

Exercise prescription for non-specific chronic low back pain (NSCLBP): a qualitative study of patients' experiences of involvement in decision making

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Abstract

Title: Exercise prescription for non-specific chronic low back pain (NSCLBP): a qualitative study of patients' experiences of involvement in decision making.

Background: The culture of current clinical practice calls for collaboration between therapists and patients, sharing power and responsibility. This paper reports on the findings of a qualitative study of exercise prescription for patients with NSCLBP, taking into account issues such as decision making and how this accords with patient preferences and experiences.

Objective: To understand the treatment decision making experiences, information and decision support needs of patients with NSCLBP who have been offered exercise as part of their management plan.

Design: A qualitative study using a philosophical hermeneutic approach.

Methods: Semi-structured interviews with eight patients (including use of brief patient vignettes) was undertaken to explore their personal experiences of receiving exercise as part of the management of their NSCLBP, and their involvement in decisions regarding their care.

Findings: The findings provide a detailed insight into patients' perceptions and experiences of receiving exercise-based management strategies. Four themes were formed from the texts: (1) patients' expectations and patients' needs are not synonymous, (2) information is necessary but often not sufficient, (3) not all decisions need to be shared, and (4) wanting to be treated as an individual.

Conclusions: Shared decision making did not appear to happen in physiotherapy clinical practice, but equally may not be what every patient wants. The overall feeling of the patients was that the therapist was dominant in structuring the interactions, leaving the patients feeling disempowered to question and contribute to the decision making.

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Introduction:

There is an increasing drive for patient-therapist interactions to be fully collaborative, in which clinicians actively engage patients to make healthcare choices, based on clinical evidence and patients' informed preferences. Traditional measures that examine adherence to treatment do not provide any information about the extent to which treatment decisions match patients' preferences [1]. For example, when considering interventions for non-specific chronic low back pain (NSCLBP) if a patient agrees to an exercise programme suggested by the physiotherapist, this does not necessarily mean they participated in the decision making process, or that the decision was based on the patient's informed preferences.

For physiotherapists, matching the right person with the right care, will lead to benefits for both the patient and the health care system. Previous research has suggested that patients prefer to share decisions or at least provide their opinion about treatment [2]. Shared decision making has also been shown to positively impact on patient experience, satisfaction and participation in care [3]. For patients with NSCLBP who are undergoing exercise therapy satisfaction may be improved by adoption of a shared decision making approach [4]. Therefore research that focuses on a patient-centred approach, taking into account issues such as treatment decision making and how this accords with patient preferences, provides an invaluable contribution to the body of evidence in musculoskeletal physiotherapy [5].

This paper forms part of a larger programme of research which also explored physiotherapists' perspectives and experiences of exercise prescription for NSCLBP which have been described in a separate report [6]. This paper focuses on the findings of the second phase in which the aim was to explore the experiences of involvement in treatment decision making, and the information and decision support needs of patients with NSCLBP who have been offered exercise as part of their management plan.

Method

This study was guided by the philosophical hermeneutic approach of Gadamer, a branch of interpretive phenomenology which seeks to understand participants' experiences through the interpretation of text [7]. Text was in the form of transcribed semi-structured interviews which were considered to have significant advantages over focus groups, allowing participants longer to talk without interruption by others, and to expand upon their personal experiences and views in more depth. It also afforded an opportunity to explore social and cultural contexts which may influence participants' views about roles in treatment decision making, generating information about what they perceive as barriers to shared decision making.

Sample and data collection

Recruitment was achieved by using information posters which were displayed in the waiting rooms of physiotherapy departments and community based spinal assessment clinics in one musculoskeletal physiotherapy service delivered across seven

departments in South West England. Physiotherapists providing care had an awareness of, and an appreciation of the importance of adopting a patient-centred care approach, but were not specifically aware that shared decision making was the main focus of the study.

People were included if they were 18 years or over and had participated in an exercise programme as a result of having low back pain for more than six weeks [8]. Individuals who expressed an interest were provided with a participant information sheet and, after confirming their willingness to participate, were telephoned by the researcher to confirm that they met the inclusion criteria for the study and were included if they consented to participate. A pragmatic decision was taken to allow for a period of eight months for recruitment of participants. Ten participants were recruited; two withdrew for personal reasons leaving a final sample size of eight. Their characteristics are displayed in Table 1.

Insert Table 1 - here

The interview situation was made as informal as possible to facilitate a more open exchange and to let participants tell their story in which ever way they wished [9]. As part of the interview, vignettes depicting different levels of patient involvement in decision making regarding exercise were used to act as a trigger for participants' thoughts about their own experiences. The aim was to enable participants to discuss more fully how their experiences were similar or different to those of the people in the vignettes which may have validated how they felt enabling them to be more open about their own experiences (please see appendix 1 in the supplemental information). All interviews were digitally recorded and transcribed verbatim by the first author to maximise familiarity with the data. All identifiable information was removed or changed

by the use of pseudonyms. This study was given ethical approval by National Research Ethics Committee South West 3 (11/SW/0042).

Data analysis

Interpretation of the texts was led by the first author (RS) and based on a thematic analysis [10] guided by the principles of Gadamerian hermeneutics. A fuller overview of the research approach and analysis strategy has been described in detail by Stenner *et al.* [6].

Findings

Four themes relating to the treatment decision making experiences, information and decision support needs of participants were formed from the texts: (1) patients' expectations and patients' needs are not synonymous, (2) information is necessary but often not sufficient, (3) not all decisions need to be shared, and (4) wanting to be treated as an individual.

Theme 1: Patients' expectations and patients' needs are not synonymous

Participants' expectation of physiotherapy was to be given exercises. This was based on either their previous experience, information from informal 'lay consultations' with other back pain sufferers, or their interpretation of what they thought physiotherapists do rather than necessarily what was important to them.

“To be honest I wasn’t quite sure what to expect from the physio appointment other than this vague idea that I would be given exercises only because it’s what I expect a physio to do, and from other people who I have spoken to, that is what their experience has been, a set of exercises that they have to complete regularly.” (Phil)

“I don’t know what I was hoping to get when I went there actually. I have been to physio in the past so I knew sort of what was going to happen, he was going give me a sheet of exercises to take home and do”. (Sarah)

However for this group of participants what mattered most was gaining a greater understanding of the causes of their back pain.

“Perhaps a clearer diagnosis of what the problem was, as up to that point I hadn’t really been given a clear explanation.” (Phil)

“I think I really wanted to know what was going on more than anything else. I wanted to know more about my back and I suppose sometimes you don’t get that, I wanted more understanding”. (Trudy)

Theme 2: Information is necessary but often not sufficient

Participants talked about how their desire for information related to their diagnosis and what it meant for them was often inadequately addressed. The findings suggest that the value of this information was perhaps to provide reassurance and allay fears or uncertainties about the cause of their problem. For many patients a lack of knowledge and understanding of their condition is likely to influence their appreciation of what is achievable in terms of an outcome, and further hinder their ability and confidence to participate in treatment decision making.

"I think reassurance is a huge part of it for any patient, they want to know that there's nothing serious". (Kim)

"There were no explanations with any models as to why I'm getting the current problem...." (Andy)

"I think I felt the same as when I was prescribed painkillers because I felt that there was a fairly vague explanation of what might be wrong with my back I wasn't sure whether what was being suggested was targeted enough."(Phil)

One of the principles of a shared decision making approach is that patients should be offered information on management options [11]. Subsequently, the therapist's role is to assist patients in evaluating the evidence for and against each option in an unbiased fashion, remembering that this may also include the option to take no action. Data shows that there was little evidence of participants being offered a choice of different management or treatment options. Exercise was seen as the 'default' approach to care, with participants reporting a lack of understanding about why they were doing the exercises and what to expect in terms of benefits.

"I wasn't offered any choice, other than exercise. I was told that was what I needed to do." (John)

"I was given my management plan which was exercise, no other options were discussed. I imagine it was to loosen or strengthen the muscles but I made that assumption myself."(Kim)

Theme 3: Not all decisions need to be shared.

Participants reported some ambivalence over their role in decision making, which was shaped by a complex array of factors such as lack of understanding and confidence in contributing to and challenging some decisions.

“It did feel like it was four exercises and that’s what they gave to everybody, and I guess I didn’t think to say how about this. If I had been more in tune with what was going on with me I could have been a little bit more challenging…….” (Mike)

Other reported factors included trust in the health care professional and the type and level of decision being considered. An exercise intervention was regarded by many as a ‘minor’ decision for which participants were generally happy to defer to the health professional. Andy, for example, expressed a clear view that it was down to the clinician to decide what was in the patient’s best interests on the basis that patients can have misattributions about their problem. He justified his views as being driven by his own line of work in which he would expect to follow instructions from someone in authority.

“I see it differently, It’s not about what we want as we can have misconceptions, I think we need to be told what we need and what we are going to get and be realistic.” (Andy)

“I think you ultimately defer to the professional because they know what they are talking about, and exercise is minor stuff.”(Liz)

Theme 4: Wanting to be treated as an individual

Whilst not all participants wanted to play an active role in treatment decision making, the apparent trust placed in clinicians to be doing the ‘right’ thing was countered by participants’ reflections on their experience of receiving an exercise-based

intervention as part of their care. They talked about the frustration of feeling that the care they received was standardised and not particularly personalised to their needs.

“In broad terms it felt very conveyor belt. I think it was very generic, it was ‘ok so you have got back pain, yeh your movements are not great, you are tall and thin and people like that suffer, and I’m going to give you some exercises’.” (John)

“I can’t put my finger on it but it was just the way I felt she was coming across to me. It was like ‘here we go again someone else with back pain’. With the physio I felt like I was one of many, which I probably was, but that is how it came across.” (Trudy)

Participants also talked about wanting a longer period of contact with the physiotherapists who they could trust and who they could get involved in the management of their condition. However many had the feeling that the physiotherapist’s aim was to reduce contact overall, which was in contrast to the significance participants placed on developing an ongoing therapeutic relationship.

“It’s all well and good you going to a physio and them saying you have got to do this, if you don’t do this it’s not going to get any better you need to help yourself, and you come out and burst into tears and think I can’t help myself I don’t know how to help myself. You can try and do the exercises but you haven’t got the motivation there.” (Trudy)

“I wasn’t given any contact details, and the minute I walked out and the doors closed behind me I felt I was in a prison when I walked out and I couldn’t get back in. I had to go and see the doctor which I had bad experiences with trying to get physio in the first place.” (Mike)

Discussion

The findings of this study provide a detailed insight into participants' perceptions and experiences of decision making about exercise-based management strategies. The culture of current clinical practice calls for collaboration and a sharing of power and responsibility so that clinicians are more responsive in terms of understanding their patients' agendas and what matters most to them, ultimately delivering a health system that informed patients want, not one that clinicians think they should have [12].

The findings from this study (Theme 1: Patients' expectations and patients' needs are not synonymous) demonstrate that the more traditional approach within physiotherapy of defining patients' expectations is not the same as establishing what matters most to patients [13]. If the main issues of importance to patients are not openly declared and discussed they cannot be addressed. In this study, all participants expected to receive exercise therapy; this has the potential to contribute to an overestimation of the extent to which patients are concerned with treatment rather than gaining information and support. From a clinical practice perspective physiotherapists may need to reflect on the wording of questions aiming to elicit patient perspectives to ensure that they focus on issues that are of most importance to them.

The second theme, 'Information is necessary but often not sufficient', underlines the importance patients place on provision of information about their condition and the options for managing it as part of a patient-centred care approach which is integral to supporting shared decision making. Patients need evidence-based information just as much as clinicians do, and this might help to avoid the problem of poor quality care. It could also help to counter misplaced perceptions about management options and outcomes, promoting better care and more rational resource allocation [14].

It is critical for physiotherapists to be aware of the importance of information and understanding to patients and how this might guide patients' preferences for treatment and the behaviours which they engage in over time. Physiotherapists need to be open and honest in explaining what information they can and, in the case of NSCLBP, cannot confidently provide relating to diagnosis, causation and time-scales (respecting natural history). It should also include an honest appraisal of the advantages and limitations of different management options, tailored to patients' individual needs and understanding. For participants in the present study, the desire for information, particularly relating to the cause of their problem, was often poorly addressed. This, combined with the limited evidence of participants being offered a choice of different management options, led to an overall feeling that they played a marginal role in the therapeutic interaction.

Participants revealed different perspectives regarding their role in decision making depending on their individual circumstances (Theme 3: Not all decisions need to be shared). Clinicians need to establish the part patients want to play in the decision making process rather than make assumptions based on observable characteristics. This raises some interesting considerations about how preferences are affected by context or learnt behaviours [15]. What is evident from this study is that some patients experience uncertainty over their role based on a perceived lack of knowledge, having trust in the healthcare professional to be doing what is right for them, and the type and level of decision being made. Patients have been found to be less likely to want to participate in decisions on treatments that will not cure them or have a low risk value [16, 17]. This may have been the case in this study where many participants regarded decisions about exercise-based interventions as 'minor'.

In theme four (Wanting to be treated as an individual), the strength of the participants' responses suggests that of the clinical level interactions considered essential for patient-centred care, individualisation of the intervention, with care tailored to their needs and not based on set routines may be of particular importance to patients with NSCLBP. This individualised approach to care was further emphasised by the significance participants placed on developing an ongoing therapeutic relationship.

Strengths and limitations

The decision to use interviews meant participants were required to reflect on their recollections of their physiotherapy experience, resulting in the selective recall of positive or negative experiences. The consequences of selective memory for this study have been managed by comparison of their perceptions with other participants (including those in the vignettes). A more elaborate interview schedule designed to promote recall of specific events may have addressed this recall issue, however it would have reduced the opportunity for participants to talk freely about their own experiences, and this open communication was a particular strength of the research. A further methodological strength was the iterative process of analysis of each interview. This helped to develop areas for exploration in subsequent interviews and facilitated the process of understanding by being true to Gadamer's description of the hermeneutic circle [7].

The self-selection of participants is a possible limitation of this study as the views of particular groups may not have been captured. This is difficult to overcome since self-selection is an unavoidable part of ethical research. However, it should be recognised that all patients have histories, presentations and experiences which are individual, so

a small number of patients cannot be considered to be simply representative of a notional, homogenous 'wider population' of NSCLBP patients. Whilst recognising this heterogeneity, the eight interviews together showed clear evidence of a consensus feeling that their role was a marginal one, with the therapist dominant in structuring interactions and making decisions.

A further limitation of this study was that participants were only interviewed on one occasion. Some authors have argued that participants' and researchers' understanding will develop over time and they recommend that researchers return to participants for a second or third interview, with the aim of focusing on new aspects of the phenomenon [18]. It became clear early on in the interviews, however, that participants found it challenging to talk freely about their experiences of sharing decisions within healthcare and so a decision was made not to pursue further interviews.

Conclusion

For physiotherapists keen to promote a patient-centred approach, it is essential to consider that dimensions of patient-centredness are likely to hold different values and importance to individual NSCLBP patients. Although shared decision making has been considered as the crux of patient-centred care [19], for the participants in this study an understanding of their condition and an individualised care package were more valued than involvement in decision making per se. There continues to be considerable debate about when, and to what extent, patients should be encouraged to participate in decision making. Based on the findings from this study shared decision making did not appear to happen in physiotherapy clinical practice, but equally may not be what

every patient wants. For patients with NSCLBP, the nature of physiotherapy with a perceived low risk value of interventions, together with the difficulty of offering detailed information about treatment outcomes means that it may ultimately prove harder for physiotherapists to embed a culture of shared decision making.

Whilst healthcare policy has called for a strengthening of patient and public engagement in health care decision making, flexibility in responding to each patient as a unique individual, recognising the preferred style and role in decision making that they want to adopt and to respond accordingly is likely to be critical to the successful application of shared decision making principles.

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References

[1] Sepucha KR, Fowler Jr FJ, Mulley Jr AG. Policy support for patient-centred care: the need for measurable improvements in decision quality. *Health Aff (Millwood)* 2004.Oct;54-62. Doi: 10.1377/hlthaff.var.54

[2] Dierckx K, Deveugele M, Roosen P, Devisch I. Implementation of shared decision making in physical therapy: observed level of involvement and patient preference. *Phys Ther.* 2013;93(10):1321–1330.

- [3] Loh A, Simon D, Willis CE, Kriston L, Niebling W, Hartner M. The effects of a shared decision-making intervention in primary care of depression: a cluster-randomized controlled trial. *Patient Educ Couns*. 2007;67(3):324–332.
- [4] Slade SC, Molloy E, Keating JL. ‘Listen to me, tell me’: a qualitative study of partnership in care for people with non-specific chronic low back pain. *Clin Rehabil*. 2009;23(3):270-80.
- [5] Berwick DM. What ‘patient-centred’ should mean: confessions of an extremist. *Health Aff (Millwood)*. 2009;28(4):555–65.
- [6] Stenner R, Swinkels A, Mitchell T, Palmer S. Exercise prescription for patients with non-specific chronic low back pain: a qualitative exploration of decision making in physiotherapy practice. *Physiotherapy* (2015), <http://dx.doi.org/10.1016/j.physio.2015.05.004>.
- [7] Gadamer HG. *Truth and method*. 2nd rev.ed. New York: Continuum; 1996.
- [8] Pengel LH, Herbert RD, Maher CG, Refshauge KM. Acute low back pain: systematic review of its prognosis. *BMJ*. 2003;327:323-27.
- [9] Koch T. Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *J Adv Nurs*. 1996;24(1):174-84.
- [10] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psych*. 2006;3(2):77-101.
- [11] Coulter A, Collins A. *Making shared decision-making a reality. No decision about me, without me*. London: King’s Fund; 2011. Available from:

<http://www.kingsfund.org.uk/publications/making-shared-decision-making-reality>

[Accessed 14 June 2012]

[12] Mulley A, Trimble A, Elwyn G. Patient preferences matter: stop the silent misdiagnosis. London: King's Fund;2012. Available from:

<http://www.kingsfund.org.uk/publications/patient-preferences-matter>

[Accessed 2 Feb 2015]

[13] Stenberg G, Fjellman-Wiklund A, Ahlgren C. "Getting confirmation": gender in expectations and experiences of healthcare for neck or back patients. *J Rehab Med* 2012;44(2):163-71.

[14] Cooper K, Smith BH, Hancock E. Patient-centredness in physiotherapy from the perspective of the chronic low back pain patient. *Physiotherapy*. 2008;94(3):244-52.

[15] Elwyn G, Edwards A, Kinnersley P. Shared decision making in primary care: the neglected second half of the consultation. *Br J of Gen Pract*. 1999;49(443):477-82.

[16] O'Neill, O. Some limits of informed consent. *J Med Ethics*. 2003;29 (1):4-7.

[17] The Health Foundation. Helping people share decision making. A review of evidence considering whether shared decision making is worthwhile. London: United Kingdom. The Health Foundation; 2012.

[18] Fleming V, Gaidys U, Robb Y. Hermeneutic research in nursing: developing a Gadamerian-based research method. *Nurs Inq* 2003;10(2):113-20.

[19] Weston WW. Informed and shared decision making: the crux of patient-centred care. *CMAJ*. 2001;165(4):438-39.

Tables

Ref: Ms. No. PHYST-15-41

Table 1. Characteristics of interview participants

Characteristic	<i>n</i>
Gender	
Male	4
Female	4
Age (years)	
18-34	0
35-54	6
55-74	2
Over 75	0
Employment status	
Employed (FT)	4
Employed (PT)	2
Retired	2
Duration of LBP (years)	
Mean	21
Range	1-40
Number of physiotherapy attendances	
Mean	2.1
Range	1-6