

The impact of health literacy on health outcomes in individuals with chronic pain: a cross-sectional study

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Abstract

Objective To establish if health literacy (HL) is linked to poorer outcomes and behaviours in patients with chronic pain.

Design A prospective cross-sectional observational study.

Setting Multidisciplinary out-patient pain clinics in three university teaching hospitals.

Patients New patients (n = 131) referred to the pain clinic with a history of chronic pain (>12 weeks).

Methods A questionnaire was distributed to chronic pain patients attending their first appointment. Those eligible for inclusion were newly referred patients who had pain lasting longer than three months. The questionnaire comprised the following sections: demographics, chronic pain status and disease-related knowledge, quality of life (SF-36), beliefs (Beliefs About Pain Control Questionnaire), and a validated HL tool (Newest Vital Sign).

Results Of the 131 participants recruited, 54% had inadequate HL. The group was subsequently stratified according to HL level. In bivariate analysis, inadequate HL was associated with older age ($p < 0.001$), being unemployed or retired ($p = 0.005$), less education ($p < 0.001$), lower income, increased comorbidities ($p = 0.038$), being less likely to utilise allied health services ($p = 0.001$), poorer disease-related knowledge ($p = 0.002$), and poorer beliefs about pain ($p < 0.05$). In multivariate analysis, disease-related knowledge (OR 2.5, 95%CI 1.0 to 6.3, $p = 0.05$) and beliefs about pain ($B = -2.3$, S.E = 0.9, $p = 0.01$) remained independently associated with HL.

Conclusion Inadequate HL is prevalent in chronic pain patients, and may impact on the development of certain characteristics necessary for effective self-management.

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Keywords: Chronic pain; Health literacy; Self-management; Beliefs

Introduction

Given the complex pathophysiology of chronic pain, international best practice guidelines advocate a biopsychosocial model for improving health outcomes for those with chronic pain, providing a multipronged approach with self-management at the core [1]. In order for patients to ‘buy

in’ to such practices, they must have adequate knowledge of their condition and the treatments options available, and actively engage with and navigate with a range of health services [2]. A well-established barrier to self-management, and improved health outcomes in a range of chronic diseases is health literacy (HL) [3,4]. This is described as ‘the personal and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health [5]. A recent European-based HL survey found that low HL levels ranged from 63% in Spain, to

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24% in The Netherlands, with Ireland reporting 40% [6]. In the USA 36% were classified as having either basic or below basic levels of HL [7].

In a recent review, we found that the impact of HL on health outcomes in people with chronic pain remains largely under-researched [4], despite the high costs associated with its management (both to the patient and health service) [8]. Of the minimal research that does exist to date, results are conflicting. One study [9] found no association between HL and symptom control, disability levels, impact on activities of daily living, and patients' beliefs; however, given that all participants in their study had adequate HL, conclusions are limited. In contrast, another study [10] found that those with low HL had poorer medication knowledge and disease awareness, although core outcomes necessary for monitoring chronic pain management were not assessed (e.g. quality of life, and beliefs).

Significantly more research has been undertaken in other chronic diseases, with associations reported between low HL and poorer health outcomes in cardiovascular diseases, chronic obstructive pulmonary disease (COPD), and diabetes [3]. However, extrapolating these results to make assumptions regarding the impact of HL in all chronic conditions cannot be considered, due to heterogeneity of study designs and conflicting results observed in the literature. For example, a significant association between poorer symptom control and low HL was reported in those with hypertension [11] and diabetes [12], but not in those with asthma [13] or arthritis [14]. Similarly, no association was found regarding HL and decision-making preferences hypertension patients [15], whereas asthma patients with low HL were more likely to prefer a passive role in decision-making processes [16]. Therefore, in order to inform the development of HL-sensitive interventions, such as those that have been shown to be effective in improving self-management in other conditions [17], a baseline assessment of the impact of HL in people with chronic pain must be established before any recommendations can be made for pain services.

Hence, the current study will determine the prevalence of low HL in people with chronic pain, and investigate a range of health outcomes and behaviours that may be impacted by varying levels of HL. In particular, associations between HL and self-management characteristics will be examined.

Methodology

Overview

A cross-sectional study was undertaken with new patients (pain > 12 weeks) referred from their General Practitioner to a pain clinic in one of three university teaching hospitals. Participants completed a battery of questionnaires that determined HL levels, health behaviours, health service utilisation, chronic pain status, quality of life, disease-related knowledge and beliefs about pain control. Associations between

varying levels of HL on patient-related outcomes was also determined.

Procedure, participants, and ethics

Prior to commencing the study, full ethical approval was gained from all three hospitals where recruitment took place. Potential participants were contacted initially by including an information letter with their clinic appointment letter, informing them about the study and that they would be invited to participate on the day of their appointment. The researcher's contact details were also included should patients have any queries in relation to the study prior to attending their appointment. At their appointment, potentially interested patients were approached by the researcher in the waiting room and asked if they were interested in participating. If so, a patient information leaflet with additional information was provided to them, and the researcher described the details of taking part, i.e. completion of a questionnaire that would take about 15 minutes, that they could withdraw from the study at any point, that their anonymity would be protected, and that no additional involvement would be required. Following this, inclusion criteria were reviewed and written informed consent was obtained. Inclusion criteria stipulated that the patient must be willing and able to give informed consent, be a new referral to the pain service, have pain lasting longer than three months, have no cognitive deficits or active psychiatric illness, and be over 18 years of age. Participants were excluded if they were unable to provide informed consent. Participants then completed a battery of questionnaires outlined below. All questionnaires were self-administered, apart from the Newest Vital Sign (NVS) – a HL assessment, which was administered by the researcher.

Sample size calculation

An online software calculator (PS) was used to determine sample size [18]. Given the 40% prevalence of inadequate health literacy previously reported in the HLS-EU survey [6], sample size calculations were performed to estimate prevalence with a precision of $\pm 10\%$ and $\alpha = 0.05$. A minimum sample of 94 participants was required, but recruitment targets were set at 130 patients, as a contingency against drop out ($n > 1.96\hat{2}(0.5 \times 0.5)/0.1\hat{2}$). This sample size is in line with other recently published studies that used the NVS to assess the impact of HL on health outcomes in conditions [10].

Battery of questionnaires

Demographics and health related questions

The following demographic information based on the Irish report of the HLS-EU study [19], and health related questions were included:

- (i) Demographics: age, gender, employment status, socio-economic status, educational attainment, income, race,

health insurance, and comorbidities (cardiac, respiratory, neurological, endocrine, musculoskeletal, mental health).

- (ii) Health behaviours: smoking, diet, alcohol intake, physical activity, and weight.
- (iii) Health service utilisation: Patients were asked for the number of times they visited their general practitioner, the number of times they used the emergency services, hospital services, and allied health services in the past 12 months based on recall.
- (iv) Chronic pain status: history/mechanism of injury, severity (numerical rating scale) and duration of symptoms, limitations due to chronic pain, medication usage, and efficacy of current regime.
- (v) Basic disease-related knowledge: a blank space was provided in the battery of questionnaires where the participant had an opportunity to provide an explanation about the cause of their pain. Acceptable explanations were identified according to International Association for the Study of Pain (IASP) definition [20] – i.e. if a participant described chronic pain as ‘a pain lasting longer than three months’, and/or describing the central mechanisms associated with chronic pain. To the best of the authors’ knowledge, no validated tools for measuring patients’ knowledge about chronic pain exists, and for this reason, the IASP definition was deemed as the most appropriate means to investigate this.

Health literacy assessment – the newest vital sign (NVS)

The NVS was developed and validated by Weiss *et al.* [21]. It assesses prose literacy, document literacy and numeracy. Average time to complete the questions is three minutes. The NVS tool consists of six questions based on a nutritional label from an ice cream container. The researcher delivers the six questions, giving the patient as much time as required to provide an answer. There is a maximum of six points. A score of 0–1 suggests a high likelihood of limited literacy, 2–3 indicates the possibility of limited literacy and a score of 4–6 indicates adequate literacy. For the current study, the results of the NVS were dichotomised into adequate (score of 4–6), or inadequate (<4) scores, in line with other studies [10].

The short form 36 (SF-36)

The SF-36 is a multi-item generic tool that measures an individual’s general health status. Originally published in 1992 and later revised in 2000 [22], the SF-36 contains 36 questions based on eight different domains: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, mental health, and health transition. Results from this tool reproduce a summary of two scores – (i) physical component scores (PCS) and, (ii) mental component scores (MCS). Possible

raw scores range from 0 to 100. This has been validated for use in rheumatological and musculoskeletal settings [23].

Beliefs about pain control questionnaire (BPCQ)

The BPCQ is a 13-item questionnaire contains three subscales that measure beliefs regarding individuals’ internal locus of pain control, that powerful others control their pain (e.g. doctors), or that pain is controlled by chance events. The internal consistency of the subscales has been established using the Cronbach’s alpha [24].

Statistical analysis

Data collected from the questionnaires were coded, manually entered in Statistical Package for the Social Sciences (SPSS, version 20) and re-checked for any errors. Data were tested for normality using the Kolmogorov–Smirnov test, revealing abnormal distribution, and therefore, non-parametric tests (i.e. Chi-squared or Mann–Whitney U) were chosen to assess differences in demographic variables (i.e. age, gender, education, employment status, household income, social class, health insurance status, number of comorbidities). Also, associations between levels of HL and the following were examined: health behaviours (i.e. smoking, alcohol, exercise, weight, and diet), health service utilisation (i.e. GP visits, emergency service use, hospital service use, and allied therapy use), chronic pain status (i.e. pain duration, medication adherence, symptom severity, limitation due to pain, medication use, and medication efficacy), mental and physical component scores of the SF-36, and beliefs about pain control. Next, the relationships between HL (adequate vs. inadequate) and any outcomes, which emerged as significant in the bivariate analysis, were explored by constructing individual multivariable linear regression or logistic regression models as appropriate for each outcome. The models controlled for potentially confounding variables (age, gender, educational attainment, and income) with the aim of identifying whether HL was an independent predictor of each of these health outcomes. The level significance was set at $p \leq 0.05$, and STROBE checklist utilised to manage reporting [25].

Results

In total, of the 131 patients included in the study, 54.% (71/131) had inadequate HL. The overall mean (SD) age was 49 (15), and 69% (89/130) of the total group was female. 41%, (53/130) were either unemployed or unable to work, 82% (107/123) considered themselves middle class, 18%, (23/131) only completed primary level education, and 56% (73/123) had a monthly household income of less than €1350. 22% (29/131) had private health insurance, and 75% (99/131) reported at least one comorbidity. It is notable that quality of life scores, and the majority of pain outcomes were poor, regardless of HL levels. Participant characteristics

Table 1
Participant characteristics.

Demographics	Adequate HL (n = 60)	Inadequate HL (n = 71)	p-value
Age, Mean (SD)	42 (12)	54 (14)	p < 0.001 ^a
Gender, n (%)			p = 0.137 ^b
Male	15 (25)	26 (37)	
Female	45 (75)	44 (62)	
Employment, n (%)			P = 0.005 ^b
Employed	31 (52)	29 (41)	
Unemployed	10 (17)	7 (10)	
Unable to work	17 (28)	19 (27)	
Retired	1 (2)	16 (23)	
Education, n (%)			p < 0.001 ^b
Primary level	2 (3)	21 (30)	
Secondary level	38 (63)	40 (56)	
Third Level	20 (33)	10 (14)	
Income (household)			p = 0.011 ^b
<€1350	27 (45)	46 (65)	
€1350-€2400	17 (28)	11 (15)	
>€2450	15 (25)	7 (10)	
Social Class, n (%)			p = 0.375 ^b
Low	5 (8.3)	9 (12.7)	
Middle	48 (80)	59 (83)	
High	0	2 (3)	
Irish nationality, n (%)	57 (95)	63 (89)	
Co-morbidities, n (%)			p = 0.01 ^b
Yes	39 (65)	60 (85)	
Cardiac	12 (20)	19 (27)	
Respiratory	12 (20)	14 (20)	
Neurology	3 (5)	4 (6)	
Mental health	18 (30)	34 (48)	
Renal	0	2 (3)	
Diabetes	5 (8)	12 (17)	
No	21 (34)	11 (16)	
Smoking, n (%)			p = 0.157 ^b
Yes	23 (38)	19 (27)	
No	37 (62)	52 (73)	
Alcohol, n (%)			p = 0.215 ^b
Light/moderate	45 (75)	43 (61)	
Excessive	1 (2)	2 (3)	
Never	14 (23)	26 (37)	
Exercise levels, n (%)			p = 0.521 ^b
Regularly	33 (55)	46 (65)	
Occasion/never	12 (20)	11 (16)	
Unable to	15 (25)	14 (20)	
Weight, n (%)			p = 0.317 ^b
Underweight	3 (5)	4 (6)	
Normal Weight	20 (33)	33 (47)	
Overweight	36 (60)	34 (48)	
Diet, n (%)			p = 0.307 ^b
Yes	39 (65)	47 (66)	
No/sometimes	16 (27)	14 (20)	
Don't know	4 (7)	10 (14)	
GP Visits, mean (SD)	8.83 (8.0)	7.8 (8.4)	p = 0.162 ^a
Emergency, mean (SD)	0.34 (0.7)	0.74 (1.6)	p = 0.646 ^a
Hospital, mean (SD)	3.81 (5.2)	3.09 (4.5)	p = 0.001 ^a
Other (Allied health), mean (SD)	6.33 (10.1)	2.91 (8.4)	p = 0.001 ^a
Disease-related knowledge			
Pain Explanation Provided, n (%)			p = 0.002 ^b
Yes	39 (65)	28 (39.4)	
No	20 (33.3)	43 (60.6)	
Pain Duration - Years, mean (SD)	5.93 (6.2)	5.934 (6.2)	p = 0.67 ^a
Medication adherence, n (%)			p = 0.220 ^b
Yes	48 (80)	62 (87.3)	
No	8 (13.3)	5 (7.0)	

Table 1 (Continued)

Demographics	Adequate HL (n = 60)	Inadequate HL (n = 71)	p-value
Symptom Severity (NRS), mean (sd)	7.05 (1.8)	7.45 (1.8)	p = 0.163 ^a
Limitation due to pain, n (%)			p = 0.504 ^b
Severely	18 (30)	25 (35.2)	
Somewhat	35 (58.3)	41 (57.7)	
Not At All	1 (1.7)	4 (5.6)	
Med Use, n (%)			p = 0.786 ^b
Yes	54 (90)	64 (90.1)	
No	5 (8.3)	7 (9.9)	
Medication efficacy (Do they work?), n (%)			p = 0.262 ^b
Yes	21 (35)	17 (23.9)	
No	34 (56.7)	43 (60.6)	
SF-36 MCS, mean (SD)	30.41 (8.6)	33.09 (8.4)	P = 0.163 ^a
SF-36 PCS, mean (SD)	42.65 (13.7)	39.89 (12.5)	p = 0.258 ^a
Beliefs about Pain Control			
BPCQ – IS, Mean (SD)	11.72 (4.4)	12.86 (5.1)	p = 0.276 ^a
BPCQ – PD, Mean (SD)	14.13 (4.4)	15.69 (4.6)	p = 0.042 ^a
BPCQ – CH, Mean (SD)	11.38 (4.1)	13.8 (4.6)	p = 0.005 ^a

Test score for Mann Whitney-U test refers to z-score. Test score for Chi-squared test refers to Yates' Correction for Continuity. GP: general practitioner; SF-36: Short Form-36; MCS: mental component summary; PCS: physical component summary; BPCQ: Beliefs About Pain Control Questionnaire; IS: internal locus of control; PD: powerful doctors; CH: chance. (SD): standard deviation.

^a Mann Whitney-U test.

^b Chi-squared test; n: number.

based on HL level (adequate or inadequate) are summarised in [Table 1](#).

Bivariate analysis of health literacy impact

Demographics

Those with inadequate HL were older [adequate, mean 42 (12); inadequate, mean 54 (14); $z = -4.796$, $p < 0.001$], were more likely to be unemployed or retired [adequate, 32% (n = 23); inadequate, 18% (n = 11); $z = 12.509$, $p = 0.005$], have poorer educational attainment [e.g. primary level only – adequate, 2% (n = 3.3); inadequate, 21% (n = 21); $z = 18.29$, $p < 0.001$], have a monthly household income of $<€1350$ [adequate, 45% (n = 27); inadequate, 65% (n = 46); $z = 8.95$, $p = 0.01$], and a greater number of comorbidities [adequate, 65% (n = 39); inadequate, 85% (n = 60), $z = 6.7$, $p = 0.038$].

Health behaviours

No associations between health behaviours and HL levels were found for the following variables: smoking, diet, alcohol intake, physical activity levels or weight.

Health service utilisation

Those with low HL were less likely to use a non-emergency hospital service (adequate, mean 3.8 (5.2); inadequate, 3.1 (4.7); -1.607 , $p = 0.001$), or allied health service (adequate, mean 6.3 (10.2); 2.9 (8.4); 3.256 , $p = 0.001$).

Chronic pain status

No differences between levels of HL and chronic pain status was found for the following variables: duration, symptom severity, limitations due to pain, medication adherence, medication usage, and efficacy of medication regime.

Quality of life (SF-36)

No associations between HL levels (adequate or inadequate) and the mental or physical component scores of the SF-36 were found.

Beliefs about pain control

Those with adequate HL were less likely to believe that powerful others controlled their pain [adequate, mean 14.1 (4.4); inadequate, mean 15.7 (4.6); $z = -2.03$, $p = 0.042$], or that their pain was controlled by chance [adequate, 11.4 (4.1); inadequate, 13.8 (4.6); $z = -2.826$, $p = 0.005$]. See [Table 1](#) for further information on bivariate analyses.

Multivariate analysis

Depending on whether the dependent outcome variable was dichotomous (i.e. disease-related knowledge), or continuous (i.e. beliefs about pain control, hospital service use, allied therapy use, comorbidities), multiple logistic or linear regression models were constructed. As standard, significant demographic variables from bivariate analysis (i.e. age, employment, educational attainment, and income) were included to control for potential confounders, along with HL as the predictor variables. Thus, the independent relationship between HL and disease-related knowledge, beliefs about pain control ('powerful others', and 'controlled by chance' subscales), health service use (hospital and allied health services) was examined. HL remained an independent predictor of disease-related knowledge (OR 2.5, 95%CI 1.0 to 6.3, $p = 0.05$), signifying that the odds of high disease-related knowledge was 2.5 times greater in those with adequate HL, compared to those with inadequate HL. Similarly, HL was an independent predictor of the 'controlled by chance' sub-

Table 2
Independent associations between health literacy and significant health outcomes.

Linear regression models for continuous variables			
	B	S.E (B)	p value
BPCQ – Chance	–2.317	0.931	0.014
BPCQ – Powerful Doctors	–1.043	0.944	0.271
Hospital service use	0.552	.996	0.58
Allied therapy use	2.932	1.957	0.137
Co-morbidities	0.044	0.248	0.859
Logistic regression model for categorical variable			
	OR	95% CI	p value
Disease related knowledge	2.517	1.0– 6.3	0.049

BPCQ: Beliefs About Pain Control Questionnaire; OR = Odds Ratio; CI = Confidence Interval.

scale of the BPCQ ($B = -2.4$, $SE = 0.9$, $p = 0.01$), indicating that the mean belief that health outcomes are due to chance was 2.4 points lower in those with adequate HL, compared to those with inadequate HL. See Table 2 for further information on the regression analyses conducted.

Discussion

The current study established the prevalence of low HL at 54% (71/131) in patients with chronic pain. Low HL was associated with older age, having less education, lower monthly income and more comorbidities. Also, low HL was associated with poorer-disease related knowledge and beliefs about pain, and lower utilisation of non-emergency health services. In multivariate analysis poorer disease related knowledge and beliefs about pain control remained independently associated with low HL, in that the odds of having greater disease-related knowledge and more appropriate beliefs about pain control were over two times higher in the adequate HL group. No differences were observed between levels of HL and chronic pain status or quality of life, which is in contrast with studies investigating other chronic disease outcomes. For example, low HL was associated with poorer quality of life in individuals with asthma [26], and increased symptom severity in cardiovascular disease [27]. These findings reflect the heterogeneity observed in the literature regarding the impact of HL. Also, a recent systematic review by Edward *et al.* [28] that reported on the impact of HL on low back pain management found only three studies suitable for inclusion, thus further justifying need for additional studies to confirm our findings in establishing what role HL has in chronic pain outcomes. Furthermore, assessment of HL-sensitive interventions in chronic pain management are needed [29]. For example, the gold-standard treatment for chronic pain is the cognitive-behavioural pain management programme [30], of which only modest outcomes have been reported long term. In their Cochrane review Williams *et al.* [31] recommended that no further studies should be conducted on the efficacy of cognitive behavioural therapy,

but further research on why or how such interventions work. Perhaps the inclusion of HL strategies should be considered to address this gap in the literature.

Levels of HL as a potential facilitator or barrier for the development and maintenance of self-management behaviours is increasingly accepted [4]. Newman *et al.* [32] proposed three behavioural models to describe the acquisition of self-management behaviours in those with chronic diseases (i.e. The Common Sense Model, The Theory of Planned Behaviour, and Social Cognitive Theory), which are built upon three discrete patient characteristics; knowledge, beliefs, and self-efficacy respectively. Therefore, based on our findings, HL may indirectly influence the development and maintenance of self-management behaviours in chronic pain patients, via their disease-related knowledge and beliefs about pain control. Given that best practice guidelines for chronic pain management highlight education and self-management as key factors for optimum outcomes [1], the role of the healthcare professional in improving patients' knowledge about their condition and beliefs about pain control in terminology and language they understand is crucial [33]. However, despite the fact that the emerging central role of HL in healthcare has been highlighted at policy level in Europe [34] and in The USA [35], it is unclear if these policies have been implemented at frontline level. For example, healthcare professionals have been found to overestimate their patient's ability to understand health-related information [36], and this gap in patient-provider communication is thought to be associated with poor awareness of the prevalence and impact of low HL in healthcare settings (39). A lack of attention to training for healthcare professionals at both undergraduate and postgraduate level may explain this disparity [36], and if recent recommendations from the HL research community are taken on board – that is to shift the focus of HL management from individual level to a health service perspective [37], increasing training and resources for HL-sensitive interventions in healthcare settings is warranted. Physiotherapists are well-placed to address this, and implement HL-sensitive approaches to their practice to facilitate a greater understanding of chronic pain mechanisms, more positive attitudes and beliefs, and management strategies in their patients [38,39]. Exposure to HL-sensitive interventions at undergraduate level has been recommended for training the future physiotherapist in how to effectively educate patients to enable them to self-manage their condition [40,41].

In conclusion, low HL has been established in patients with chronic pain attending pain clinics in Ireland, which may impact on the development of self-management behaviours. However, due to the nature of cross-sectional design, caution must be taken when assuming direct causal relationships regarding the findings from the current study. Also, it is of note that quality of life and pain status (i.e. pain severity, limitations due to pain, and medication efficacy) were poor for most participants, regardless of levels of HL. It is unclear whether this reflects the limited range of treatments available for chronic pain, current provision of services in Ireland, or

the lack of chronic pain-specific HL assessment tools. Further research on the impact of HL in chronic pain, assessment of HL in a chronic pain population, and the efficacy of HL-sensitive interventions in demographic-matched populations is needed, to determine the pathways between HL and health outcomes in chronic pain patients.

Key messages

- This study establishes the prevalence of low health literacy in individuals with chronic pain using a validated health literacy tool.
- It investigates associations between HL and chronic pain status, as well as other outcomes such health behaviours, health service and medication utilisation, and quality of life, thus confirming the heterogeneous nature regarding the impact of low HL on these health outcomes – and the need for additional studies to confirm our findings.
- It identifies areas for further research regarding chronic pain management and the role that health literacy might have in enhancing interventions for chronic pain.
- It highlights the importance of health literacy in developing patient self-management strategies, and the need for HL to be addressed at undergraduate level in order for physiotherapists to be aware of this relationship.

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