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Title: Living well with chronic pain in later life: the role and meaning of activity and involvement

Short title: Living well with chronic pain in later life

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Living well with chronic pain in later life: the role and meaning of activity and involvement

Abstract

Objective: To examine how older people can best be helped to live well with musculoskeletal pain. **Methods:** A mixed-methods study integrating quantitative analysis of a longitudinal cohort survey with 60 semi-structured interviews. **Results:** Comparison of 'expected' to 'reported' interference suggested that social activity, physical activity, and 'involvement' were important for participants who reported minimal interference from their pain. **Discussion:** For many older people with chronic pain, activity and involvement may not simply be outcomes of living with minimal interference from pain, but factors that contribute to this outcome and give meaning to their lives.

Key words

chronic pain; salutogenesis; living well; mixed methods

Living well with chronic pain in later life: the role and meaning of activity and involvement

Research shows that chronic musculoskeletal pain affects older people's health and well-being, and is associated with increased use of health and/or social care services and a decline in quality of life (Dawson et al, 2005; Reyes-Gibby, Aday & Cleeland, 2002). Applied research on chronic joint pain characteristically mirrors the medical model, and emphasizes deficits and risk factors. Biomedical models of 'successful aging' similarly emphasize burden, disease and decline (Bowling, 2006), a perspective that may adversely influence consultations between doctors and older patients (Bowling & Dieppe, 2005). However, many older people with chronic conditions describe themselves as healthy. General Household Surveys in the UK, for example, have found that although 60% of those aged over 65 report some form of chronic illness or disability, less than a quarter rate their health as poor (Sidell, 1995); sometimes referred to as the 'disability paradox' (Albrecht & Devlieger, 1999). In the original longitudinal program of research from which our study arose, 58% of older people with chronic joint pain reported 'good', 'very good' or 'excellent' general health (Thomas et al, 2004; Jordan et al, 2012).

Antonovsky's (1979) salutogenic approach enables these paradoxes to be explored. In the salutogenic approach, wellness (absence of morbidity) and illness (presence of morbidity) are seen as a continuum rather than a dichotomy; the focus is on factors that support health rather than factors that cause disease, and questions such as why some people manage better than others can be explored. Research adopting this perspective sometimes uses the idea of people 'beating the odds' or 'punching above their weight'

(metaphors also used for resilience) (Bartley, accessed 2012; Dupre & George, 2011; Canvin et al, 2009). Previous studies exploring why some people do better than others have compared, for example, healthy and unhealthy 'agers' in deprived areas (where no differences were found in terms of life histories and current circumstances) (Gilhooly et al, 2007) or people whose self-reported health status differed from that predicted by a model derived from questionnaire responses (Bryant, Corbett & Kutner, 2001). The salutogenic approach thus has great potential for exploring health in later life (Sidell, 1995).

In this article, by taking a salutogenic approach to chronic pain and by focussing on interference from pain (rather than pain *per se*), we hope to explain why some older people 'beat the odds' and experience minimal interference from their pain, against expectations. The aim of our research was to suggest how older people can best be helped to live well in the presence of musculoskeletal pain. In order to do this we used a mixed-methods approach, combining secondary statistical analysis of an existing longitudinal cohort survey with in-depth interviews. The original study raised questions as to, for example, why so many older people with chronic joint pain described their health as good or excellent (Thomas et al, 2004; Jordan et al, 2012) and why some people with chronic pain appear to experience only minimal interference from that pain. The secondary analysis and interviews were designed to answer these questions raised by, but not able to be answered by, the original cohort study.

Methods

The original study

The original longitudinal cohort study (North Staffordshire Osteoarthritis Project (NorStOP) (Thomas et al, 2012) examined joint pain in adults aged fifty and over, based in six general practices in North Staffordshire, UK. Their registered populations were representative of the wide range of sociodemographic status found in the area. Participants had previously completed questionnaires at three time points – baseline, three years and six years – including items on pain and interference from pain. The measure of pain was based on reporting at least one area of pain that lasted for more than a day in the past four weeks based on a body manikin (Jordan et al, 2012; Lacey et al, 2005). For those reporting pain, the presence of interfering pain was assessed using a single item from the Short Form-36 (SF-36), “During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?” (Ware & Sherbourne, 1992). Having pain that interfered was defined as a response of “moderately”, “quite a bit” or “extremely” on the five-category response scale (Thomas et al, 2004).

The new study

Sample

The sample for the new study was taken from those participants in the cohort study who had agreed to further follow-up at six years and had consented to medical record

review. Based on their pain status at the three time points (baseline, three-year follow-up and six-year follow-up), we identified three groups,

Group 1) 'No pain', no pain reported at all time points ($n=421$)

Group 2) 'Pain with interference', reported pain that interferes with life at all time points ($n=899$)

Group 3) 'Pain with no interference', reported pain but no interference from this pain at all time points ($n=560$).

This approach enabled us to determine three groups that were very different in terms of their long term pain status over six years. The third group – 'pain with no interference' – were of particular interest in terms of what they might tell us about how to live well with a chronic condition, and it is on this group that we focus in this article.

Participants for interview were sampled from each of the three pain status groups and stratified further on the basis of three broad age bands, pre-retirement (55–64 years); post-retirement (65–79 years); and the oldest old (80+ years). We aimed to recruit men and women in each of these age bands, in order to access as broad a range of experiences as possible; that is, a maximum variation sample (Patton, 1990). We sampled from those scoring higher than 5 on a 10-point pain scale. We invited 226 people for interview, based on these groupings. Table 1 shows the age and pain status distribution for the 60 interviews conducted.

Table 1. Sample distribution of interviews in terms of age and pain status

	Group 1, 'No pain'		Group 2, 'Pain with interference'		Group 3, 'Pain with no interference'		Total
	Male	Female	Male	Female	Male	Female	
56–64	3	5	6	3	3	7	27
65–79	6	4	2	1	6	2	21
80+	1	1	3	3	1	3	12
Total	10	10	11	7	10	12	60

Interviews

The interviewer (AJM) used a topic guide, Lifegrids (Richardson et al, 2009) and a Health Events Sheet to guide the interviews. The topic guide covered areas of daily life. Lifegrids (using a paper grid of rows, showing years of a person's life, and columns, showing important areas of his or her life, such as family, personal, work, leisure, health, pain) enable a focus on experiences across the lifecourse, set within a social context and taking into account individuals' perceptions of relevant experience. They have been found to be useful for interviewing older people with chronic conditions (Richardson et al, 2009). The Health Events Sheet contained GP consultation and prescription data over eight years (routinely collected as part of the NorStOP study in those consenting to medical record review), and NorStOP questionnaire data (alcohol, smoking, non-prescribed treatments), which were used to explore participants' use of health services and of prescribed and non-prescribed medication and treatment for pain. Although original questions from the survey questionnaire were not asked again

directly, relevant terms from the questionnaire, for example 'interference', were used by the interviewer to explore participants' understanding of their meaning.

Six pilot interviews were carried out in order to refine the interview tools, following which the remainder of the 60 in-depth interviews were carried out in participants' homes, between September 2010 and April 2011. The interviews lasted an average of 50 minutes. All interviews were digitally recorded (with informed consent), professionally transcribed, and then checked and anonymized by the interviewer. NVivo 8 software was used to manage the data and to enable between- and within-case comparisons during analysis. All participants have been given pseudonyms.

Analysis was in two phases. The first phase involved a thematic analysis and the second phase a further comparative analysis, based on expected and unexpected level of pain interference.

Phase One

Analysis

We analysed the interview data using thematic content analysis (Boyatzis, 1998). A case-by-case analysis helped to identify themes arising from individuals' accounts. These themes were then compared across accounts. The analysis was done across all individual accounts independent of which pain category they fell into, until a broad set of themes and a coding frame had been developed. This was done to reduce the likelihood of any initial bias based on assumptions and expectations about each pain group.

Analysis was an iterative process, with the interviewer drawing out an initial set of themes. Other members of the team independently analysed transcripts at regular intervals and the emerging themes were then discussed and modified in team meetings. The analysis was informed by the use of an advisory group. The advisory group included older people with chronic painful conditions (for example, osteoarthritis), health care professionals and representatives from Third Sector organizations associated with arthritis. Initial interpretations of the findings were fed back to the advisory group for comments.

The analysis of the interviews and the further statistical analysis were iterative (O’Cathain, Murphy & Nicholl, 2010), with the initial findings from the interviews leading to the development of the further groupings and the second phase of the research which will be described in more detail below.

Results of Phase 1

In a broad coding comparison of the in-depth accounts provided by the three pain groups, basic differences emerged in the coding between the groups. Participants in the ‘no pain’ and the ‘pain with no interference’ groups talked more about three areas – social activity, physical activity, and ‘involvement’ – in comparison to those in the ‘pain with interference’ group.

This led to two questions. First, were the findings simply a reflection of participants’ pain status – in other words, are people with lower levels of pain simply able to be more

active and more involved? Second, was the greater degree of involvement and activity a reflection of other factors?

Our survey data provided a partial answer to these questions, suggesting that the simple answer to the first question is 'no', in that pain with no interference can be a long-term state, characterized by high levels of pain. As previously stated, we found that people in the survey reporting pain that did not interfere with their lives often had pain that was widespread and of high intensity. We sampled from those who reported pain above point 5 (on a 10-point scale) to ensure that our sample included people with higher levels of pain. People with pain that did not interfere were similar to those with no pain in terms of social factors and comorbidity and different only in that they were more likely to be female and younger. The group with non-interfering pain were distinct from those with interfering pain in terms of sociodemographic and comorbid measures (Jordan et al, 2012).

As stated previously, the group of people who had pain with no interference were of particular interest and, following a salutogenic approach, we focussed on this group in the second phase of analysis.

Phase Two

Further analysis

In order to explore these questions further, through the interview data, we compared participants who had sociodemographic and comorbidity factors associated with their

reported pain interference status (i.e. pain with no interference) with those who had characteristics that were more common in those with a different pain interference status. In other words, we were comparing those we expected ('expecteds') and those we did not expect ('unexpecteds') to be in the group they were in, based on the statistical data.

We developed a statistical model to predict which of the two pain groups (interfering or non-interfering) we would expect participants with pain to be in. We used data in NorStOP from all of the 560 people who reported pain that did not interfere with their lives at all three time points (baseline, three years and six years) and from the 899 who reported interfering pain at all three time points. The model used self-reported six-year survey data on widespread pain, obesity, multi-morbidity, financial problems and socio-economic circumstances that had been found, at the population level, to differentiate between the 'pain with no interference' and 'pain with interference' groups (Jordan et al, 2012). A binomial logistic regression model was used and the predicted probability of being in the 'pain with interference' group (rather than the 'pain with no interference' group) was determined for each person from these two groups. Cut-off probability for being a predicted member of the 'pain with interference' group was 0.50 and above. The final model correctly predicted 69% of those in the non-interfering pain group and 85% of those in the interfering pain group (area under the receiver operating curve (AUC) = 0.86; Nagelkerke R^2 explained variation = 0.48).

We then compared the accounts of those interviewed whose reported pain interference was the same as that predicted, with the accounts of those whose pain interference status differed from that predicted, i.e. those we expected with those we did not expect to be in the group they were in. In keeping with the salutogenic approach (i.e. what

contributes to wellness) we focus in this article on the people in the 'pain with no interference' group, in answering the question of what aspects of older people's lives are linked with minimal interference from chronic pain.

Results

Of the 22 people in the 'pain with no interference' group, 15 were 'expected' in that they were predicted to be in that group and 5 were 'unexpected' in that they were predicted to be in the pain that interferes group, with probabilities ranging from 0.64 to 0.87 (2 others were borderline with probability 0.50 and 0.53 of being in the interfering pain group).

Focussing on the three key and interlinked themes of social activity, physical activity and involvement that had emerged in the initial analysis, we found little difference in the accounts between the 'expecteds' and the 'unexpecteds' in the 'pain with no interference' group. Before exploring the implications of this, we will first give some examples of the physical and social activities and involvement described by the participants in the 'pain with no interference' group, including the ways in which they felt these activities helped them to minimize the impact of chronic pain. The examples also illustrate the meaning of 'living well' for older people with chronic pain, with minimal interference from that pain.

Physical activity was important for many participants, and for some was a key part of their sense of self and identity, particularly where the physical activity had been lifelong,

I did lots of very active things in my teens [...] when I started teaching I used to take kids caving [...] outdoor activity has always been an important part of life [...] there is an

element of you get up and get on with it, [...] I suppose you become pretty self-reliant in those circumstances. (Gerald. 'Pain no interference', expected)

I've always done it, ever since I've been little, I've always played sport. [...] If you're physically fit I think you're mentally fit as well. [...] If you don't do your exercises regularly for the different ailments that you've got, then I think that's when you start getting aches and pains with 'em. And if you're doing the exercises and they're not going, then you go and get a bit of physio for them. (Robert. 'Pain no interference', expected)

Gerald saw himself as an independent person, able to 'get up and get on with it'. His lifelong physical activity was directly related to his present attitude towards his pain. For Robert, physical fitness was linked to mental fitness, with both of these contributing to being able to deal with pain. Robert's approach did not, however, dismiss obtaining help when necessary.

Social activities described by participants included music concerts, University of the Third Age¹, playing bridge, an archery club, and voluntary activities such as Scouts. Participants described the importance of these kinds of activities as providing social interaction, guarding against a narrowing of one's world and providing an alternative to thinking about pain, as Betty ('Pain no interference', expected) explained,

If you're sitting knitting at home, that's not going to do you a lot of good, is it? It's company, isn't it? [...] If somebody can't play bridge I ring somebody else up and they'll

¹ a self-help organisation for people no longer in full time employment providing educational, creative and leisure opportunities

come and play. [...] I think I should be miserable if I wasn't busy. And then you start and think and this aches, that aches and the other aches...

Although social activities could be seen as the continuation of lifelong habits, there was also a sense of strategic planning, or of making the most of opportunities, as illustrated by Betty and Kath,

I started playing bridge before he [husband] died, knowing that he wasn't going to be with us for much longer so I needed something to fall back on. (Betty)

I've always got plenty to do. I don't know how I found time to go working, I really don't. Erm, sometimes I go visit friends which, because some of them have finished work now, so we didn't have time, you catch up more. We go out for lunch and things like that, which I didn't do before. (Kath. 'Pain no interference', expected)

Social networks were important to maintaining physical activities, as they provided an incentive to walk, to take part in sports like golf or football, or just to go shopping, further highlighting the social context in which people pursue these activities,

I think a lot depends on your, sort of, social network as well, because if you have friends who you do things with regular, you know, that you look forward to doing things with then that gives you the incentive to want to keep doing it. (Robert. 'Pain no interference', expected)

Involvement was part of physical and social activity and was also seen as important in its own right,

And I think for our own sake we have to be involved because being involved is one of the key things to [...] making us a whole person really. You can't opt out of the world. You've got to be part and parcel of it. [...] And so I think involvement is absolutely vital. But involvement within your capabilities. (Ray. 'Pain no interference', unexpected)

Involvement can have many meanings, but to our participants it was largely about being, in Ray's words, 'part and parcel' of the world. That world may be localized, as Elizabeth ('Pain no interference', unexpected) described,

Even if it's just going down to the local shop and talking to people, is very, very important. [...] listening to the local gossip and, it is part of, of living, isn't it?

For some participants, involvement related to a world of a previous 'life'. For example, Robert ('Pain no interference', expected) still carried out consultancy work, based on his previous job, for four to five days a month, and Loraine ('Pain no interference', unexpected) cut her family's hair although she was no longer employed as a hairdresser. Loraine also described herself, laughingly, as having "too many old folks I've to keep an eye on",

No because I've always been, because I had my mother for 20 years to look after [husband's] parents, and I helped his parents with grandparents, if you know what I mean. We've got an elderly lady that we look after now who, well she's 80, erm, her and her husband were friends of ours. He died when he was 63, so we've had her under us wing for all those years, because they've no family, no children, no nothing, no cousins, no brothers or sisters. So, in fact, I've just been and done some shopping for her so that she doesn't go out in the snow.

Lorraine's description of involvement can be looked at in terms of the World Health Organization's (2002) definition of participation as "involvement in a life situation", including purposeful behaviours with societal involvement where an individual interacts with his or her environment and with other people (Dijkers, 2010). Participation, or involvement, can also be seen as relating to fulfilment of social roles and social identity, which vary according to the individual and their context (Gignac et al, 2008). This aspect of involvement was a strong theme in our participants' accounts.

Discussion

This study integrated quantitative and qualitative data analysis to explore the question of how older people with chronic pain manage to reduce its impact. The integration of the quantitative and qualitative methods at all stages of the study, and the interdisciplinary nature of the research team, were intended to achieve a more nuanced exploration of the data, capitalizing on the various data available and thus aiming to achieve a 'whole greater than the sum of its parts' (O'Cathain, Murphy & Nicholl, 2010).

The lack of difference in the accounts of the 'expecteds' and 'unexpecteds' in the 'pain with no interference' group is important in answering the questions that arose in Phase One of our research, are people with lower levels of pain simply able to be more active and more involved and is the greater degree of involvement and activity a reflection of other factors? The salutogenic concept of resilience led us to a deeper comparative analysis of people in the 'pain with no interference' group. Using a model to identify those participants whom we would expect to be in that group ('expecteds') and those

whom we would not expect to be in it ('unexpecteds') enabled us to compare these accounts.

The fact that there was little difference in the narratives of those whom we would have expected to be in the non-interfering pain group compared to the narratives of those whom we would not have expected to be in that group is important because it tells us that, for people who manage to live with pain with minimal interference, this is not due simply to their pain being less severe, nor to socio-economic differences, as these characteristics were evident in the 'unexpecteds' in the 'pain with no interference' group. We have suggested that this may be due to physical activity, social activity and involvement.

Looking at chronic pain from a salutogenic perspective, for the older people in our study the key to living well with chronic pain was being active physically and socially, in an everyday context, within their capabilities, and being involved in life, while maintaining a flexible attitude and an ability and willingness to adapt activities. Our study therefore moves beyond previous studies as it focusses on aging well in the specific context of chronic pain and interference.

A possible weakness of the study is around the meaning of the term 'interference' to the participants in the original questionnaire. Some of those who reported "no interference" from their pain may have defined interference as something that was beyond their control. If people have adjusted their expectations of how and to what extent pain can be managed, they may no longer perceive their pain as interfering (McCracken & Eccleston, 2003; McCracken, Vowles & Eccleston, 2004). It has been suggested that

emotional and cognitive factors become more important in managing change as control over other areas of life diminishes with age (Johnson & Barer, 1997). Thus the meaning of being able to take part in a valued activity is more important than the fact that the activity has to be done differently (Moore et al, in press). This again highlights the importance of focussing on interference and not just on pain in older people's lives and in terms of living well.

Previous research has shown the importance of participation in physical and social activity in improving the lives of older people. Our findings take this further by showing how these areas are also applicable to minimizing the impact of chronic pain on older people's lives. Our findings support Bowling's (2006) assertion that "the presence of illness should not be equated with 'unsuccessful' ageing". In Bowling's study, lay people's definitions of successful aging incorporated much broader factors than did medical models, and included social roles and activities. This is supported by our study, which suggests that social activity, for example, is not simply an outcome of but also a contributor to aging well, and also part of its meaning. Other lay definitions of healthy aging include 'going and doing something meaningful' (Bryant, Corbett & Kutner, 2001), which equates to the concept of 'involvement' in our study.

Our findings also support previous explanations for the disability paradox, which suggests that a good quality of life includes acknowledging the impairment, having a degree of control, being able to fulfil roles, having purpose and meaning in life, and engaging in reciprocity (Albrecht & Devlieger, 1999). These equate in our study to physical and social activity and involvement, within one's capabilities, and with flexibility

to adapt. It has also been suggested that one dimension of the self may compensate for a lack in another dimension (Albrecht & Devlieger, 1999) and that in later life people may be resilient in one area but not in others (Wild, Wiles & Allen, 2013). While we have not explicitly explored the concept of resilience in this research, it is appropriate to refer to it here. The concept of resilience can be applied to the context of older people with chronic pain, acknowledging that it can incorporate and balance vulnerability alongside strength across a wide range of contexts (Wild, Wiles & Allen, 2013; Wiles et al, 2012).

It is important to emphasize that social activity, physical activity and involvement are not simply outcomes of living with minimal interference from pain. For the people in our study, social activity, physical activity and involvement in life were contributors to, and also part of the meaning of, living well with chronic pain. Acknowledging that older people can consider themselves well while living with chronic pain, and suggesting ways in which they might do this, has important implications for clinicians and other practitioners concerned with supporting people to 'age well' (see, for example, Department of Health, 2011). Clinicians could develop a more balanced approach in a consultation, focussing not only on pathogenesis but also on salutogenesis. Clinicians might, for example, consider asking patients with chronic pain about valued activities and how they can be supported in their continuation. They could enquire about sports or activities that patients were last engaged in and discuss what possibilities might exist to re-engage with valued activities given the right circumstances. The data suggest that social activities were just as valued as physical activities, and while people could no longer engage in certain physical activities, they might be able to engage more in social

activities, affording them continued opportunities to build meaning into their lives. This supports a salutogenic approach to maintaining a sense of well-being, striking the balance between the physical and social is key to finding a quality of life when the capacity for engaging with both domains is challenged. It also shows the importance of not just medical input but broader support for and from community initiatives designed to increase activity.

Our findings also support calls for better preparation for old age in midlife (see for example, Gidlow & Ellis, 2010), and supporting older people to develop personal and community-based resources that would carry them through into late old age (Hildon et al, 2009). Our research extends the value of this to older people with chronic pain, suggesting that they too would benefit from policies and community initiatives that address aging well, thus assisting them to continue living with minimal interference from their pain.

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