Health Literacy Research and Practice

Brief Report

The impact of inadequate health literacy in a musculoskeletal pain population

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Acknowledgments

This study comprises additional analysis of the Keele Aches and Pains (KAPs) dataset. The KAPs study is part of a programme grant funded by the National Institute for Health Research (NIHR; RP-PG-1211-20010) and Arthritis Research UK (13413). The views and opinions expressed within this manuscript are those of the author(s), and not necessarily those of the NHS, the NIHR, or the Department of Health. Funding was also secured by the North Staffordshire Primary Care Research Consortium for NHS and service-support costs. The authors would like to thank all members of the Keele Aches and Pains Study team.

Plain Language Summary

This study asked “How does the health literacy level of primary care patients affect their aches, pain or stiffness, 6 months after seeing their family doctor?” We found that patients with low health literacy had worse aches, pain or stiffness after 6 months than those with high health literacy. Future studies should develop treatments that support all musculoskeletal pain patients to manage their pain successfully.

Abstract

Musculoskeletal conditions are a major cause of ill-health and disability. Inadequate health literacy may partly explain why musculoskeletal self-management programmes are not effective for some patients. This study prospectively evaluates the impact of patients’ health literacy level on their musculoskeletal pain and physical function (PF) following usual primary care. 4720 primary care patients who had consulted for musculoskeletal pain were mailed a baseline questionnaire; responders were sent a 6-month follow-up. Outcome measures: PF and pain intensity at 6-months. Health literacy: Single-item Literacy Screener at baseline. Analysis was by linear regression. 1890 patients responded (40%). 17.3% (95%CI 15.6%-19.0%) of patients had inadequate health literacy. Inadequate health literacy was associated with older age ($p<0.05$), lower education, mental health and co-morbidities (all $p<0.001$), but not gender ($p=0.642$). At 6-month follow-up, patients with inadequate health literacy had lower PF (mean difference -12.2; -16.7,-7.6) and higher pain intensity (1.0; 0.6,1.4), adjusted for age, gender, education, mental health and co-morbidities, than patients with adequate health literacy. Differences in PF and particularly pain scores between patients with inadequate and adequate health literacy increase over 6 months. Future studies should develop interventions that better support musculoskeletal pain patients with inadequate health literacy to successfully manage their pain.

Keywords: Health Literacy; Musculoskeletal pain; Primary care

Total word count: 2254

Introduction

Musculoskeletal conditions are a major cause of ill-health and disability worldwide, with substantial impacts on patients' quality of life and healthcare resource use (Woolf & Pfleger, 2008). Musculoskeletal conditions, including osteoarthritis, are generally considered to be long-term conditions, for which the mainstay of treatment is supported self-management. However, a recent review of self-management education programmes for osteoarthritis concluded that these programmes conferred 'little or no benefit' for self-management skills, or health outcomes (Kroon et al., 2014). Self-management programmes require patients to have a high level of participation and engagement (Adams, 2010). There is growing evidence that factors related to health equity (e.g. socio-economic disadvantage, inadequate health literacy) may be partly the reason that some patients benefit less from musculoskeletal self-management interventions (Kapoor, Eyer & Thorn, 2016; Beneciuk et al., 2017).

Health literacy refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health (Dodson, Good & Osborne, 2015). People with low socio-economic status or low levels of education are more likely to have poorer health literacy (European Health Literacy Project Consortium, 2012), and this is associated with poorer health outcomes, poorer use of health care services (Berkman, Sheridan, Donahue, Halpern & Crotty, 2011) and impacts on self-management skills (Mackey, Doody, Werner & Fullen, 2016). Evidence from subgroup analyses in a review of self-management education programmes for osteoarthritis showed that some outcomes differed according to factors associated with health literacy (e.g. education level; Kroon et al., 2014).

However, only 14% of included trials provided information on participants' health literacy, leading Kroon et al. (2014) to suggest that future intervention development for self-management programmes should consider patient health literacy to explore issues of health equity.

Few studies have investigated the effect of health literacy specifically on musculoskeletal pain and physical function (PF). A cross-sectional study of adults aged ≥60 years found that those with low health literacy had a significantly higher prevalence of arthritis (Kim, 2009), and emerging evidence suggests that health care professionals find pain management in patients with low health literacy challenging, as these patients have less understanding and less control of their pain (Adams et al., 2016). However, no research to date has considered the prospective effect of health literacy on outcomes for those with musculoskeletal pain; this is needed to inform interventions that better meet the needs of patients with low health literacy. The aim of this study is to prospectively evaluate the impact of patients' health literacy level on their musculoskeletal pain and PF outcomes following a primary care consultation.

Methods

We conducted secondary data analysis of the Keele Aches and Pains Study (KAPS), a prospective cohort study in 14 UK primary care practices. Full details of the protocol have been published (Campbell et al., 2016). Ethical approval for the KAPS was granted by the South East Scotland Research Ethics Committee, UK (14/SS/0083).

Consecutive patients aged ≥18 years who visited their family doctor with ≥1 of five musculoskeletal pains (back, neck, shoulder, knee, or multisite pain), including chronic and acute pain, were invited to take part in the study. Inclusion criteria were patients registered at participating general practices, aged 18 years or over, consulting with the included musculoskeletal pain presentations, and able to read and understand English. Exclusion criteria were indication of serious pathology (e.g. suspected

fracture, cancer), inflammatory arthritis, crystal disease, spondyloarthropathy, polymyalgia rheumatica, pregnancy-related pain problems, urgent cases (e.g. cauda equina syndrome), or vulnerable patients (e.g. experienced recent trauma, cognitive impairment, dementia, or terminal illness). There was no intervention in this cohort study, and patients received usual care from their family doctor. 4720 eligible patients were mailed a study pack (including information sheet and baseline questionnaire) from their family doctor shortly after their musculoskeletal pain consultation. Information regarding the study included that completion and return of the baseline questionnaire would signify participants' willingness to take part and receive a follow-up questionnaire. All patients who consented to participate were mailed 6-month follow-up questionnaires. Non-responders at both stages were mailed reminders at 2 weeks and repeat questionnaires 2 weeks later.

Outcome measures: PF and pain intensity, both measured in baseline and 6-month questionnaires. PF was measured using the Physical Functioning sub-scale of Short Form-36 (SF-36 PF) which consists of 10 items; scores range from 0 to 100, with lower scores indicating worse health (Ware, 2000). Three pain intensity questions specifically asked about the aches, pain or stiffness that patients had visited their doctor about (current pain; average usual pain in last 2 weeks; and least pain in last 2 weeks), each on a 0-10 numerical rating scale, 0 indicating no pain, 10 indicating pain as bad as it could be (Deyo et al., 2015; Campbell et al., 2016).

Predictor variable: Health literacy was measured at baseline using the Single-item literacy screener (SILS): "How often do you need to have someone help you when you read instructions on pamphlets, or other written material from your doctor or pharmacy?" (Morris, MacLean, Chew, & Littenberg, 2006). Response options: often, always, sometimes, rarely, never.

Potential confounding variables (measured at baseline):

Three stages of education: “How old were you when you left school?” (years); “Did you go into full-time education (College or university)?” (yes, no); “Have you gained qualifications through study as an adult?” (yes, no) (Campbell et al., 2016).

Co-morbidities: diabetes; breathing problems/chronic pulmonary obstructive disease/asthma; heart problems/high blood pressure; chronic fatigue syndrome/myalgic encephalomyelitis/fibromyalgia; anxiety/depression/stress; other (Campbell et al., 2016).

Mental health: mental component summary score of SF-36 (Ware, 2000).

Statistical analysis

Characteristics of the study population were analysed according to level of health literacy, using one-way ANOVA trend test with linear contrast (1 df). Associations between health literacy, and PF or pain intensity (average of the three pain intensity scores), were analysed using linear regression (adjusted for age, gender, three stages of education, co-morbidities, mental health). For regression analyses, health literacy was dichotomised into inadequate health literacy (always, often, sometimes need help) and adequate health literacy (never, rarely need help) as used previously (Morris et al., 2006). Results are presented as mean differences (MD) with 95% confidence intervals (95%CI), and standardised mean differences (SMD), i.e. effect size relative to baseline standard deviation of 28.7 (SF-36 PF) and 2.37 (pain) (Cohen, 1988). Effect sizes were interpreted as suggested by Cohen (1988): 0.2 'small', 0.5 'moderate', 0.8 'large'. To give context, the percentage change in PF and pain scores were calculated (mean difference at baseline or 6 months / mean score for study population).

Results

1890/4720 patients consented to the baseline invitation (40% response). The mean age of participants was 58.3 years (range 18 to 98 years), and 60.6% were female. 1452 responded at 6-

months (76.8%). No differences were found between responders and non-responders at 6-months for baseline gender, later stages of education, co-morbidities, or PF (Appendix 1). Non-responders at 6-months were more likely to have left school earlier, inadequate health literacy (25% vs 15%), higher pain score, poorer mental health, and be younger, than responders.

17.3% (95%CI 15.6%-19.0%) of patients reported inadequate health literacy (Table 1). Inadequate health literacy was associated with older age (60.2 years versus 57.9, $p<0.05$), lower education (all stages), poorer mental health and co-morbidities (all $p<0.001$), but not gender ($p=0.642$).

At baseline, patients with inadequate health literacy had lower PF and higher pain scores than those with adequate health literacy, and these associations remained after adjustment for age, gender and all education stages (Table 2). The difference in PF and pain scores between health literacy groups was reduced after additional adjustment for co-morbidities and mental health but remained significant ($p<0.001$).

At 6-month follow-up, patients with inadequate health literacy at baseline had significantly lower PF (MD -22.2; 95%CI -27.1,-17.4, $p<0.001$) and higher pain (MD 1.79;1.35,2.24, $p<0.001$) scores after adjustment for age, gender and all education stages, than those with adequate health literacy, with large effect sizes (PF: -0.77; -0.94,-0.61, $p<0.001$; pain: 0.76;0.57,0.95, $p<0.001$; Cohen, 1988; Table 2). Additional adjustment for co-morbidities and mental health reduced the difference in PF (MD -12.2;-16.7,-7.6) and pain (MD 0.99;0.56,1.41) scores between the health literacy groups, and effect sizes for PF (-0.42;-0.58,-0.26) and pain (0.42;0.24,0.59) to small to moderate. The difference between the health literacy groups remained larger at 6 months than at baseline, particularly for pain (24% higher pain at 6 months vs 12% higher at baseline) for inadequate compared to adequate health literacy.

Discussion

To our knowledge, this is the first prospective observational study to provide evidence that health literacy level has an impact over time on musculoskeletal pain and PF in primary care patients. Six months after consulting their family doctor for musculoskeletal pain, differences in PF and particularly pain scores between patients with inadequate and adequate health literacy had increased, suggesting that those with poor health literacy benefit less from current primary care management strategies. Adjustment for potential confounders reduced the effect sizes between those with inadequate and adequate health literacy, although the differences remained significant representing 23% lower PF and 24% higher pain at 6 months, for inadequate compared to adequate health literacy.

Our results contrast with the findings from a systematic review, which found no consistent association between low health literacy and poorer functional outcomes in patients with chronic musculoskeletal conditions (Loke et al., 2012). One included study reported an association between low health literacy, and more pain and functional limitation (Kim, 2009), although Loke et al. (2012) identified a number of methodological weaknesses in the included studies. A UK back pain trial reported that participants with low socio-economic status (based on occupation) benefitted less from a prognostic stratified care intervention for low back pain than those with high socio-economic status (Beneciuk et al., 2017). Our results may partly explain these findings. Indeed, Beneciuk et al. (2017) suggested that barriers to good health outcomes experienced by low socio-economic status patients, such as low health literacy, may have influenced their results.

Little evidence exists for the impact of low health literacy on self-management skills for musculoskeletal conditions, although a recent preliminary study of patients with chronic pain at low-income clinics found that lower levels of health literacy were associated with greater catastrophizing and lower pain-related self-efficacy (Kapoor, Eyer, & Thorn, 2016). A systematic review of the effectiveness of educational interventions in people with low literacy levels showed a modest effect on knowledge and self-efficacy, although there was a lack of high quality evidence (Lowe et al.,

2013). We support the authors' recommendation that future patient education interventions for musculoskeletal conditions should recruit and engage people with lower levels of literacy.

This study has several strengths. We used a large, prospective cohort of musculoskeletal consulters in primary care. We used a validated health literacy screening measure (SILS) because it is a short, simple measure developed from the 16-item Short Test of Functional Health Literacy in Adults (Baker, Williams, Parker, Gazmararian, & Nurss, 1999), suitable for postal questionnaires (Morris et al., 2006). We adjusted for several potential confounders (socio-demographic factors, educational history, co-morbidities and mental health). There are some limitations to this study. The SILS is a screening test and not a direct measure of health literacy, although it was developed to efficiently identify patients who need help reading health-related materials (Morris et al., 2006). In our study, the ability to read and understand English could have excluded patients on the basis of their functional health literacy. Non-responders at 6-month follow-up were more likely to have baseline inadequate health literacy than responders, which may have resulted in an unavoidable under-estimate of low health literacy in this cohort. This is supported by our prevalence of low health literacy (17%) being less than a general population interview survey suggests (43-61%; Rowlands et al., 2015). Response to our study was 40%, although retention in the cohort was good at 6-months. 40% is a moderate response, although similar mean pain intensity values and other baseline characteristics are reported in other primary care consultation musculoskeletal cohort studies (Dunn et al., 2006) with higher response rates. Misclassification of outcomes could have occurred if responders to the questionnaires did not answer the PF and pain questions in relation to their aches, pain or stiffness, but to pain more generally. However, extensive work with our patient and public Research User Group resulted in the term "aches, pain or stiffness" being used for musculoskeletal pain in our questionnaires. Further limitations may be the lack of information on race or ethnicity, socio-economic status, income and BMI, as low health literacy is reported to be associated with these factors (Sperber et al., 2013; European Health Literacy Project Consortium, 2012; Geboers et

al., 2016). There is scope to investigate these and other potential confounders (e.g. treatments and medications, duration of pain) in future research.

This study has shown that primary care patients' health literacy level impacts their musculoskeletal outcomes after seeing their family doctor: differences in PF, and particularly pain, between patients with inadequate and adequate health literacy increase over 6 months. We suggest that the disappointing results of self-management approaches for patients with musculoskeletal pain may be partly explained by low health literacy. Future studies should develop interventions that better support musculoskeletal pain patients with low health literacy to successfully manage their pain.

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Table 1. Characteristics of study population by baseline health literacy response categories

	Need help reading health-related materials							
	Never	**Rarely**	**Sometimes**	**Often**	**Always**	**Adequate[#]**	**Inadequate[#]**	**Total**
Overall, n (%)	1321 (70.3)	234 (12.4)	185 (9.8)	72 (3.8)	68 (3.6)	1555 (82.7)	325 (17.3)	1880[$]
Age (years), mean (SD)*	57.4 (15.6)	60.5 (16.7)	61.2 (17.5)	59.1 (16.2)	58.5 (17.7)	57.9 (15.8)	60.2 (17.2)	58.3 (16.1)
Gender, n (%)								
Female	812 (61.5)	133 (56.8)	106 (57.3)	50 (69.4)	37 (54.4)	945 (60.8)	193 (59.4)	1138 (60.5)
Male	509 (38.5)	101 (43.2)	79 (42.7)	22 (30.6)	31 (45.6)	610 (39.2)	132 (40.6)	742 (39.5)
Education								
Age left school (years), n (%)***								
≤16 years	1009 (77.4)	198 (86.1)	159 (89.3)	54 (78.3)	62 (96.9)	1207 (78.7)	275 (88.4)	1482 (80.4)
≥17 years	294 (22.6)	32 (13.9)	19 (10.7)	15 (21.7)	2 (3.1)	326 (21.3)	36 (11.6)	362 (19.6)

Full-time education, n (%)***								
No	857 (65.4)	188 (81.0)	152 (83.1)	56 (78.9)	60 (89.6)	1045 (67.7)	268 (83.5)	1313 (70.4)
Yes	454 (34.6)	44 (19.0)	31 (16.9)	15 (21.1)	7 (10.4)	498 (32.3)	53 (16.5)	551 (29.6)
Gained qualifications as an adult, n (%)***								
No	494 (38.7)	126 (57.0)	111 (63.8)	46 (67.6)	44 (67.7)	620 (41.4)	201 (65.5)	821 (45.5)
Yes	782 (61.3)	95 (43.0)	63 (36.2)	22 (32.4)	21 (32.3)	877 (58.6)	106 (34.5)	983 (54.5)
Co-morbidities, n (%)***								
No	449 (34.0)	56 (23.9)	34 (18.4)	14 (19.4)	11 (16.2)	505 (32.5)	59 (18.2)	564 (30.0)
Yes	871 (66.0)	178 (76.1)	151 (81.6)	58 (80.6)	57 (83.8)	1049 (67.5)	266 (81.8)	1315 (70.0)
Mental health, mean (SD)								
Baseline***	67.8 (21.0)	59.0 (20.8)	52.3 (21.7)	47.6 (23.9)	40.1 (25.0)	66.5 (21.2)	48.7 (23.3)	63.4 (22.6)
6 months***	73.4 (19.2)	67.2 (21.5)	59.1 (22.7)	55.0 (25.7)	46.7 (28.4)	72.5 (19.6)	56.8 (24.2)	70.3 (21.0)

Pain (average), mean (SD)								
Baseline***	5.0 (2.3)	5.6 (2.2)	6.5 (2.1)	6.2 (2.3)	7.0 (2.2)	5.1 (2.3)	6.6 (2.2)	5.3 (2.4)
6 months***	3.9 (3.0)	4.7 (2.9)	5.7 (2.9)	5.9 (2.7)	6.7 (2.5)	3.9 (2.7)	5.8 (2.6)	4.1 (2.8)
Physical functioning, mean (SD)								
Baseline***	53.7 (27.6)	45.3 (27.4)	32.7 (27.0)	32.0 (24.9)	33.3 (32.6)	52.4 (27.7)	32.7 (27.7)	49.0 (28.7)
6 months***	58.1 (29.5)	50.2 (29.7)	32.6 (27.9)	33.4 (26.9)	30.6 (33.2)	57.0 (29.6)	32.5 (28.2)	53.6 (30.6)

[$]n=10 missing data for the health literacy question.

*p<0.05, ***p<0.001 by one-way ANOVA trend test with linear contrast (1 df) for comparison across the five subcategories of health literacy.

[#]Adequate health literacy = never, rarely need help; Inadequate health literacy = sometimes, often, always need help.

Table 2. Differences in physical function and pain intensity scores between patients with inadequate and adequate health literacy[#]

	Unadjusted		Adjusted*			Adjusted**		
	Mean difference (95% CI)	Effect size (95% CI)	Mean difference (95% CI)	Effect size (95% CI)	% change in score	Mean difference (95% CI)	Effect size (95% CI)	% change in score
Physical function								
Baseline	-19.8 (-23.1, -16.4)	-0.69 (-0.80, -0.57)	-19.2 (-22.6, -15.7)	-0.67 (-0.79, -0.55)	-39.2	-9.5 (-12.8, -6.2)	-0.33 (-0.45, -0.22)	-19.4
6 months	-24.5 (-29.2, -19.7)	-0.85 (-1.02, -0.69)	-22.2 (-27.1, -17.4)	-0.77 (-0.94, -0.61)	-41.4	-12.2 (-16.7, -7.6)	-0.42 (-0.58, -0.26)	-22.8
Pain intensity (average pain)								
Baseline	1.49 (1.21, 1.77)	0.63 (0.51, 0.75)	1.28 (0.99, 1.57)	0.54 (0.42, 0.66)	24.2	0.65 (0.37, 0.94)	0.27 (0.16, 0.40)	12.3
6 months	1.96 (1.53, 2.40)	0.83 (0.65, 1.01)	1.79 (1.35, 2.24)	0.76 (0.57, 0.95)	43.7	0.99 (0.56, 1.41)	0.42 (0.24, 0.59)	24.1

[#]Inadequate health literacy = often, always, sometimes need help; Adequate health literacy = rarely, never need help. Mean difference from linear regression analyses calculated as: mean score (inadequate HL group) minus mean score (adequate HL (reference group)). Percentage change in score calculated as mean difference at baseline or 6 months / mean score for study population. *Adjusted for age, gender, age left school, further education,

qualifications as adult; **additionally adjusted for baseline co-morbidities and mental health score. CI = Confidence Interval. All tests of association were significant at $p<0.001$.