Introduction

Patient empowerment is a concept of growing importance in health care and health-related research. Studies have shown that involving and empowering patients with chronic diseases increases patient satisfaction with care, adherence, and care outcomes (Anderson & Funnell, 2010; Anderson et al., 2009; Hibbard & Greene, 2013; Holman & Lorig, 2004; Jerofke, Weiss, & Yakusheva, 2014; Lorig & Holman, 2003). Cancer is increasingly viewed as a chronic illness, due to more patients surviving or living with cancer for long periods of time (Bulsara, Styles, Ward, & Bulsara, 2006; Loh et al., 2011; Wilson, Lydon, & Amir, 2013). The concept of empowerment has thus gained in relevance in relation to cancer patients. It is relevant in all phases of the cancer trajectory, but there is increasing awareness of its specific importance in follow-up (Ganz & Hahn, 2008; Loh et al., 2011; McCorkle et al., 2011; Wilson et al., 2013).

In line with the definition of the Danish Board of Health (Sundhedsstyrelsen, 2016), this study defines follow-up as the time after first line therapy when patients are enrolled in a follow-up program. Follow-up may include more or less frequent contact with the health care system for longer or shorter periods of time and programmes may entail further treatment, screening activities, and rehabilitation depending on the diagnosis and severity of disease. Patients in follow-up may all be considered cancer survivors (Hewitt & Ganz, 2006). They are a diverse group of patients where some have been cured and others may have a chronic disease, but often share the anxiety of relapse. As resources are getting more scarce, they may also be expected to Loh et al., 2011; McCorkle et al., 2011; Wilson et al., 2013), emphasizing the importance of empowerment in this stage.

Empowerment has been described by Rappaport (1984) as “a process, a mechanism by which people, organizations, and communities gain mastery over their affairs” (p. 3), including both an individual and a collective level of analysis. Zimmerman (1995) has focused on the individual level of empowerment—what he calls “psychological empowerment” and distinguishes between empowerment as a process and an outcome. Empowerment processes are processes whereby “people create or are given opportunities to control their own destiny and influence the decisions that affect their lives” (p. 583). Empowerment outcomes include three components: the intrapersonal component (individually perceived degree of control), the interactional component (understanding of the context of one’s options and choices), and the behavioral component (particular actions taken).

Both Rappaport (1981, 1984) and Zimmerman (1995) are writing from a community psychology perspective, but the term empowerment is also increasingly used in health-related disciplines and in relation to patients. “Patient empowerment” most often focuses on the individual level of analysis, and thus resembles Zimmerman’s concept of psychological empowerment. Although processes of patient empowerment are usually described in relational terms (e.g., indicating the need for Health Care Professionals [HCPs] to share or hand over control to patients and provide narrow the focus of the term ‘empowerment’. It is now clear that this term is central to the review and it is now providing contextual information rather than mere definition.
the necessary information in order for patients to make decisions), outcomes of patient empowerment are mostly conceptualized as individual (focusing on the patients and their increased understanding of themselves, control, and self-management) (Aujoul, d’Hoore, & Deccache, 2007). However, as Rappaport (1984) and Zimmerman (1995) argue, experiences of empowerment are also highly personal, contextual, and timely. Patients’ perceived mastery or control of themselves and in relation to HCPs may vary significantly depending on their particular condition, the setting in which they interact with HCPs, and the stage of their illness.

In a recent review, Fumagalli, Radaelli, Lettieri, Bertele’, and Masella (2015) have identified three main ways in which patient empowerment has been used within the literature: first, as “emergent states” where patients have the necessary skills, knowledge, or motivation to become engaged and take control of their own health care; second, as “processes” leading to patients’ having such “emergent states”; and finally, as “behaviours” whereby patients participate in self-management and shared decision making. They argue that whereas “emergent states” and “processes” do not necessarily involve patients acting on their skills, knowledge, and motivation or exercising control, “behaviours” implicitly question whether patients can be considered empowered if they remain inactive (p. 5). This distinction illustrates the important difference between conceptual understandings of empowerment and more empirically observable manifestations of empowerment that often overlap, precede, or supersede other closely related concepts, such as coping, self-management, and enablement. A conceptual understanding of empowerment, which recognizes that empowered patients may or may not choose to exercise their power, is thus key to fully grasp the complexity of empowerment in relation to health and its impact on particular phases of an illness journey.

Only a few studies have explored patient empowerment of cancer patients in relation to cancer follow-up (Bulsara et al., 2006; van den Berg, van Amstel, Ottevanger, Gielissen, & Prins, 2013). The positive role of empowerment in coping with cancer and pain management has been discussed in an integrative literature review by te Boveldt et al. (2014). In addition, Groen et al. (2015) and Kuijpers, Groen, Aaronson, and van Harten (2013) have reviewed the effect of web-based interventions for the empowerment of cancer survivors. These reviews are useful for understanding empowerment in relation to their specific areas of interest (coping with pain and web-based interventions, respectively). However, questions still remain as to what facilitators and barriers to empowerment different types of cancer patients experience in managing their own care in general.

This article presents findings from a qualitative systematic review developed to explore this question. The review was part of a larger mixed method study of empowerment among Danish cancer patients in follow-up. The main purpose of the review was to compile, analyze, and learn from what had already been written about the experiences of cancer...
patients in follow-up in relation to empowerment facilitators and barriers. Due to our wish to explicitly explore the experiences, perspectives, and understandings of this group, it was decided to focus on the qualitative literature in this area, and the following question was developed to guide the review:

What facilitates the processes and outcomes of patient empowerment for cancer patients in follow-up and what barriers to empowerment do they experience?

For the purpose of the review, patient empowerment was defined on the basis of Rappaport (1984) and Zimmerman’s (1995) definitions of the concept as the process by which patients develop knowledge, skills, and motivation to take control of their own situation and the state in which they have a sense of being in control or having mastery. This definition guided the search strategy and the screening of the articles. Empirical manifestations of empowerment, in the form of particular actions or types of behavior, were not the focus of the review, even though several of the articles reviewed described particular outcomes of interventions or health initiatives and thus had a behavioral component. When analyzing such articles, our main focus was to understand how and why these potential empirically observable actions (for example, participating in a group or searching for information on the Internet) impacted on a patient’s sense of control, rather than seeing these actions themselves as an expression of empowerment.