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What facilitates 'patient empowerment' in cancer patients during follow up – a qualitative systematic review of the literature.

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Abstract

Empowerment is a concept of growing importance in cancer care, but little is known about cancer patients' experiences of empowerment during follow up. To explore this area, a qualitative systematic literature review was conducted in PubMed, CINAHL and PsychINFO. A total of 2,292 papers were identified and 38 articles selected and included in the review. The thematic synthesis of the papers resulted in seven analytical themes being identified: empowerment as an on-going process, knowledge is power, having an active role,

communication and interaction between patients and health care professionals, support from being in a group, religion and spirituality, and gender. Very few articles explicitly explored the empowerment of cancer patients during follow up and the review identified a lack of attention to patients' own understandings of empowerment, a lack of specific focus on empowerment during follow up, insufficient attention to collective empowerment and ethnic, social and gender differences.

Keywords

Power, Empowerment, Cancer, Agency, Equality, Inequality

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; Holman & Lorig, 2004; Lorig & Holman, 2003; Hibbard & Greene, 2013; Anderson et al., 2009; Jerofke, Weiss, & Yakusheva, 2014). 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 (Loh et al., 2011; McCockle et al. 2011; Wilson, Lydon, &Amir 2013; Ganz & Hahn 2008).

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 programme. Follow up may include more or less frequent contact with the health care system

for a longer or shorter period of time depending on the diagnosis and severity of disease. The follow up programs may entail further treatment, screening activities and rehabilitation depending on the 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 pay increasing attention to their own symptoms and take on more responsibility in managing their own health (Loh et al., 2011; McCockle et al. 2011; Wilson, Lydon, &Amir 2013; Ganz & Hahn 2008), emphasising 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 intra-personal (individually perceived degree of control), the interactional component (understanding of the context of one's options and choices) and the behavioural 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. While 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 the necessary information in order for patients to make decisions), outcomes of patient empowerment are mostly conceptualised as individual (focusing on the patients and their increased understanding of themselves, control, and self-management) (Aujoulat, 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 et al. (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 questions 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, & 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 amongst Danish cancer patients in follow up. The main purpose of the review was to compile, analyse 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 behaviour, 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 behavioural 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.

Method

Qualitative systematic reviews are different from the more traditional quantitative systematic reviews, in that they seek to explore the complexities of people's experiences by integrating findings across studies, rather than formally aggregating findings from the selected literature (Hughes, Closs, & Clark, 2009; Kingod, Cleal, Wahlberg, & Husted, 2017). Qualitative systematic reviews enable an exploration of the context in which findings are situated and interventions may be developed (Flemming, Closs, Hughes, & Bennett, 2016). However, it could be argued that in the process of summarizing such findings, this context may be lost (Thomas & Harden 2009: 11). Qualitative systematic reviewers thus have to consider how best to summarize and extract findings from the literature while at the same time trying to maintain the context, characteristic of the qualitative approach.

Several methods have been developed to conduct a meta-synthesis of qualitative research. The approach most closely related to the process followed in our review is the 'thematic synthesis' described by Thomas and Harden (2009) in their article on barriers to, and facilitators of, healthy eating amongst British children. This approach describes a preparatory

phase which includes searching the literature, assessing the quality of the papers and extracting data from the selected literature. The preparatory phase is followed by the thematic synthesis itself, which involves three stages: 1) coding text, 2) developing descriptive categories and 3) generating analytical themes. In addition, this phase also includes consideration of context, rigour and study quality. The rest of the present article follows these general headings from Thomas and Harden's approach and includes references to their work when relevant.

Preparing for the thematic synthesis

Literature search

A broad search of the literature was conducted of the databases PubMed, CINAHL and PsychINFO. Journal articles written in English and published between January 2000 and February 2015 were reviewed. The search combined three areas: 1) Cancer, 2) Empowerment (including concepts such as 'Patient-Centered Care', 'Self Care', 'Patient Participation'), and 3) qualitative methods (See Table 1 for the full search string). Articles were included if they described studies where a) at least half of the included patients had cancer, b) part of the patients had ended their primary treatment and were in the follow up period after treatment, c) only adults were included, d) the patients' perspectives were explored, e) a qualitative research design was used and f) at least one empowerment indicator was described. Based on the conceptual definition of empowerment used for this review, these indicators were: feeling in control, having mastery, being in charge, having influence, agency, or autonomy.

The search gave 2,292 articles (1,396 from PubMed, 185 from PsychINFO and 609 articles from CINAHL), and 2,108 articles after having removed duplicates. Of these, 38 articles

were identified as meeting the inclusion criteria and were included in the review (see PRISMA figure 1).

Qualitative studies may present a challenge when developing a search strategy as authors and searchers may understand and define concepts differently (Cooke, Smith, & Booth, 2012). The relatively clear and comprehensive definition of empowerment which was used to guide our search was, in our view, a strength of the review. However, as it was theoretically based, and thus not directly derived from the experiences of the patients in the studies themselves, it could also be perceived as a limitation. Having a theoretically driven definition as a basis for the review may to some extent have resulted in the review not being able to answer how patients themselves experienced or verbalised empowerment. Nevertheless, it was considered important to have a definition to guide the search, as otherwise we would not have known what to look for. The definition thus enabled us to carry out this review of what facilitates and what constitutes barriers to empowerment.

Screening and Quality assessment

All references from the search were reviewed by at least one author of this article. Relevant references and all cases of doubt were read in full and discussed by Jørgensen and Johnsen. Whether or not qualitative studies should undergo quality assessment as part of the systematic review process is an area of on-going debate (Carroll, Booth, & Lloyd-Jones, 2012). As mentioned by Thomas and Harden (2009, p. 12) there is no generally accepted way of excluding qualitative studies based on their quality (or lack of same). Due to the varied and broad spectrum of qualitative methodologies, the process of assessing the quality of qualitative research is highly complex. Using a standardized set of criteria may pose the risk of excluding studies, which do not describe their methods accordingly, but may nevertheless

contain material of high quality or novelty (Thorne 2017). Acknowledging this complexity, and because we aimed to obtain as broad a picture of empowerment as possible, we adopted an approach similar to Thomas and Harden (2009) and did not apply any standard quality assessment criteria in the present review. All articles were from peer reviewed journals and obtained from acknowledged search databases assuming a certain level of quality. However, no articles were excluded due to methodological criteria or design unless they did not meet the inclusion criteria.

Extracting data from the selected articles

The selected articles were carefully read and findings relating to empowerment were entered into a template, along with information about the study (aims, age and gender of participants, types and stages of illness described, and the methods applied). Through this process, information was extracted from the articles about any facilitators and barriers to empowerment reported by the study participants. These were entered into the template using as much original text as possible from the papers and adopting the same concepts as their authors.

Thematic Synthesis

Coding the text and developing descriptive categories

The text entered into the template was coded, initially with broad codes and later with more refined and specific ones. For example, data relating to patients' preferences with regards to level of and access to information, sources of information and levels of knowledge were initially coded under the broad heading of 'information/knowledge'. Later, this code was

divided into sub-headings, such as 'access to information', 'information from the Internet' and 'lack of information' to begin the process of developing descriptive categories. 20 descriptive categories evolved from the initial coding: 1) control, 2) processual experiences of control, 3) communication, 4) knowledge, 5) access to information, 6) sources of information, 7) the internet, 8) engaging in healthy behaviours, 9) having an active role, 10) collective empowerment, 11) health care professionals, 12) patient-health care professionals communication, 13) support groups, 14) interventions, 15) confidence, 16) new insights and perspectives, 17) personality, 18) spirituality, 19) ethnicity/culture, and 20) gender.

Generating analytical themes

In the third stage of the thematic synthesis, the 20 descriptive categories were further analysed, joined where appropriate, and developed into seven analytical themes: 1) empowerment as an on-going process, 2) knowledge is power, 3) having an active role, 4) patient-HCP communication and interaction, 5) support from being in a group, 6) religion and spirituality, and 7) gender. These themes were the result of the refined coding and critical comparison of the findings from the 38 papers in the review. The following describes how the themes figured in the reviewed literature (for an overview, see Table 2). We have aimed to include enough information about the individual studies to understand the context in which the findings have been developed.

Analytical themes

Empowerment as an on-going process

Several of the articles reviewed reflected a processual understanding of empowerment and showed how patients may go through different stages of feeling more or less in control. Mok, Martinson & Wong (2004) identified three stages of Chinese cancer patients' paths to empowerment; 1) *Motivation*, where patients seek to find meaning to life after diagnosis by focusing on their family, hope, or faith; 2) *Mastery over the illness*, where patients develop their own knowledge of the illness and deal with it individually and together with HCPs and 3) *Transformational thought*, where patients change the way they think about the illness and their life in general.

Meiklejohn, Heesch, Janda & Hayes (2013) identified social, individual and disease related factors which influenced changing perceptions of control over time among Australian lymphedema patients, and Schulman-Green, Bradley & Nicholson et al. (2012) argued that transitions can be particularly distressing periods. Another study by Schulman-Green, Bradley & Knobf et al. (2011), however, also found that transitions may potentially "present opportunities for individuals to re-evaluate their health, find meaning, and gain a sense of control" (p. 518), depending on a number of factors relating to the transition (e.g. expectations, knowledge, skills to manage it, resources, planning and well-being). This highlights both individual and social factors in patients' varying and on-going experiences of control.

An article on effective communication between Dutch patients with malignant lymphoma and their HCPs similarly describes empowerment as a process or emergent state and identifies three possible states of communication (van Bruinessen et al., 2013). In the first, (the overwhelmed, passive state) patients are *unconsciously incompetent* and unaware of their own role in the encounter with HCPs; in the second (the pro-active, self-motivated state) patients become *unconsciously competent* as they begin to learn about their own role and the skills they need and finally, in the third (the proficient and empowered state) patients are

consciously competent and increasingly taking control. In parallel with these shifts, also the barriers and facilitators the patients experience as part of their communication with HCPs undergo change.

The articles within this theme establish empowerment as an on-going process, which may evolve differently depending on the individual and the context. Understanding empowerment as an on-going process supports the case for analysing facilitators of and barriers to empowerment in the light of patients' stages in their cancer journeys and their various points of contact with HCPs.

Knowledge is power

Competence and knowledge were emphasised in several of the papers as a key element of empowerment and patients' understanding of their treatment and prognosis was described as essential to them maintaining a sense of control and engaging in informed decision-making (Rees & Bath, 2001; Brazier, Cooke, & Moravan, 2008). Within this analytical theme, three sub-themes were identified: Access to and provision of information, The Internet, and Educational interventions.

Access to and provision of information

Baudendistel et al. (2015) discussed the views of German colorectal cancer patients on having access to a personal electronic health record. They showed that the interviewed patients had a strong belief in increased access to information and felt that this would make them better equipped to take an active role and help them engage in more advanced communication with their doctors. Similarly, patients interviewed as part of an evaluation of an integrative cancer care program in Canada (Brazier, Cooke & Moravan, 2008) believed

that the information provided as part of the programme put them in a better position to make complementary and non-complementary decisions about their health and treatment options. Patients reported that attending the programme had given them an increased sense of control and empowerment in decision making regarding their cancer. Confirming this, also the US patients interviewed in Koithan, Bell, Caspi, Ferro & Brown's study (2007) of an Integrative Medicine Clinic reported increased empowerment as a result of the partnership with providers and the information given. Finally, Wiljer et al. (2013) showed how reflective interviews between breast cancer survivors and health care clinicians in Canada (the 'Survivorship Consult') made survivors feel more adequately equipped to look for additional information, know what to expect and who to turn to if in need of help. This made them feel more supported, hopeful and empowered in their cancer journey.

Access to information was also a theme in Evans et al.'s (2007) article on male cancer patients' decisions to use complementary and alternative medicine (CAM). Having the necessary information, particularly about complementary and alternative medicine, was perceived as empowering, as it "led to opportunities for self-care and gave feelings of control and hope in a potentially fearful and life-threatening situation" (p. 5). Most participants, however, would have preferred to obtain information about CAM through the National Health Service (NHS) to help them make the appropriate choices.

These papers indicate that knowledge and information are key aspects of empowerment and that HCPs have an important role not only in providing patients with information, but also in giving them the necessary explanations to make them feel enabled to make informed choices (Koithan et al., 2007) and the tools to search for more information themselves (Kvåle &

Bondevik, 2008). However while some patients feel empowered by information, others may find too much information anxiety provoking and unsettling (Evans et al., 2007).

The Internet

The impact of the internet on cancer patients and survivors was discussed by Dickerson, Boehmke, Ogle, & Brown (2006), who argued that using the Internet could be an empowering process as it helped patients ask more informed questions and verify treatment decisions. The Internet was also mentioned by van Bruinessen et al. (2013) as one of the factors that could move patients from one communication state to the next, showing the importance of this source of information. At the same time, however, van Bruinessen et al. (2013) mention that while the Internet may have motivated some of their patients to ask more informed questions, it confused others and thus was a barrier to empowerment. Similarly, Loh, Packer, Yip, & Low (2007) showed how Malaysian breast cancer survivors' search for information on the Internet resulted in misconceptions and distress. While the patients described it as important to educate themselves about their illness, doing this on the Internet without guidance or support from health care professionals presented a barrier to empowerment. Emphasising a similar point, Broom (2005), argued that while the Internet allowed people to look up information and actively seek answers, its empowering effect to a large extent depended on the way in which the medical specialists involved in the patients' care acknowledged or considered their knowledge or questions.

The literature reviewed thus acknowledged the potentially empowering effect of the Internet, but also illustrated that this effect cannot be seen in isolation from other sources of information accessible to patients, their relationship with their health care provider, and the

wider context of health care and information. Relevant in this context is the important distinction between searching the Internet as a whole for information and accessing particular sites, where support or advice is provided. In their discussion of an on-line Dutch Lung Cancer Information Center (DLIC), Schook et al. (2014) showed how the most popular page on the site was 'Ask the physician' where patients were given answers from a qualified lung cancer specialist within 48 hours. This suggests a demand, not only for flexible, but also reliable information, obtained through the Internet. However, in general, the articles reviewed did not explore diverse ways of using the Internet, nor did they provide any indication as to when the Internet worked as a facilitator of empowerment and when it constituted a barrier.

Educational interventions and programmes

In several of the reviewed articles, educational programmes or interventions were discussed in relation to their impact on participants, including empowerment (Loh et al., 2011; Wiljer et al., 2013; Adamsen, Rasmussen, & Pedersen, 2001). Stang and Mittelmark (2009) described a group intervention for Norwegian breast cancer patients, including a component aimed to increase empowerment. They identified four processes of empowerment: (1) consciousness-raising; (2) acquisition of objective knowledge; (3) learning from others' experiences and (4) discovery of new perspectives about life and about self. They showed that attending the group was an important way for the participants to obtain information that their HCPs had not provided, and that other participants encouraged and assisted them in looking for further information. Similarly, Kane, Jasperse, Boland, & Herst (2014) described the Living Well Cancer Education Programme (LWCEP) in New Zealand as a source of information and this, combined with the 'normalising effect' of belonging to a cancer community, helped people gain perspective, make increasingly informed choices, gain confidence and communication

skills and feel more in control. Another important point in this particular article was that couples who attended the programme together felt that their *collective* sense of control had been strengthened by their increased communication and problem solving.

Having an active role

Engaging in healthy behaviours, remaining physically active or adapting ones daily routines and activities were mentioned in several articles as a way of strengthening a sense of control (Meiklejohn et al., 2013; Mok et al., 2004; Sterba et al., 2013). Giving up smoking or alcohol consumption was described by Björklund, Sarvimäki, & Berg (2008) as part of a bottom up, individual empowerment strategy. Similarly, Mitchell, Yakiwchuk, Griffin, Gray & Fitch (2007) showed that engaging in the ancient Chinese team sport of 'Dragon Boating' helped women with breast cancer regain physical and emotional control over their lives and bodies.

Having an active role in investigating and deciding on treatment options was generally described as empowering, as it gave patients a sense of control (Howell, Fitch, & Deane, 2003; Verhoef, Mulkins, & Boon, 2005). However, as illustrated by Swainston, Campbell, van Wersch & Durning's (2012) study of 20 female breast cancer patients in the UK, patients may also prefer a passive role in the decision-making process, and not being involved in decision making processes is thus not necessarily an indicator of disempowerment, particularly if the passive role is adopted due to acceptance and trust in HCPs. The same theme was discussed in Rotegård, Fagermoen, & Ruland's (2012) article on cancer patients' perceptions of strength, where participants explained that trust and confidence in HCPs enabled them to relax and let go of some control. Such confidence and trust was however described as rare.

Patient-HCP Communication and Interaction

HCPs play a key role in the empowerment of patients – a process often understood as 'handing over power'. However, as described by Begley et al. (2014) doctors taking charge may also increase patients' motivation to actively participate. Patient empowerment is thus not only about handing over power but also about increasing the total amount of power.

A reoccurring theme in the literature on patient empowerment was the extent to which patients felt valued in their communication with HCPs (Mok et al., 2004; Wiljer et al., 2013; Kvåle & Bondevik, 2008). Skea, MacLennan, Entwistle, & N'Dow (2014) showed that positive communication with HCPs helped patients understand their condition and health care options, made them feel respected and trusted as partners in their own care, and provided an important basis for their exercise of autonomy and agency. Similarly, Mok et al. (2004) identified a number of HCP characteristics perceived as empowering, including: showing a caring attitude, delivering expert information, kindness, being approachable and being cheerful (p. 70).

Support from being in a group

Several of the articles reviewed, discussed the way in which groups may support patients' processes of empowerment (Mitchell et al., 2007; Eziefula, Grunfeld, & Hunter, 2013; Adamsen et al., 2001; Stephen et al., 2013; van Uden-Kraan et al., 2008). As already discussed, groups can be an important source of information, and in this way facilitate the empowerment of their participants. The articles however also described some of the more social and relational effects of being in a group. Women, who attended a self-management programme in Malaysia following treatment for breast cancer, reported becoming

increasingly empowered due to the comradeship of the group (Loh et al., 2011). Similarly, Ussher, Kirsten, Butow, & Sandoval's (2006) discussion of cancer support groups showed that participants experienced an increase in empowerment and control both in relation to self, in relation to others (particularly HCPs), and in relation to cancer.

Religion and Spirituality

Vonarx and Hyppolite, (2013) argued that spirituality and religion can act as a facilitator of individual empowerment, but also facilitate acceptance of the condition, a process which may be potentially both empowering and disempowering. Other articles emphasised the role of religion and spirituality in empowerment. Mok et al. (2004) showed how Chinese cancer patients sought support from their cultural beliefs to create meaning, and in a US study of African American men with prostate cancer, faith was described as a source of strength and an element in experiencing a new meaning to life (Maliski, Connor, Williams, & Litwin, 2010). Exploring control preferences of an ethnically diverse group of US advanced cancer patients, Volker and Wu (2011) identified different types of control and argued that while people want to maintain control over the daily lives, more "existential control" is often left to a higher power (God, the Lord). This is an important point in relation to empowerment, as it shows that mastery and control may exist simultaneously at different levels.

Gender

Several of the articles reviewed included either female or male participants, but only three explicitly commented on gender as an important factor in experiences of empowerment (Broom, 2005; Adamsen et al., 2001; Wenger & Oliffe, 2014) and all three described the particular experiences of men. Adamsen et al. (2001) discussed how a group intervention involving physical activity for Danish male cancer patients helped the men "bridge the gap

of isolation and provides the individual with a feeling of being in control." (p. 533). Broom (2005) argued that the option to engage in anonymous support groups on-line may have had particular empowering effects for men. Finally, Wenger and Oliffe (2014) discussed self-management and help-seeking strategies among Canadian male cancer patients and described how some of these men took control of their situation, by selecting how they presented their illness to others and whom they engaged with socially. As suggested by these articles, men and women may experience empowerment in different ways, but the lack of comparative studies makes it difficult to draw conclusions as to how.

Discussion

In this systematic review, we screened 2,108 journal articles and selected 38 articles which contained qualitative information about understandings of empowerment and facilitators of and barriers to empowerment for adult cancer patients. Very few of the articles explicitly explored empowerment and it was often only a very small part within each article that was used for the review itself. Furthermore, only a few studies were investigating cancer patients in follow up specifically, making it difficult to focus on this part of the disease trajectory. Consequently, we had to include studies where only part of the patients had ended initial treatment.

Discussing the issue of study quality, Thomas and Harden (2009, p. 12) describe how they, in their review, found that the poorer quality papers contributed relatively less than the better quality papers. Due to the lack of specific focus on empowerment in most of the papers included in our review, we did not find a similar pattern, and no individual article stood out as contributing significantly more than others. Instead, it was the articles as a whole which

were able to provide a comprehensive overview of empowerment of cancer patients after initial treatment.

Existing reviews of empowerment of cancer patients have focused on particular issues, and thus also been able to provide some relatively straightforward conclusions or recommendations. Based on their review of empowerment in relation to coping with pain amongst cancer patients, te Boveldt et al. (2014), for example, propose a conceptual model which highlights the specific importance of the pain treatment given by the HCP, the active involvement of the patient and the interaction between the two. In their review of web-based interventions for cancer survivors, Groen et al. (2015) conclude that these may have a positive effect on the empowerment of cancer survivors and furthermore identify seven key features of successful interventions. The more general scope and conceptual focus of our review does not allow for such conclusions, but the thematic synthesis of the literature brought out several important insights and allows for a number of recommendations for further research.

First, it showed that in the experiences of many cancer patients, empowerment is an on-going and fluctuating process. The processual view of empowerment is acknowledged by both Zimmerman (1995) and Fumagalli et al. (2015) in their generic analysis of psychological empowerment and patient empowerment. However, within the broad context of cancer, patients may experience the process of empowerment differently depending on their disease trajectory. Our review thus highlights the importance of illness and stage specific understandings of patient empowerment. Furthermore, as not much is known about how patients felt prior to their diagnosis and treatment, it is difficult to make any firm conclusions as to how these relate to their feelings of empowerment after treatment (Ranchor et al., 2010). More contextual and longitudinal qualitative research of patients' sense of control and mastery would be needed in order to fully address this important question.

The key facilitators of empowerment deducted from this review were: the importance of having access to manageable information through various channels, feeling respected and valued, engaging in positive communication, partnership, and learning from the experiences of others. Information was a significant factor in several of the studies, but by comparing them we found that the link between information and empowerment is not always straightforward and that some patients may prefer less information than others, or prefer particular sources of information over others. Feelings of respect and value were eminent in the relationship with HCP and related closely to some of the other facilitators, such as positive communication and partnership. Learning from the experiences of others was a theme described in several papers, and support groups or other networks were important in this context. However, only one study (Kane et al., 2014) described a collective element of patient empowerment within families. Considering the impact of cancer on families, this could be an important area to explore further in relation to facilitators of empowerment.

Barriers to empowerment emerged mostly in the review as the opposite of the above mentioned facilitators (e.g. not having access to information, not feeling well-informed, feeling rushed in meetings with HCPs, and perhaps low intake of certain groups in specific empowerment facilitating programmes (Kane et al., 2014)). It was however also in relation to barriers, that the gaps in the literature were most evident. Even though a few papers explored empowerment in relation to masculinity and the particular experiences of men, gender was a significantly under-researched area in the literature on empowerment amongst cancer patients. Similarly, ethnicity was almost invisible, and even though some of the papers discussed the experiences and perspectives of particular ethnic groups, this was mostly in relation to religion and spirituality rather than more subtle cultural differences, which may also have an important impact on feelings of empowerment.

The studies reviewed for this paper were, with a few exceptions, all from Anglo-Saxon and Northern European countries (perhaps partly because only papers written in English were included). It thus also has to be acknowledged, that they may represent a particular set of cultural understandings of empowerment. No major differences were identified in the three articles included from Malaysia and Hong Kong, but to make any firm comparisons more literature would be required. Finally, the impact of socio-economic status on patient empowerment is an area which would benefit from being researched in further depth and one which could be expected to vary significantly across countries, health care systems and types of follow up provision.

Conclusion

This qualitative systematic review has analysed the literature on the empowerment of cancer patients with a focus on empowerment during follow up after initial treatment – a topic which is both under-researched and seldom explored from a qualitative perspective. The review identified a number of key themes in relation to the process of empowerment and the facilitators that may support it, such as: information, respect, positive communication, partnership and learning from others. However, a number of important gaps were also identified. To fully understand the contextual and varying levels of empowerment of different groups of cancer patients during follow up, more comprehensive studies, which explicitly explore perceptions and experiences of empowerment of different groups (gender, ethnicity, social class and age) and also carefully analyse these in relation to the particular local context, would be a welcome addition to the rather limited body of literature on the experiences of empowerment of various groups of cancer patients in follow up.

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Conflict of Interest

No conflicts of interest are declared in relation to this article.

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