

Strategies used by an osteoporosis patient group to navigate for bone health care after a fracture

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Abstract

Objective To examine experiences and behaviours with bone health management post-fracture among members of a national osteoporosis (OP) patient group.

Methods A qualitative study was conducted in English-speaking members of the group who had sustained a fragility fracture at 50+ years old and were not taking OP pharmacotherapy at the time of that fracture. Participants were

recruited through an advertisement in the patient group newsletter and interviewed for ~1 h by telephone, responding to questions regarding visits to health care providers and their behaviours regarding bone health. We analysed the data following Giorgi's methodology.

Results Twenty-eight eligible participants (26 females, two males; 78 % response rate) aged 51–89 years old completed an interview. More than half of our participants described effective consumer behaviours, including making requests of health care providers for referrals to bone specialists, bone mineral density tests, and prescription medication.

Conclusion Members of an OP patient group described effective consumer behaviours that could be incorporated as skill sets in post-fracture interventions to improve bone health.

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Introduction

Individuals with chronic illness may have difficulty navigating the health care system due to factors such as low health literacy [1] and poor information exchange between them and providers [2]. At the same time, the rise of person-centred care documented in the literature [3–7] suggests that patients are well-equipped to navigate or negotiate for care. Implicit in the person-centred care movement is the assumption that patients are “effective” [8] or “activated” [9] consumers. However, there is lack of agreement about what constitutes an effective health consumer [10]. This may be partly explained by the fact that most of the

literature on patient-centred care is from the perspective of the health care system or the provider. Those studies that do address the patient perspective tend to focus on patient preferences [11–13] rather than on what patients are *doing*. There is a need to examine patients' actions rather than preferences as patient preferences with regard to issues like decision-making and information-seeking do not match these respective behaviours [14, 15].

Like other chronic diseases, effective osteoporosis (OP) management requires patients to develop self-care and decision-making skills as well as the ability to access appropriate health care services [16]. It has been well documented that OP investigation and treatment rates are low after patients have had a fragility fracture [17, 18], even though this type of fracture is a symptom of compromised bone health. While many interventions to improve OP management post-fracture exist, these have had a modest effect on investigation and treatment rates [19, 20]. Patient education is often one component of post-fracture interventions, but patient education rarely includes skills training in how to navigate for care.

To narrow existing investigation and treatment gaps in bone health, the purpose of our study was to examine the experiences and behaviours with bone health management post-fracture among members of an existing national OP patient group. Our assumption was that these members were effective consumers or patient advocates [21] and that they were experts in navigating for care due to their affiliation with the patient group. To our knowledge, no study has examined an OP patient group to determine how the general fracture patient population can learn from them.

Methods

Consistent with qualitative research guided by a phenomenological approach, we recruited participants who had experiences with navigating for bone health care [22]. By targeting an OP patient group, we conducted extreme purposeful sampling to recruit unusual cases who illustrated the target behaviour [23]. The aim was to elicit detailed information that provided a new perspective on experiences with navigating for care [23]. The OP patient group was comprised of 4,842 members at the time of this study (95 % female; 5 % male). Group members received information and interacted about OP-related interests and issues in a virtual environment. Eligible members of the patient group were English-speaking males and females, residing in Canada who sustained a fragility fracture at 50+ years old and were not on antiresorptive medication *at the time of this fracture*. Because minimal data are collected on the patient group, we were unable to determine how many members met these eligibility criteria. The study was advertised in three consecutive issues of the patient group newsletter, which was sent

out electronically to all members who had electronic circulation and by hard copy to members who did not receive the electronic circulation. Individuals who were eligible and interested in participating were invited to call a toll free number where they left their contact information for the study coordinator. The study was approved by the Research Ethics Board at St. Michael's Hospital, Toronto, Canada.

Participants were interviewed by telephone. The consent form was mailed to each participant in advance of the interview and a signed copy returned to the study centre prior to the telephone interview. Interviews lasted ~1 h and were audio-taped. An interview protocol, with probe questions embedded within the main questions, guided the conversation. The interviewer asked participants to talk about their prior fracture(s), visits to health care providers for their bone health, and behaviours regarding bone health. Brief demographic information was collected by the interviewer so we could describe the study sample as a whole.

Audio-taped discussions were transcribed verbatim with the transcripts verified against the tapes [24] and downloaded into NVivo [25]. Data analysis began after the first interview and was an iterative process whereby codes were identified immediately and then revised as more interviews were conducted. Giorgi's procedures served as a guide to analysis [26, 27]: (a) transcripts were read in their entirety to appreciate a sense of the whole interview; (b) transcripts were re-read and 'meaning units' assigned a code; (c) codes relevant to our objective were grouped together; (d) themes were developed and reflected upon as expressed in the language of the participant; and (e) a description of the structure of our findings was synthesised. Two coders (JS, CC) who were experienced qualitative researchers analysed the first three transcripts to develop an initial coding template. The coders met to compare and discuss the coding template until the template was finalised. The remaining transcripts were coded by the same two coders to promote a comprehensive examination and interpretation of the data [28]. Emerging themes were reviewed by the co-authors as data collection and analysis progressed.

To promote rigour during data collection, we suspended or "bracketed" [29–31] preconceptions derived from existing research that focused only on diagnostic testing and medication use and were open to all behaviours described by our participants. Imaginative variation, the process whereby researchers consider multiple other thematic possibilities during data analysis [29, 30], occurred between the two coders and among all the co-authors via email discussions.

Results

Forty-six individuals responded to the study recruitment initiatives. Ten were not eligible (three on OP medication at

the time of their index fracture, one did not speak English, one without a fracture, one <50 years old, two with high-trauma fractures, two with fracture before age 50 years). An additional five participants were eligible but did not return the consent form. Three who inquired about the study did not respond to additional follow-up. Twenty-eight eligible participants (26 females, two males; 78 % response rate) ranging in age from 51 to 89 years completed an interview. This sample size meets recommendations for qualitative studies guided by a phenomenological approach [29, 32, 33]. Participants were located across Canada with 15 from the province of Ontario, two from Quebec, two from Manitoba, one from Saskatchewan, two from Alberta, four from British Columbia, and two from Nova Scotia. Our sample was representative of the patient group by gender and province, with the exception that only 7 % were recruited from Nova Scotia where 23 % of members actually reside. All participants had at least one bone mineral density (BMD) test, four had never initiated antiresorptive medication and three reported that they had never been diagnosed with OP. Nineteen participants were taking antiresorptive medication at the time of the interview. Twelve participants had experienced two or more fragility fractures and the remaining 16 had experienced a single fragility fracture (see Table 1).

Our objective was to examine effective consumer behaviours in this patient group. We created a code labelled “effective consumer” and coded all experiences related to the continuum of navigating for care under this code. This code captured 3,669 paragraphs from the transcripts for all 28 participants and overlapped with many other codes in the coding template such as “health care system”,

“recommendations for testing”, and “recommendations for treatment”. Most participants described behaviours on the extreme ends of the continuum (“few” versus “many” effective consumer behaviours) with the exception of seven participants who described both types of behaviours. The only demographic variable that appeared to explain participants’ position on the continuum was the number of fractures sustained. Participants describing many effective consumer behaviours had sustained more fractures than those who described few effective consumer behaviours or those who described both types of behaviours.

Few effective consumer behaviours

We categorised five participants as currently describing little or no effective consumer behaviours. These participants described behaviours that reflected minimal involvement in one’s bone health care and included not questioning or discussing any aspect of that care with a health care provider. In this group, care was described as unidirectional from the physician to the participant with participants indicating that they initiated few activities or behaviours regarding bone health care.

Some participants in this group actually described themselves as being a “good patient” or a “good girl”. Participants told us, it’s up to me to “do what the doctor [family physician] says...take the pills, that’s it” (ID11); “I’ve always been a good patient...when they’re told to do their exercises, they do them, when they’re told how to take their medication, they take it” (ID12); “I take my medication—I’m a good girl” (ID14). One participant described herself as doing what she was told to do and being a “follower” (ID3). Participants in this group followed instructions about bone health while appearing to have little knowledge about OP, “I just went [for a BMD] because she [physician] suggested I should go” (ID6). One participant (ID7) questioned whether she should be more pro-active about her bone health “maybe if I had asked for it [more information], it would have been there”.

All participants in this group were taking antiresorptive medication and described themselves as taking medication and/or supplements as prescribed; “apparently, this is what you have to do” (ID1) or “because she [physician] told me to” (ID7). One of two participants who did not consider they had a choice about taking medication said, “it was something I was supposed to do and that was that. I didn’t think there was a choice in the matter” (ID28). Another participant said “of course I would take it [OP medication], anything that is going to help, benefit me in the end” (ID16). One participant took her OP medication on the physician’s advice despite experiencing side effects she attributed to the medication, “it [OP medication] makes me very sick...it’s like I have the flu and I ache, and I run a [temperature]” (ID16).

Table 1 Description of study sample ($n = 28$)

Characteristics	
Age in years, range	51–89
Female, n (%)	26 (93)
Years of membership in patient group, range	1–8
History of previous fracture(s), n (%)	
1 fracture	16 (57)
2+ fractures	12 (43)
Location of previous fracture(s), n (%) ^a	
Wrist	10 (36)
Hip	1 (4)
Vertebrae	11 (39)
Other	16 (57)
History of 1+ BMD test, n (%)	28 (100 %)
Reported diagnosis of OP, n (%)	25 (89)
History of antiresorptive medication use, n (%)	24 (86)
Taking antiresorptive medication at time of interview, n (%)	19 (68)

^a Number of persons with one or more fractures at this location

Participants demonstrating few effective consumer behaviours did not appear to take an active role in directing their care, nor did they demonstrate that they were partners in health care decisions. For example, one participant told us “I presume that I get a bone density test once a year. I don’t know whether I do or not” (ID14). For individuals in this group, the role of physicians was to advise and give information (ID7), or to “inspire the patient to be cooperative” (ID12) and the role of the patient was to “follow through” with recommendations (ID7).

Many effective consumer behaviours

In general, patients who we categorised as effective consumers ($n = 16$) described behaviours that actively directed the nature of their care and included making requests of their health care providers. In most cases, care was described as unidirectional from the participant to the health care provider with participants reporting many activities and behaviours related to bone health management.

Participants in this category actively sought referrals to bone specialists. Participants explained that they sought referrals because family physicians were “cavalier” (ID12) or overwhelmed or “taxed” (ID20). One participant said she had persisted with the request for a referral for 1 year (ID25). One participant filled out a referral form herself and asked the family physician to sign it (ID2) and another had the referral form faxed to her family physician from the specialist’s office (ID21). Another two participants self-referred themselves to an OP specialist (ID4; ID5). One participant also requested a referral to see other health care providers such as a physiotherapist (ID4).

Participants who we categorised as effective consumers also spoke about requesting BMD tests (ID8; ID12; ID13; ID15; ID17; ID21; ID25). Some participants spoke about persisting with the request to their family physician for a BMD test because of concern about their bones. For example, one participant said “we had to wheedle and deal around that a long time before he [family physician] finally agreed...it took a couple of months because I couldn’t convince him” (ID26). Participants talked about bringing copies of X-rays to their family physician (ID2), following up on BMD test results, sometimes “having to nag” (ID2), being aware of their BMD test results (ID17), or questioning the results of their BMD test (ID8).

A couple of participants had requested a second opinion about their bone health (ID6; ID16). For example, one individual said, “I think I trusted my first doctor [family physician] too much when she said there’s nothing there...You just can’t always be so gullible. You need a second opinion” (ID16). A couple of participants purposefully kept their family physicians out of the circle of their bone health care (ID21; ID23). For example, one participant told us “I

probably won’t talk to my family physician about my bone health unless something comes back from [specialist’s office]” (ID21). Another participant saw her family physician as having no role in her OP care since she considered a geriatrician and orthopaedic surgeon as responsible for her bone health (ID23).

Participants also described engaging in several behaviours related to antiresorptive medication. They requested prescriptions for general (ID5; ID26), or a specific, antiresorptive medication (ID11; ID17; ID21) and switched OP medications over the years (ID4; ID5; ID18; ID20; ID21; ID22; ID24; ID25; ID26). They also talked about researching all the different OP medication options (ID8; ID16; ID17) or finding out more information about the medication prescribed by their physician (ID21; ID24). Only nine of the 16 participants in this group were currently taking antiresorptive medication, therefore, being an effective consumer was not associated with current antiresorptive medication use. Six participants were not taking medication for a variety of reasons including refusal to initiate the first prescription, refusal to continue the prescription, or deciding to take a drug holiday. Some participants in this group refused to take the medications they had been prescribed and did research to justify that decision to the family physician (ID9; ID19). One participant who refused to take the medication felt that she was engaging in as many non-pharmacological strategies as possible to manage her bone health because she was not relying on OP medication (ID15). Another participant had negotiated with her family physician to take the medication as a trial test for 1 year only (ID17).

Participants in this group spoke about being aware of the need to advocate for themselves (e.g. ID4; ID24; ID13; ID24; ID25). Participants felt they needed to take charge because the medical and family physician communities were “overwhelmed” (ID20). Sometimes, it required one to be “pushy” (ID22; ID26) and not take “no” for an answer (ID22). And sometimes, it resulted in them feeling they were “not being a good patient” (ID5). However, participants were also aware of the limits of advocating for themselves especially in geographic regions where there was limited or no access to family physicians or specialists. A few participants were able to switch family physicians because they were unhappy with their bone health care (ID4; ID5; ID25; ID26). However, others were unable to switch because there were no other family physicians available to them (ID5; ID8; ID12; ID22; ID28). For example, one participant told us, “I phoned that provincial health line...and they said, well, you have to quit your existing doctor before we can find you a new doctor and there’s no guarantee we will find you one. And I said, well, why would I quit even though he’s useless?” (ID8). Therefore, engaging in effective consumer behaviours did

not necessarily result in perceived access to, or receipt of, appropriate bone health management.

Effective consumer participants appeared to believe that the role of physicians in their bone health was to prescribe the medication that patients requested (ID4); to do other routine activities such as annual exams (ID9); and to facilitate access to tests and provide current information (ID20). Only one participant in this category felt that family physicians needed to have a bigger role in bone health (ID22). On the other hand, the role of patients was to seek physicians who would “do something for you” (ID5). Participants believed they needed to be responsible for their own health (ID10; ID15; ID22; ID27), to be selective about doctors (ID12), to look after themselves and be informed (ID13), to prepare questions in advance of visiting their family physician because the family physician had no time (ID13), and to take control of their bone health by seeking information and asking the right questions (ID16). One participant said “you have to be your own doctor sometimes—you need to be aware of what’s going on, not just put trust in your doctor (ID17)”.

Patients who described both few and many effective consumer behaviours

Seven participants described current behaviours on both extremes of the effective consumer continuum. Some participants in this group described a progression in their behaviours over time (ID6; ID8; ID10; ID16). For example, one participant “did as [he] was told” by his physician regarding OP medication use in the early years but then gradually began researching OP medication extensively in later years and requested that his family physician send him to a specialist (ID6). However, he did not question medication use because he believed “there’s a solid science behind it”. One participant (ID8) appeared to be progressing to a high effective consumer role because she had had multiple fractures and currently described not having confidence in her physician to manage her bone health. She had requested a BMD and had done research on her condition. ID11 was an older woman who felt that her family physician did “nothing” but she still deferred to him, saying “after all, he’s a doctor, I’m just the [patient]”. Initially, she indicated that she had “put [herself] on [OP medication]” but then later talked about taking that medication because her family physician had recommended it. ID12 described herself as a “good patient” but she had also requested a referral to a specialist and was heavily involved in the patient group.

Only one participant in this group described having a strong positive relationship with her family physician who she described as coordinating her bone health care. She told us, “I take responsibility for my own health in partnership with my family physician”. She reported having had

a negative experience with the specialist to whom she was referred and was reluctant to return to the specialist (ID10).

Discussion

In our qualitative study on members of an OP patient group, we found that participants described two types of behaviours along an effective consumer continuum. Most participants described behaviours at extreme ends of the continuum with seven participants describing both types of behaviours. This was contrary to our expectations that all participants who were members of an OP patient group would describe many effective consumer behaviours. It is important to note that while participants believed it was necessary to have the skills to navigate for bone health care, engaging in effective consumer behaviours, and possibly utilizing many health care resources, did not necessarily guarantee perceived access to, or receipt of, appropriate bone health management. In addition, those participants who we categorised as engaging in many effective consumer behaviours were often the participants not taking OP medication as prescribed. It could be that these participants felt it was necessary to develop and/or maintain a high advocacy role because their refusal to use medication was treated with suspicion by their providers [16].

While “effective” or “activated” consumers are purported to manage their disease by demonstrating a range of skills such as understanding health information, communicating well with health care providers, possessing knowledge about their disease and treatment options, and having confidence in their ability to minimize or prevent symptoms [8, 9], our findings only highlighted participants’ behaviours. For example, we did not ask participants about confidence in their abilities to manage their bone health and we did not rate knowledge of their condition and treatment options.

Our findings are similar to those of Auduly and colleagues [34] who studied patients with a variety of chronic diseases and found that those who assumed responsibility for their health engaged in more health-related behaviours than those who believed someone else was responsible for their health. Our findings are also similar to those of Koch and colleagues [35] who described three models of asthma self-management. These authors found that most patients were passive about self-management while some patients demonstrated self-agency or expertise in self-management and some patients demonstrated both behaviours [35]. Finally, our findings are supported by Rasmussen and colleagues [2] who reported that Type I diabetic patients negotiated for health services by seeking access to specialists. Some of these patients had been recruited through a diabetes consumer association.

While our participants who demonstrated few effective consumer behaviours appeared to be receiving appropriate bone health management, patients like them may need more direction and mentoring in bone health to *maintain* their engagement in bone health self-management. For example, strategies demonstrated by our effective consumer group such as seeking out specialist referrals, requesting BMD tests, and researching medications available and/or prescribed could be incorporated into the patient education components of post-fracture interventions. Interventions that encourage patients to assert a more active role have been shown to increase patients' confidence in self-management and understanding of their medication regimen, and also to decrease rehospitalisation rates [36]. Further, "activated" patients are more likely to demonstrate health seeking behaviours [9] and to have better health outcomes [37] than those who are not. However, placing responsibility on patients may further stigmatize those with complex needs who require support or those who do not see themselves as experts of their own care [38].

One limitation of our study was that we examined the patient perspective only. We did not verify patients' behaviours nor could we provide physicians' opinions of these behaviours. Another limitation was our assumption that the patient group from which we sampled was an empowered group, many of whom would be patient advocates for bone health. However, this sample was purposefully recruited as we believed group members would give us an understanding of modifiable behaviours that would inform future interventions in bone health. We acknowledge that these participants were not representative of the general fragility fracture patient population in terms of characteristics such as personality and socioeconomic status/education. Because only English-speaking members were eligible for our study, we cannot comment on the transferability of our findings to non-English speaking members of the patient group. Finally, we were unable to determine how many members of the patient group were eligible for our study and received and read the newsletter so cannot comment on the sampling frame for our study.

Despite these limitations, our study demonstrated that most members of an OP patient group engaged in many behaviours to navigate for bone health care. We propose that these behaviours be translated into skill sets that can be incorporated in the growing number of post-fracture interventions to improve bone health.

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References

- Powell CK, Hill EG, Clancy DE (2007) The relationship between health literacy and diabetes knowledge and readiness to take health actions. *Diabetes Educ* 33:144–151. doi:10.1177/0145721706297452
- Rasmussen B, Wellard S, Nankervis A (2001) Consumer issues in navigating health care services for type I diabetes. *J Clin Nurs* 10:628–634
- Epstein RM, Street RL (2011) The values and value of patient-centred care. *Ann Family Med* 9:100–103
- Finset A (2011) Research on person-centred clinical care. *J Eval Clin Pract* 17:384–386
- Cloninger CR (2011) Person-centred integrative care. *J Eval Clin Pract* 17:371–372
- Mezzich JE, Snaedal J, van Weel C, Botbol M, Salloum I (2011) Introduction to person-centred medicine: from concepts to practice. *J Eval Clin Pract* 17:330–332
- Miles A, Mezzich JE (2011) The care of the patient and the soul of the clinic: person-centred medicine as an emergent model of modern clinical practice. *Int J Person Cent Med* 1:207–222
- Kristjansson E, Tugwell PS, Wilson AJ, Brooks PM, Driedger SM, Gallois C, O'Connor AM, Qualman A, Santesso N, Wale J, Wells GA (2007) Development of the effective musculoskeletal consumer scale. *J Rheumatol* 34:1392–1400. pii:0315162X-34-1392
- Hibbard JH, Stockard J, Mahoney ER, Tusler M (2004) Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 39:1005–1026. doi:10.1111/j.1475-6773.2004.00269.x
- Tugwell PS, Wilson AJ, Brooks PM, Driedger SM, Gallois C, O'Connor AM, Qualman A, Santesso N, Wale J, Wells GA (2005) Attributes and skills of an effective musculoskeletal consumer. *J Rheumatol* 32:2257–2261. pii:0315162X-32-2257
- Bastiaens H, van Royen P, Pavlic DR, Raposo V, Baker R (2007) Older people's preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries. *Patient Educ Couns* 68:33–42
- Ende J, Kazis L, Ash A, Moskowitz MA (1989) Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 4:23–30
- Thompson SC, Pitts JS, Schwankovsky L (1993) Preferences for involvement in medical decision-making: situational and demographic influences. *Patient Educ Couns* 22:133–140
- Beisecker AE, Beisecker TD (1990) Patient information-seeking behaviours when communicating with doctors. *Med Care* 28:19–28
- Tariman JD, Berry DL, Cochrane B, Doorenbos A, Schepp K (2010) Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review. *Ann Oncol* 21:1145–1151
- Thorne SE, Nyhlin KT, Paterson BL (2000) Attitudes toward patient expertise in chronic illness. *Int J Nurs Stud* 37:303–311
- Giangregorio L, Papaioannou A, Cranney A, Zytaruk N, Adachi JD (2006) Fragility fractures and the osteoporosis care gap: an international phenomenon. *Semin Arthritis Rheum* 35:293–305
- Rabenda V, Vanoverloop J, Fabri V, Mertens R, Sumkay R, Vannecke C, Andre D, Verpoorten GA, Reginster J (2008) Low incidence of anti-osteoporosis treatment after hip fracture. *J Bone Joint Surg Am* 90:2142–2148
- Sale JEM, Beaton D, Posen J, Elliot-Gibson V, Bogoch E (2011) Systematic review on interventions to improve osteoporosis investigation and treatment in fragility fracture patients. *Osteoporos Int* 22:2067–2082

20. Little EA, Eccles MP (2010) A systematic review of the effectiveness of interventions to improve post-fracture investigation and management of patients at risk of osteoporosis. *Implement Sci* 5:80
21. Williamson C (1998) The rise of doctor-patient working groups. *BMJ* 317:1374–1377
22. Jasper MA (1994) Issues in phenomenology for researchers of nursing. *J Adv Nurs* 19:309–314
23. Rice PL, Ezzy D (2000) *Qualitative research methods*. Oxford University Press, South Melbourne
24. Kvale S (1996) *Interviews: an introduction to qualitative research interviewing*. Sage Publications, Thousand Oaks
25. NVivo 10 [Computer Program] (2010) *Qualitative Solutions and Research Pty Ltd*, Victoria, Australia
26. Giorgi A (1989) Some theoretical and practical issues regarding the psychological phenomenological method. *Saybrook Rev* 7:71–85
27. Giorgi A (1997) The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *J Phenomenol Psychol* 28:235–260
28. Kvale S, Brinkmann S (2009) *Interviews: learning the craft of qualitative research interviewing*. Sage Publications Ltd, Thousand Oaks
29. Giorgi A (2008) Concerning a serious misunderstanding of the essence of the phenomenological method in psychology. *J Phenomenol Psychol* 39:33–58
30. Wertz FJ (2005) Phenomenological research methods for counseling psychology. *J Couns Psychol* 52:167–177
31. Gearing RE (2004) Bracketing in research: a typology. *Qual Health Res* 14:1429–1452. doi:10.1177/1049732304270394
32. Creswell JW (1998) *Qualitative inquiry and research design: choosing among five traditions*. Sage Publications, Thousand Oaks
33. Polkinghorne DE (1989) Phenomenological research methods. In: Valle RS, Halling S (eds) *Existential-phenomenological perspectives in psychology*. Plenum Press, New York, pp 41–60
34. Auduly A, Asplund K, Norbergh K-G (2010) Who's in charge? The role of responsibility attribution in self-management among people with chronic illness. *Patient Educ Couns* 81:94–100
35. Koch T, Jenkin P, Kralik D (2004) Chronic illness self-management: locating the 'self'. *J Adv Nurs* 48:484–492
36. Coleman EA, Smith JD, Frank JC, Min SJ, Parry C, Kramer AM (2004) Preparing patients and caregivers to participate in care delivered across settings: the care transitions intervention. *J Am Geriatr Soc* 52:1817–1825. doi:10.1111/j.1532-5415.2004.52504.x
37. Michie S, Miles J, Weinman J (2002) Patient-centeredness in chronic illness: what is it and does it matter? *Patient Educ Couns* 51:197–206
38. Lawn S, McMillan J, Pulvirenti M (2011) Chronic condition self-management: expectations of responsibility. *Patient Educ Couns* 84:e5–e8