Suggestions for a research agenda for Health Literacy and musculoskeletal health – reflections following a qualitative evidence synthesis

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Abstract

Objective: To conduct a qualitative evidence synthesis to explore patient education experiences of people with musculoskeletal conditions who also have lower levels of literacy.

Methods: The sources searched in December 2012 included the Cochrane Central Register of Controlled Trials, OVID MEDLINE, CINAHL (Cumulative Index to Nursing and Allied Health Literature), PsychINFO, ERIC (Educational Resources Information Centre) and EMBASE. Grey literature was searched using databases such as Mednar, MAGiC and ETHOS. Websites searched included government departments, charitable bodies, professional associations and some universities.

Results: A total of 365 titles and abstracts were found through the searches. There were only 28 records concerning MSK conditions and only 9 of these were literacy related. None of these were qualitative research exploring the needs and preferences for patient education of people with MSK conditions who had lower levels of literacy.

Conclusions: There has been no research inquiring into the information needs, experiences and preferences of people with musculoskeletal conditions who also have lower levels of literacy. A program of research is suggested in order to decrease the health disparities for people with lower levels of literacy by including their voice through qualitative research.

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Introduction

Health literacy can be defined as the social and cognitive skills that enable individuals to access, understand and use health information in a way that will promote their own health[1,2.] It is therefore a relevant concept for both health professionals and patients alike. Not only is the concept of health literacy relevant, there is also an urgent need to attend to the problems associated with lower health literacy to prevent the existing health disparities from becoming worse[3,4,5]. Lower health literacy predisposes an individual to poor health and unsatisfactory experiences with the health system and the health professionals within them[6.] And yet few UK health professionals consider their patients literacy levels[7].

Key words:
Rheumatoid Arthritis, Osteoarthritis, arthritis, musculoskeletal conditions, patient education, self-management, literacy, numeracy, health literacy, qualitative evidence synthesis.

Role of the funding source
This work was supported by Arthritis Research UK although the organisation played no part in the collection of data or reporting of the qualitative evidence synthesis.

Most of the research on health literacy emanates from the United States[2]; there has been minimal engagement with the concept of health literacy by health professionals in the UK in spite of the current UK government policy emphasis on increasing patient participation in health care[7-9]. This paper is concerned with a qualitative evidence synthesis that was conducted to explore health professional research on the perspectives of individuals who have a musculoskeletal condition and lower levels of literacy on written and electronic health information or patient education.

Patient education is considered an important component of the management of musculoskeletal conditions such as rheumatoid arthritis and osteoarthritis[10,11]. Health professionals advise patients on how to manage their pain, limited mobility and activities of daily living through regimes including medication, exercise, diet and assistive devices. In order of priority, musculoskeletal patients have identified pain, immobility, problems with social adjustment and emotional/psychological problems as being most pertinent to them[12]. Patient's perceptions of their arthritis symptoms do not always match the health professionals' perceptions therefore it is important not to rely on the assumptions of the health service providers[12]. Moreover, health professionals may not feel confident about delivering advice on pain relief or exercise[13] or there may be a knowledge gap in understanding different musculoskeletal conditions[14]. This is in spite of the high prevalence of musculoskeletal conditions whereby one in three GP consultations are concerned with advising patients on their care[15]. Within this context, service delivery issues relevant to individuals who have lower levels of literacy are rarely considered.

A recent systematic review identified six studies that tailored their patient education intervention to meet the needs of people with lower levels of literacy[16]. The outcomes within the randomised controlled trials included within the review focused on changes in knowledge, self-efficacy, and self-reported arthritis, in order to determine the effectiveness of the interventions. The studies were not designed for the participants to give their feedback and therefore didn't include their experiences nor their perspectives on the intervention. Other qualitative researchers have investigated the use of different modalities for delivering musculoskeletal information but none considered the literacy level of their sample or population[17-22]. While resources exist for delivering information about musculoskeletal conditions in plain language[23,24], these have not been linked to patient preferences nor are they widely utilized in health care in the UK.

Consideration of qualitative research on patient preferences and experiences is vital in order to include the patient voice in the healthcare setting[25]. Inclusion of qualitative research in a review is a way of moving beyond effectiveness reviews[26]. Qualitative reviews therefore acknowledge that patient education is a social process and one that is socially constructed, situated and relies on the contingent identity of both the health professional and patient[27,28]. Taking the constructed nature of patient education into account and including the patient voice within that account means that a more comprehensive approach is taken to knowledge production and legitimation within an interpretivist constructivist epistemology[29,30]. A more comprehensive approach to the review of qualitative research could open up different lines of inquiry[27] which may ultimately benefit patient outcomes through the improvement of health professional practice[28,31]. Therefore this study sought to explore the patient education experience of people with a musculoskeletal condition who also had a lower level of literacy.

Aim

The qualitative evidence synthesis considered any qualitative research that described, explored or analysed the patient education experiences of people with MSK conditions who also had lower levels of literacy according to a pre-defined protocol[32]. The synthesis also considered the perspective of patient carers.

Method

The research questioned "What are the experiences of patients with lower levels of literacy and musculoskeletal conditions in all healthcare settings about patient education they receive from health professionals about managing their musculoskeletal condition?"
The SPICE[33,34] format was used for the development of the research question, inclusion and exclusion criteria, and MeSH headings.
Setting – Primary, secondary and tertiary care
Perspectives – Patients with lower levels of literacy and a musculoskeletal condition or their carers
Interest – Patient education for musculoskeletal conditions
Comparison – Not applicable
Evaluation – Experiences, needs, preferences, perceptions

Data Sources and Selection

The sources searched in December 2012 included the Cochrane Central Register of Controlled Trials, OVID MEDLINE, CINAHL (Cumulative Index to Nursing and Allied Health Literature), PsychINFO, ERIC (Educational Resources Information Centre) and EMBASE. Grey literature was searched using databases such as Mednar, MAGiC and ETHOS. Websites searched included government departments, charitable bodies, professional associations and some universities. The MeSH headings were developed by a technical expert panel with expertise in health literacy and qualitative evidence syntheses (JA, CB, WL, RP).

Inclusion Criteria

The inclusion criteria were developed using the Population Intervention Comparison Outcome (PICO) system[32] (Appendix 2) from the systematic review[16] in order to provide consistency between both the qualitative evidence synthesis and a related systematic review for inclusion/exclusion criteria[16]. The components were then translated into the SPICE[33,34] system for qualitative reviews as demonstrated above. An inclusion grid was developed and used to include/exclude journal articles. Two independent reviewers identified research that met the inclusion criteria. A third reviewer (JP) was available for arbitration on unclear inclusion/exclusion issues.

Data Extraction and Quality Assessment

A structured analysis of qualitative research (SAQR) tool was developed from existing qualitative review tools prior to conducting the review[27,35-37]. Two independent reviewers agreed by consensus the methodological design of the different research papers. A third reviewer (JP) was available for arbitration. The SAQR tool included all the components of the Joanna Briggs Institute tool of qualitative review35. In addition, the SAQR analysed how the qualitative research was constructed and considered the location of the research object within the field or context of the study[27]. The SAQR tool collected information on the theoretical framework, methods, data collection and analysis, ethics, and policy and practice implications. The reflexivity[27-29] of both the researcher(s) and the reviewer(s) formed the final part of the review tool. The reason for including this double loop of reflexivity was to make explicit the assumptions and theoretical knowledge that the researcher(s) and the reviewer(s) bring with them and how this may affect the review process[30].

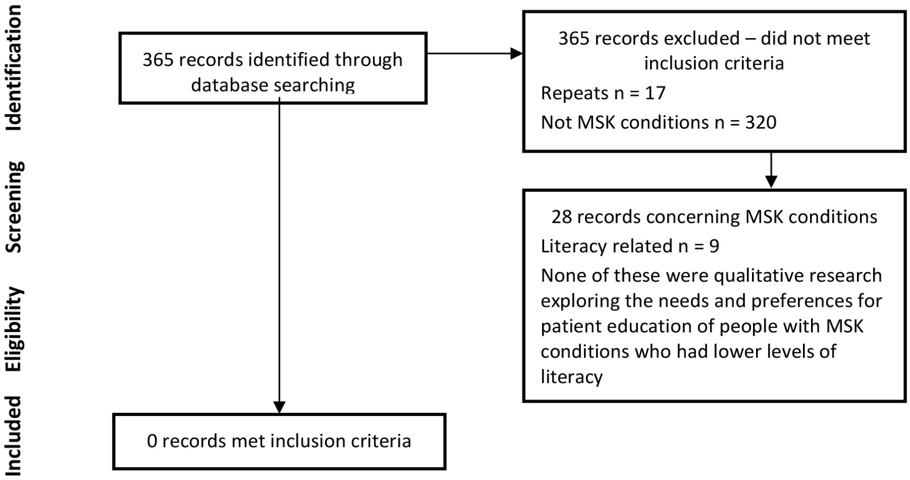

Fig 1. Study Flow Diagram [38]

Data Synthesis and Analysis

The data were to be synthesized from the extraction and quality assessment forms using a summary table of features. However, this did not prove necessary as no papers were identified as meeting the inclusion criteria from the review.

Results

A total of 365 titles and abstracts were found through the searches. The study flow diagram shows the process of inclusion/exclusion for the qualitative evidence synthesis.

The majority of articles were not concerned with MSK conditions. Of the few that were concerned with MSK conditions, only nine explored health literacy or literacy. These studies were not qualitative research and therefore did not ask or record the needs or preferences of patients with lower levels of literacy in relation to MSK patient education and information. There were many more studies exploring literacy and patient education for other chronic diseases such as asthma, cardiovascular disease and diabetes. These findings are relevant to the following discussion on musculoskeletal conditions.

Discussion

The extent to which health literacy and literacy levels have been reported in musculoskeletal patient education interventions, including self-management, by health professionals or peers is nil. Reported clinical models of musculoskeletal patient education tend to focus on a few of the individual's medical characteristics rather than how their program is tailored to that individual. This medical focus on the part of health professionals may contribute to a lack of translation of health advice to patients' lives and so compromise the effectiveness of musculoskeletal patient education interventions in engaging people with lower levels of literacy to sustain desired behaviour change or self-management strategies in musculoskeletal conditions.

Patient literacy needs and preferences have been collected for those with conditions (for example, asthma[39], cardiovascular disease[40], hypertension and diabetes[41] as well as cancer[42]) other than musculoskeletal ones. The findings of research from other clinical areas are relevant because they represent the patient voice of this particular group within healthcare. Qualitative research has shown that accessing healthcare for lower literacy adults is a problem because of the lack of recognition and denial of reading problems acts as a barrier to effective care[42]. Patients try to avoid medical care or hide their lower literacy and find the experience stressful because they feel anxious[42]. The emotional impact of accessing healthcare could represent a significant need and experience that requires consideration by health professionals[42-46].

Using health information relies on the motivation as well as the cognitive and social skills of individuals[1]. These may well be altered by individuals' different expectations and priorities in relation to their health. For example, a group of vulnerable older adults (lower health literacy, lower education and lower socioeconomic status) demonstrated a different set of health promotion priorities from people with higher health literacy, education and socioeconomic status[47]. These individuals gave priority to being comfortable, getting rest and eliminating pain[47]. They had low health and life expectations. The main message they took from health care encounters was to take their medications above everything else[47]. Whilst this research was not specifically aimed at people who had musculoskeletal conditions, the findings did relate to pain which is a common musculoskeletal symptom. These differences may not yet be reflected in the theory, interventions and evidence base for patient education interventions.

While it is clear that musculoskeletal pain and its treatment provide an imperative[48] for health professionals to develop strong theories, interventions and evidence base; the way forward in engaging individuals as active partners in their care or self-management is not so clear. Promoting behaviour change is a complex challenge for individuals who may well struggle with a multitude of factors as well as a musculoskeletal condition[49-51]. Whilst seven key abilities for health literacy have been identified by patients including knowing when and where to seek health information, verbal communication and assertiveness, literacy skills and the capacity to process, retain and apply information[51], these perspectives are not always translated across to the multitude of printed consumer health information leaflets[52] and patient education programmes. Moreover, patients may not always read these leaflets[53] or health professionals may not engage with relevant guidelines on patient education[54]. There is hope that by raising awareness of disease symptoms and treatment options, attending to symptoms earlier and educating the public about risk factors such as obesity, ageing and genetics that what was previously believed to be an inevitable decline in musculoskeletal health, can be reversed[55.] Understanding the perspectives of individuals who have a musculoskeletal condition is vital in order to develop effective patient education interventions.

Musculoskeletal patient education interventions have not been effective in part due to the limited engagement of health professionals involved in delivering them[56,57]. The limited engagement on the part of health professionals may be due to a number of reasons including a lack of confidence in delivering patient education[13] and a limited understanding and application of their role as health promoting practitioners[58,59.] While many reasons have been posited for the lack of transformation of health services into health promoting organisations[59], one of the core gaps occurs in the training of health professionals where health literacy tends not to be mentioned. As a consequence, patients with lower levels of health literacy are generally not considered during the development of interventions. This could be one of the main reasons why the health literacy of their patients may not occur to health professionals in the research literature.

The lack of information on health literacy at the research and curriculum level could be due to the fact that the concept of health literacy is relatively new and still evolving[1]. Health literacy could sit well within communication skills curricula where use of the concept could encourage a patient centred approach. More basic research is required to develop effective theories and frameworks for implementations of health literacy interventions in relation to musculoskeletal patient education[60]. There is a demand for tailored patient education: patients have consistently emphasized the need for health professionals to tailor information to patient needs and preferences by using different formats to assist understanding[51]. However, it could be that the current model of health professional education does not provide the basis for effective patient education.

Suggestions for a research agenda could therefore include:

- Development of effective theories and frameworks for implementations of health literacy interventions in relation to musculoskeletal patient education[61] through:
- Better understanding of causal pathways including epidemiology and associations with lower levels of health literacy and musculoskeletal conditions[61];
- Development of educational tools that can be integrated with routine care61;
- Understanding how to engage patients with lower levels of literacy in their musculoskeletal care[61];
- Development of interdisciplinary collaborative research that draws on the strengths and unique role of each different disciplines[61]; and
- Embedding health literacy concepts and research in undergraduate and postgraduate health professional training.

Conclusion

There has been no research inquiring into the information needs and preferences of people with musculoskeletal conditions who also have lower levels of literacy. A program of research is suggested in order to decrease the health disparities for people with lower levels of literacy. It is vital to include the patient voice through the use of qualitative research on patient education before developing patient education programs and health professional curricula.

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Appendix 1

Qualitative evidence synthesis search strategy 8/12/2012
MEDLINE
s1. Arthritis, Rheumatoid+/
s2. Osteoarthritis+/
s3. rheumat*
s4. reumat*
s5. arthrit*
s6. artrit*
s7. disease*
s8. condition*
s9. nodule*
s10. s3 or s4
s11. s5 or s6 or s7 or s8 or s9
s12. s10 w3 s11
s13. osteoarthr*
s14. degenerative w2 arthritis
s15. Health Literacy/
s16. literac*
s17. literate*
s18. illitera*
s19. Reading/
s20. Educational Status/
s21. Mathematics
s22. numera*
s23. numerical
s24. skill* or problem* or difficult* or understand*
s25. s23 w2 s24
s26. Patient Education/
s27. patient or consumer
s28. educat*
s29. S27 n2 s28
s30. Health Promotion+/
s31. health promot*
s32. Behaviour Therapy+/
s33. therap*
s34. behave* or exercise or occupational
s35. s33 n s34
s36. Self Care+/
s37. care or management
s38. Self
s39. s38 n s37
s40. Adaptation, Psychological+/
s41. Experience/
s42. subjective*
s43. mean*
s44. Perception OR Thinking+/
s45. cope or coping
s46. psychological behav*
s47. adapt* or adjust*
s48. s46 n s47
s49. PT Qualitative
s50. Qualitative
s51. Qualitative Research/
s52. focus group*
s53. interview*
s54. participat*
s55. mixed method*
s56. case stud*
s57. narrative*
s58. s1 OR s2 OR s3 OR s4 OR s5 OR s6 OR s7 OR s8 OR s9 OR s12 OR s13 OR s14
s59. s15 OR s16 OR s17 OR s18 OR s19 OR s20 OR s21 OR s22 OR s25
s60. s26 OR s29 OR s30 OR s31 OR s32 OR s35 OR s36 OR s39 OR s40
s61. s41 OR s42 OR s43 OR s44 OR s45 OR s48
s62. s49 OR s50 OR s51 OR s52 OR s53 OR s54 OR s55 OR s56 OR s57
s63. s58 AND s59 AND s60 AND s61 AND s62
s64. s58 AND s59 AND s60 AND s61 AND s62 Limiters – English Language; Age related: All adult: 19+ years

Appendix 2

Inclusion criteria

(a) Research of adults (aged 16 and over) with a diagnosed musculoskeletal condition that matches the American College of Rheumatology (ACR) criteria. This MSK condition may be acute or chronic and people may be receiving current active treatment or not.

(b) Qualitative research including mixed methods, using interviews or focus groups, where participants' literacy levels had been recorded and reported in the format of either (i) a standardized validated scale such as the REALM, TOFLA or Newest Vital Sign; or (ii) a proxy indicator such as level of formal education and/or socioeconomic status.

(c) Research of people who received surgery for their MSK condition.

(d) Research of people identified through primary, secondary and tertiary care.

(e) National and international studies.

(f) Research of participants with multiple pathologies and trials where participants' MSK is a primary or secondary diagnosis i.e. co-morbidity.

(g) Research with participants living independently and those living in residential settings

Exclusion criteria

(h) Research of participants with cognitive or neurological impairments or a learning disability.

(g) Research of participants for whom English is a second language. That is, trials where the spoken language affected literacy.

HELISK Qualitative Evidence Synthesis Marking Grid

Study No.	OA	RA	Other MSK	Literacy	Pt Education/Info Intervention Meanings & Experiences			IN	OUT
					Qualitative	Interviews Focus Groups	Mixed Methods		