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.

Discussed the issue of study quality, Thomas and Harden (2008) described 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 among 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 ongoing 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 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 programs, 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 underresearched area in the literature on empowerment among 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 article 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 socioeconomic 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 analyzed the literature on the empowerment of cancer patients with a focus on empowerment during follow-up after initial treatment—a topic which is both underresearched 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 analyze 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.