitimate source of information. The involvement of patients in knowledge co-creation processes in health care have, however, been limited (Pittens, 2013; van de Bovenkamp and Zuiderent-Jerak, 2015). Until now, initiatives mainly focus on the first step of knowledge articulation (Andersson and Olheden, 2012) and are seldom optimal (van der Ham *et al.*, 2014; Boivin, 2012). Limited time and money, for instance, restricts representation of patients, thereby hindering the breadth of the knowledge articulation process (van der Ham *et al.*, 2014). Knowledge integration occurs only sporadically because of limited interaction between patients and health professionals, and creates challenges in stimulating double- and triple-loop learning (Pittens, 2013). Knowledge embedment is especially challenging because it requires new ways of thinking, organizing and doing (Caron-Flinterman *et al.*, 2007) and therefore it rarely takes place (Shippee *et al.*, 2015). Equal attention to all three steps of knowledge co-creation is needed for this complex process to be successful. In addition, process facilitation is required that stimulates the development of good social conditions (Pittens, 2013). These conditions are needed to create a balanced relationship between patients and health professionals in which patients’ voices are equally heard (van der Meide *et al.*, 2015).

**2.4 | EMPOWERMENT**

Within a collaborative relationship, both at an individual and collective level, patients and health professionals should adopt new roles in which their power is shared (Ocloo and Matthews, 2016). Empowerment enables individuals to fulfil these roles (Ocloo and Matthews, 2016) through changing attitudes and improving knowledge and skills (Anderson and Funnell, 2005; Smith *et al.*, 2009). By empowering both patients and health professionals, the current barriers to knowledge co-creation, as mentioned in the previous section, could be overcome. This will enhance the impact of involving patients in current knowledge co-creation processes to stimulate patient-centred care.

**2.4.1 | PATIENT EMPOWERMENT**

The concept of empowerment was developed as a way to increase the power of oppressed groups, such as ethnic minorities and the poor, and evolved from Freire’s pedagogy of the oppressed (Freire, 1999) and different philosophical theories (Hage and Lorensen, 2005) among other sources. In the 1980s, the concept of empowerment was introduced into health care in the context of self-management (Roberts, 1999). The attention paid to patients’ empowerment has increased recent years, allowing patients to potentially take an active role in within their own care (Bruegel, 1998; Anderson and Funnell, 2005).
CHAPTER 2

**Conceptualization of patient empowerment**

Patient empowerment has many different definitions, which vary according to different contexts (Anderson and Funnell, 2010; Roberts, 1999; Jupp *et al.*, 2010; Zimmerman, 2000). The focus of these definitions range from (1) a transformative process, to (2) the principles and ethos of empowerment and to (3) empowerment interventions (Bravo *et al.*, 2015). Empowerment can be seen both as a process – transferring power to disempowered stakeholders – and as an outcome of this process (Swift and Levin, 1987). Most definitions focus more on the outcome of empowerment, describing it as a way in which patients can become autonomous, having control over their own illness and care process (Aujoulat *et al.*, 2007; Funnell and Anderson, 2003). The most cited (11%) definition is that of Funnell *et al.* (1991): “helping patients discover and develop the inherent capacity to be responsible for one’s own life.” Because this thesis focuses both on the process and outcomes of patients’ empowerment at an individual and collective level, the definition used by Alsop and Heinsohn (2005) was found to be more appropriate. They describe empowerment as “the process of gaining power and capacities to make informed-choice.”

Different models have been created to conceptualize patient empowerment in the context of empowerment interventions (Prigge *et al.*, 2015; Small *et al.*, 2013; Bravo *et al.*, 2015). Based on a review of existing definitions and conceptualizations, Bravo *et al.* (2015) created a model capturing the full complexity of the concept. This model describes patients’ empowerment on multiple levels. This means that patients’ empowerment is influenced – directly or indirectly – by the ‘ethos’ of patients, health-care providers and the health system. The actual level of empowerment can be determined by two indicators: the patients’ capacities or states and resources of empowerment (‘the state’); and patients’ empowerment ‘behaviours’. There is a reciprocal relationship between the two types of indicators, which means that patients’ resources influence their behaviour and in turn leads to acquiring certain resources. Patients’ empowerment behaviours and states together influence patients’ level of empowerment, influencing outcomes such as quality of life and well-being, and subsequently clinical outcomes. The empowerment indicators are described in more detail in Chapter 7 and Chapter 8.

**Operationalization of patient empowerment**

Like patient involvement, patient empowerment can be situated at both an individual and collective level. Patient empowerment at an individual level means that individual patients gain control over their own health, positively influencing their well-being (Wallerstein, 1992). At a collective level, empowerment is used to describe patients’ active role in health-care decision-making at an organizational and policy/planning level.

In this thesis, we study patient empowerment at both an individual and a collective level – involving patients in knowledge co-creation processes regarding the organization of care services. The current literature on patient empowerment mainly focuses on empowering patients at an individual level and specifically on their education. The effectiveness of current empowering (education) interventions has, however, been sub-optimal (Mason *et al.*, 2008; Samoocha *et al.*, 2010; Viklund *et al.*, 2007; Kuijpers *et al.*, 2013). Paterson (2001), for instance, showed that patient empowerment strategies in interactions between patients and health professionals was hindered by a lack of...
inclusion of patients’ experiential knowledge and the provision of information needed for shared decision-making. As a result, patient empowerment can become just ‘empty rhetoric’ (Paterson, 2001).

2.4.2 | HEALTH PROFESSIONAL EMPOWERMENT

To empower patients to be able to be involved in knowledge co-creation processes also demands a change in health professionals’ roles and tasks, and consequently their attitudes and skills (Gagliardi et al., 2008; Anderson and Funnell, 2005). For example health professionals’ attitudes towards experiential knowledge and their relationship with the patient were found to be associated with the success of initiatives to involve patients (Vahdat et al., 2014; Davis et al., 2007). To involve patients in knowledge co-creation, health professionals have to become confident in sharing both knowledge and power (Henderson, 2003). As Quinn and Spreitzer (1997: p.47) stated: “It is nearly impossible for unempowered people to empower others.” In line with this, Aujoulat et al. (2007) describe patient empowerment as a complex process that occurs in the interaction with health professionals. To what extent patients are involved in knowledge co-creation processes and thus becoming empowered depends on health professionals’ level of empowerment (Spence Laschinger et al., 2010).

With respect to the empowerment of professionals, Spence Laschinger et al. (2010) distinguish between structural and psychological empowerment. Structural empowerment relates to health professionals’ work settings, where psychological empowerment indicates their reaction – or intrinsic motivation – in these settings (Laschinger et al., 2001). The different categories of work settings and health professionals’ reaction to these work settings are described in Chapter 8.

Barriers to health professional empowerment
Paterson (2001) brought forward that although health professionals perceived themselves as sufficiently skilled to empower chronically ill patients, they rarely presented participatory behaviour in practice. According to Pelzang (2010) current education programmes in teaching health professionals to empower patients through providing patient-centred care, are still limited. In addition, a lack of resources (Brett et al., 2014), such as time to explore patients’ needs and to discuss care options, was found to be a barrier to providing empowering care services (Paterson, 2001).

2.5 | RELATIONSHIPS BETWEEN THE CONCEPTS

To better understand how patient involvement – in the form of knowledge co-creation – and empowerment could enhance patient-centred care, insights into the relationships between these concepts are needed. Fumagalli et al. (2015) describes a recursive relationship between patient involvement and empowerment. On the one hand, patient involvement can be seen as a precursor to their empowerment, meaning that by involving patients in health-care decision-making patients will become more empowered (Fumagalli et al., 2015). Initiatives to involve patients have been found useful in empowering patients through self-management, shared decision-making and patient activation (Barr et al., 2015). On the other hand, patient involvement can be seen as an outcome of empowerment, meaning that more empowerment will lead to more opportunities
to become involved. Once patients have acquired more knowledge, skills and awareness, they are expected to demand a greater involvement in decision-making processes (Fumagalli et al., 2015). Along the same lines, Engström and Elg (2015) showed that self-determination (an indicator of the empowerment ‘state’) can influence patients’ involvement in their care by, for example, wanting to have contact with others or make a contribution. In addition, the empowerment of health professionals has also been specified as a precursor to involving patients (Gagliardi et al., 2008). In conclusion, the empowerment of patients and health professionals in knowledge co-creation processes has been put forward as a way to stimulate patient-centred care, subsequently empowering both (Morgan and Yoder, 2012).

However, more insight is needed into how and when patient empowerment leads to their involvement, or when involvement leads to empowerment, to improve the quality of this causal relationship (Fumagalli et al., 2015). As Fumagalli et al. (2015: p.391) puts it: “empowered patients might still translate into inappropriate behaviours, while non-empowered patients might decide to participate in self-care with negative results.” In addition, empirical studies only focus on one of the above-mentioned relationships. Knowledge about the relationships between the concepts could be helpful for creating a self-reinforcing effect towards patient-centred care.

Figure 2: Conceptual framework
Based on literature about the relationships between the concepts of patient-centred care, patient involvement in knowledge co-creation and patient/health professional empowerment, as described above, a conceptual framework was created (see Figure 2). This framework has been used as a basis to reflect on the relationship between patients’ involvement in knowledge co-creation and empowerment, and how these concepts can be mutually strengthen each other in the context of patient-centred care. This framework shows a recursive relationship between patient-centred care and involving patients in knowledge co-creation. Through knowledge co-creation, more patient-centred care could be achieved which in turn would stimulate patient involvement. At the same time, there is expected to be a recursive relationship between patients’ involvement in knowledge co-creation and their empowerment. Involving patients in knowledge co-creation is expected to lead to a more empowered relationship, which subsequently enables patients and health professionals to co-create knowledge.