TITLE PAGE

# Title: 'Self-management skills in chronic disease management: what role does health literacy have?'

Authors: Laura M. Mackey BSc (Hons)[1]; Dr. Catherine Doody[1]; Dr. Erik L. Werner[2,3]; Dr. Brona Fullen[1].

1. University College Dublin, Belfield, Dublin 4, Ireland.

2. Research Unit for General Practice, Uni Health, Bergen, Norway.

3. Department of General Practice, Institute of Health and Society, University of Oslo, Norway.

Corresponding Author:

Laura M. Mackey

A312 Postgraduate Office, Health Sciences Centre, University College Dublin, Belfield, Dublin 4, Ireland.

Email: lauramackeyphysio@gmail.com.

Phone: +353 86 8394413

Abstract Word Count: 275

Article Text Word Count: 3614

Keywords: health literacy, chronic disease, self-management, self-efficacy, beliefs.

# ABSTRACT

Background:

Self-management based interventions can lead to improved health outcomes in people with chronic diseases, and multiple patient characteristics are associated with the development of self-management behaviors. Low health literacy (HL) has been implicated in poorer self-management behaviors and increased costs to health services. However, the mechanisms behind this relationship remain unclear. Therefore, the aim of the current review is to assess the association between HL and patient characteristics related to self-management behaviors (i.e. disease-related knowledge, beliefs, and self-efficacy).

Methods

The review comprised three phases: (i) database searches, (ii) eligibility screening, and (iii) study quality assessment and strength of evidence. Inclusion criteria specified that a valid HL screening tool was utilized, that at least one self-management behavior was assessed, and that patients had a chronic condition.

Results

An initial search generated a total of 712 articles, of which 31 studies fulfilled the eligibility criteria. A consistent association was found between low HL and poorer disease-related knowledge in musculoskeletal and renal diseases, diabetes, and multiple disease categories. A significant association between low HL and poorer self-efficacy was reported in in cardiovascular diseases, diabetes,

HIV, and multiple disease categories. HL was significantly associated with poorer beliefs in respiratory, musculoskeletal, and cardiovascular diseases.

Discussion

The findings from the current review suggest that low HL may impact on behaviors necessary for the development of self-management skills. Given that self-management strategies are core components for effective treatment of a range of chronic diseases, low HL poses a considerable health concern. Further research is needed in order to understand the mediating influence of HL on disease-related knowledge, self-efficacy, and beliefs. From this, HL-sensitive, self-management interventions ought to be devised and implemented.

# 1. INTRODUCTION

It has been established that self-management strategies can result in improved health outcomes, particularly for those with chronic diseases (1). Self-management is defined as 'the ability of an individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, and lifestyle changes' (2). The development of chronic conditions such as cardiovascular disease and diabetes is largely associated with unhealthy lifestyle behaviors (3, 4), and have surpassed infectious diseases as the leading causes of mortality worldwide (2, 5). A consequence of the traditional biomedical approach has resulted in patients often having a passive role in their healthcare choices (6), which has been proven to be less effective in treating such 'lifestyle acquired' conditions (7). Managing chronic conditions requires individuals to choose healthier behaviors of their own volition, and self-manage using a skill-set developed through information and support obtained from various educational and healthcare resources (8). Much research exists on a variety of self-management based interventions, such as disease-related education sessions, and community initiatives (3, 8). However, the effectiveness of these interventions is mixed (2, 9), and further research on potential facilitators and barriers to attaining self-management skills is required.

More recently, researchers and policy makers have identified health literacy (HL) as a potential facilitator or barrier to improved health outcomes (10-12). HL is defined as 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (13). Low HL has been linked to health outcomes such as poorer quality of life (14), increased emergency service use and mortality risk (15), which results in an increased burden on health budgets worldwide (16). Furthermore, low HL is associated with poorer health-related behaviors - namely self-management skills (17-19). However, despite the myriad of research in this area, the causal pathways behind this association remains unclear, and current recommendations from the literature suggest that further investigation is warranted (20, 21).

Deconstructing self-management may provide a basis for understanding how HL influences the development and maintenance of self-management behaviors. Newman et al (22) proposed three models which describe the development of self-management behaviours in those with chronic diseases – The Common Sense Model (CSM) by Leventhal et al (23), Bandura's Social Cognitive Theory (SCT)(24), and Ajzen's Theory of Planned Behavior (TPB)(25). At the foundation of these models are three distinct patient attributes – knowledge (CSM), self-efficacy (SCT), and beliefs (TPB), and previous literature corroborates the importance of these attributes combined for effective self-management (8, 26-30). For example, disease-related knowledge is integral to actively engaging in decision-making processes (26, 27), and is key to understanding health markers for disease control – a fundamental component of self-management (29, 30). In addition, poorer beliefs can result in poorer adherence to self-management strategies (28), whereas improving self-efficacy levels in patients can result in increased confidence in making lifestyle changes, which is inherent to self-management (8).

To date, no review has considered the impact of HL on factors associated with self-management behaviors, as described by these three behavioral models. Interestingly, a HL model developed by Passche-Orlow and Wolf (21) describes possible causal pathways between HL and health outcomes, highlighting knowledge, self-efficacy, and beliefs as mediating factors (Figure 1). Therefore, the current review aims to investigate the impact of HL on self management skills, with reference to the initial stages of behavioral change, as described by the CSM, SCT, and TBP - i.e. disease-related knowledge, self-efficacy, and attitudes and beliefs.

# 2. METHODS

## 2.1. Overview

The review comprised three phases: (i) a systematic search of the literature, (ii) study selection and data extraction, (iii) quality assessment of papers, and grading the strength of evidence.

### *2.1.1. Phase (i): Search Strategy*

Chronic non-malignant diseases were included based on two reports by The World Health Organisation. The first included the top 10 diseases of greatest mortality risk, reporting cardiovascular diseases, diabetes, HIV, and respiratory diseases among the leading causes of death worldwide (5). The second report ranked cardiovascular diseases, respiratory diseases, diabetes, renal diseases, and musculoskeletal diseases highest in terms of global burden of disease (31). From this initial inclusion criterion, keywords were chosen and reviewed by two researchers (L.M.M., B.M.F.), and a database thesaurus was developed and used where possible (see appendix). A search string of keywords was generated and electronic searches of PUBMED, CINAHL, EMBASE, Cochrane Central Register of Controlled Trials (Central), and PEDro were conducted (inception – November 2013), and additional hand searches were conducted where suitable. The search was subsequently updated up to June 2015.

### *2.1.2. Phase (ii): Study Selection and Data Extraction*

Potentially relevant articles were identified from the titles, abstracts and keywords provided, and were scrutinized by two researchers (L.M.M., B.M.F). It was not necessary to include a third reviewer, as there were no disagreements regarding the selection of appropriate studies. The full papers of accepted abstracts were retrieved, and relevant data were extracted using a detailed proforma developed to capture, and subsequently categorize the methodology and results of each paper. Initial inclusion criteria specified that studies were written in English, were observational in design (cross-sectional, longitudinal/cohort), included adults only (>18 years), that a validated HL tool was utilized, and that patients had at least one chronic condition. In addition, only papers that included assessment of at least one of the following were included in the current review: disease-specific knowledge, self-efficacy, and beliefs. In the revised search (i.e. to June 2015), the search extended to interventional studies (experimental, randomized control trials), to allow for potential causal relationships to be assessed. Accepted papers were categorized by chronic condition.

*2.1.3. Phase (iii): Quality assessment and Strength of Evidence*

The Effective Public Health Practice Project (EPHPP) quality assessment tool was chosen to assess the quality of eligible articles (32). This tool has been identified as one of the most appropriate for assessing both randomised control trials (RCTs) and non-RCTs (33), and has been used in 29 previous systematic reviews (34). The tool comprises six components that are rated as strong, moderate, or weak (see Table 1 for detailed information). The studies included in the current review were split evenly between all authors, with L.M.M. and C.D. co-reviewing the first half, and B.M.F. & E.L.W co-reviewing the remainder. No disagreements occurred regarding the quality appraisals. From this, the strength of evidence

(Level A to E) was reported using The Agency for Health Care Policy and Research (AHCPR) Guidelines (35). To calculate the strength of evidence, the consistency between findings from included studies was assessed (i.e. a consistent association was allocated when findings from all studies were in agreement, whereas an inconsistent association was allocated when findings from included studies were conflicting). Then the quality ratings of studies were considered before a final strength on evidence was graded. Minor amendments were made to include a Level B category for trials of moderate quality (36) (see Table 2 for further information).

# 3. RESULTS

## 3.1. Overview

In total 31 papers were included in the current review: cross-sectional (n=24), cohort/longitudinal (n=4), and randomized control trials (RCT) (n=3). Details of the search strategy are summarized in Figure 2.

Seven chronic disease categories were included: cardiovascular, respiratory, renal, musculoskeletal, HIV, diabetes, and multiple diseases. HL was assessed in primary care (n=10), tertiary care (n=13) and community settings (n=8), and six validated HL tools were utilized: The Short Test of Functional Health Literacy (s-TOFHLA) (37), The Rapid Estimate of Adult Literacy in Medicine (REALM) (38), The Test of Functional Health Literacy (TOFHLA) (39), The Newest Vital Sign (NVS) (40), the Korean TOFHLA (41), and The Three-Item Literacy Questionnaire by Chew et al (42). Studies varied in how they presented HL data, with some reporting HL as two categories (i.e. adequate or inadequate), or three categories (i.e. adequate, marginal, or inadequate). Furthermore, HL levels were most commonly described in percentages, although some studies provided mean and standard deviation values.

Included studies were rated as: strong (n=6), moderate (n=12), or weak (n=13), none of which were excluded on the basis of quality, as all provided sufficient information to be assessed by the EPHPP tool. Most studies utilized multivariate analyses, controlling for various demographic factors such as race, education and income. Three studies included structural equation modeling to further investigate potential mediating relationships between HL and health outcomes. The study methodologies and findings are summarized in Table 3.

3.2. Respiratory Diseases

Three studies assessed the impact of HL on asthma (43, 44), and COPD and asthma (45).

*3.2.1. Knowledge*

Two studies found a consistent association (Level B) between low HL and lower disease-related knowledge (44, 45). Mancuso and Rincon found a correlation between lower HL levels and poorer scores on the 'Check Your Asthma IQ' knowledge assessment tool, with bivariate analysis ($r=0.39$, $p<0.0001$). Those with low HL were significantly less likely to correctly answer questions about asthma, for example, that breathing problems are dangerous (89% vs. 66%, $p=0.003$), and people with asthma should exercise (95% vs. 75%, $p=0.001$). The second study (45) found that HL remained the strongest predictor if asthma knowledge in multivariate analysis (adjusted diff. -1.1, CI 95% -1.7, -0.5, $p<0.001$).

*3.2.2. Beliefs*

One study (43) found that lower HL was associated with suboptimal beliefs about asthma (Level D), i.e. no symptoms–no asthma: 60% adequate HL versus 34% inadequate HL ($p = 0.01$); asthma is temporary: 23% versus 9% ($p = 0.07$); asthma is curable: 54% versus 25% ($p = 0.004$); medication works better if not used all the time: 44% versus 21% ($p = 0.03$).

*3.2.3. Self-Efficacy*

One study found no correlation between HL and patient self-efficacy (Level D), with bivariate analysis (r=0.05, p=0.66) (44).

3.3. Musculoskeletal Diseases

Six studies assessed HL and its impact on those with musculoskeletal diseases: chronic pain (46), rheumatoid arthritis (47, 48), osteoporosis (49), chronic low back pain (50), and osteoarthritis (51)

*3.3.1. Knowledge*

There was inconsistent evidence from three studies (Level D) that HL and disease-related knowledge were associated (46, 48, 49). One paper (46) found that after controlling for race, education, and income, that chronic pain patients with higher HL had better knowledge about over-the-counter medications, alternatives to medication for pain management, and knowing where to get medical assistance (F change (1,70) = 4.48, p=0.038) - overall, HL explained 36% of variance in medication knowledge. The second reported that HL was independently associated with arthritis knowledge (B=0.266, p=0.002) (48). However, Levinson et al (49) found no association between HL and osteoporosis knowledge (p>0.05). It is noteworthy that 97% of participants in this study had adequate HL.

*3.3.2. Beliefs*

There was inconsistent evidence from two studies (47, 50) regarding the impact of HL on beliefs in people with musculoskeletal diseases (Level D). One paper reported that HL and disease specific beliefs such as fear avoidance and catastrophizing were not associated ($p>0.05$) (50). However, all participants in this study had adequate levels of HL as measured by the S-TOFHLA, therefore, making comparisons between HL levels difficult. Martin et al (47) found that low HL was associated with greater risk perceptions regarding disease modifying anti-rheumatic drugs ($B=0.82$, $p<0.01$), and therefore, a reduced willingness to take these medications in rheumatoid arthritis patients ($B=0.86$, $p<0.01$).

#### *3.3.3 Self-efficacy*

One RCT found that changes in self-efficacy post intervention were not associated with baseline HL (51).

### 3.4. Cardiovascular Diseases

Fifteen papers assessed the impact of HL in cardiovascular diseases: heart failure (52-57), hypertension (58-62) stroke (63, 64), and general cardiovascular diseases (65, 66).

#### *3.4.1. Knowledge*

Disease-related knowledge was assessed using both validated and non-validated tools, with the majority focusing on patients' knowledge regarding medications and disease characteristics. Of the 15 papers included, an inconsistent association (Level D) between low HL and poorer knowledge was found (52-66). All but one paper (53) reported a significant association between HL and disease-related knowledge. Hwang et al (53) identified barriers and factors to promoting self-care in health failure patients utilising analysis of variance methods. They stratified the sample into four different groups based on knowledge and self-care levels (see table 3), finding no differences in HL levels ($p=0.59$). One study reported bivariate findings only (56), finding that lower HL was associated with poorer dietary sodium knowledge in patients with heart failure. A further two studies utilized analysis of variance methods, with one (54) finding a significant association between low HL and poorer heart failure knowledge scores ($F(2,92)=12.7$, $p<0.001$), and the other (57) reporting that HL predicted 27% of variance in stroke education recall ($B=0.53$, $p<0.01$). Two studies (52, 59) utilized structural equation modeling to explain potential mediating pathways between HL and disease-related knowledge. Chen et al (52) found HL predicted 36.6% variance in knowledge as assessed by The Heart Failure Knowledge Questionnaire ($B=0.46$, $p<0.05$). Whereas Osborn et al (59) assessed knowledge using a set of questions derived from a validated questionnaire, and reported a 5% variance in knowledge according to HL ($B=0.22$, $p<0.001$). The remaining papers analyzed data using multivariate regression techniques (55, 60-64, 66), reporting significant associations. One paper (64) found conflicting results regarding patients' stroke knowledge - that while HL did not impact on patients knowing why they take warfarin (AOR 2.2, 95% CI 0.8-5.7), it was associated with discordant stroke perceptions (i.e. when asked 'what is a stroke') (AOR 5.8, 95% CI 2.1-15.6), after controlling for demographic factors. Two RCTs found that while HL scores was not associated with improvements in disease-related knowledge, participants in both studies showed improvements in post-test knowledge scores after completing a HL-sensitive intervention, regardless of baseline HL. In contrast, one of the RCTs found no improvements in knowledge scores for participants assigned to the control group, regardless of HL (i.e. usual care).

*3.4.2. Self-efficacy*

Three papers reported on the relationship between HL and self-efficacy with conflicting results (Level D). Macabasco et al (55) found that patients with higher HL also had higher self-efficacy levels regarding the management of their condition (adjusted diff. 0.99, 95% CI 1.55-0.43, $p=0.01$), whilst the other papers found no association (59). Similarly, the third paper found that HL was neither directly ($B=0.19$, $p>0.05$) or indirectly ($B=0.02$, $p>0.05$) associated with self-efficacy levels (52).

*3.4.3. Beliefs*

Hwang et al (53) found a significant correlation between low HL and beliefs about the degree of control patients have regarding their condition ($r=0.095$, $p<0.05$).

<u>3.5. Diabetes</u>

Three studies assessed the impact of HL in diabetes patients (62, 67, 68).

*3.5.1. Knowledge*

Two papers found a consistent association (Level C) between patients HL scores and disease-related knowledge (62, 68). One paper found that after controlling for demographic variables, HL significantly predicted diabetes knowledge (p<0.001) (62). The other paper found that despite patients attending a diabetes education class, repeat analysis at three months found that those with lower HL had significantly lower diabetes knowledge (19.9±0.51 vs. 18.0±1.08, p<0.001) (68).

*3.5.2. Self-Efficacy*

One paper found that patients with higher HL had more self-efficacy regarding diabetes self-care using structural equation modeling (r=0.14, p<0.01) (67).

<u>3.6. Renal Diseases</u>

One study reported on the impact of HL on kidney transplant knowledge (69), finding no association between HL and knowledge (p>0.05) (e.g. 'do they know what a transplant is') with bivariate analysis. Whereas a second study found that low HL was independently associated with poorer knowledge of chronic kidney disease (B=-0.21, -0.36.-0.06; p=0.006) in adjusted analysis (70), (Level D).

<u>3.7. HIV</u>

One study (71) assessed the impact of HL in HIV patients, and multivariate analysis found that low HL significantly predicted self-efficacy levels (AOR 5.8, 95% CI 2.0-15.7) and disease-related knowledge, as assessed by the subsequently validated 'Brief Estimate of Health Knowledge and Action' questionnaire (72) (AOR 2.4, 95% CI 2.2-2.6), (Level D).

<u>3.8. Multiple Chronic Diseases/Multi-Morbidity</u>

Three studies investigated the impact of HL on multiple chronic diseases collectively (62, 73, 74). Conditions included cardiovascular, respiratory and musculoskeletal diseases, and diabetes. One study (62) reported on conditions separately (i.e. diabetes and hypertension), and therefore, were included in the diabetes and cardiovascular results sections respectively.

*3.8.1. Knowledge*

Gazmararian et al (74) found that patients' level of HL was independently associated with knowledge of chronic disease (Level D), after controlling for demographic factors ($p<0.001$).

*3.8.2. Self-Efficacy*

One paper reported that HL indirectly affected physical and mental health via self-efficacy ($B=0.41$, $SE=0.13$, $p=0.001$), as measured by The General Self-Efficacy Scale (73).

# 4. DISCUSSION

## 4.1. Overview

The current review assessed the impact of HL on characteristics associated with self-management, in the most prevalent and costly chronic diseases (5, 31). Three distinctive characteristics that are considered core to supporting self-management, via well-established behavioral models were evaluated - disease-related knowledge (CSM), self-efficacy (SCT), and beliefs (TPB). The findings were based on 31 studies, the majority of which were reported as either moderate or weak quality. Out of 25 studies that reported on the relationship between low HL and poorer disease-related knowledge, all but one reported significant findings. In addition, four out of eight papers found a significant association between low HL and poorer self-efficacy, and three out of four studies found an association between low HL and beliefs. According to the proposed behavioral models outlined by Newman et al (22), possessing such attributes is key to the development of self-management abilities, particularly for the conditions included in the current review. Therefore, these findings highlight a potential deleterious association between HL and self-management. As most best practice guidelines for chronic conditions support the use of self-management, it is vital to understand the behavioural processes required to ensure patients adopt these practices.

Deconstructing health behaviors associated with self-management may highlight further areas for Departments of Health to further incorporate the concept of HL as part of public health campaigns, to support engagement in self-management practices. Several countries have initiated such programmes, e.g. the U.S. National Action Plan to improve Health Literacy (12); the Scottish 'Making it Easy: A health literacy Action Plan for Scotland' (75); and Ireland's 'Health literacy and Primary Care' (76). A study by Kiser et al (77) assessed the effectiveness of a HL-sensitive, self-management intervention with chronic obstructive pulmonary disease patients, finding that self-management practices significantly improved, regardless of HL levels. Similar findings have been reported in studies assessing HL-sensitive interventions in diabetes (78) and hypertension (79). Therefore, self-management interventions that are HL-sensitive may not only improve health outcomes for patients, but may also have a positive impact on healthcare cost. Currently in the U.S.A, the cost of poor HL is between 3-5 per cent of the health budget a year (16). Additional expenditures per year for each person with limited HL compared to an individual with adequate HL range from $143 to $7,798. In England, the NHS budget is £95.6 billion (80) - a saving of 3-5 per cent from adequate patient HL would be in the range of £2.87 billion to £4.78 billion – equivalent to the whole of the current skills budget for England and Wales (81).

## 4.2 Main Findings

### *4.2.1. Knowledge*

While the majority of studies that assessed the relationship between low HL and poorer disease-related knowledge reported a significant association, not all disease categories had multiple papers from which conclusions could be drawn. Also, methods of assessment varied between studies, as a range of both validated and non-validated tools were utilized. This made synthesizing data between studies difficult, and could also explain the conflicting reports regarding the impact of HL on disease-related perceptions (82). Furthermore, only two studies investigated the mediating effect of HL on disease-related knowledge and development of self-management skills (52, 59), despite previous reviews highlighting the need for more in-depth studies that investigate causal pathways between HL and self-management (20, 83). Future research should include newly developed disease-related knowledge assessment tools, that are validated in a range of chronic conditions, e.g. COPD (84), cardiovascular diseases (85), and diabetes (86).

#### *4.2.2. Self-efficacy, and Beliefs*

Few studies included self-efficacy and beliefs in their assessments. Four out of seven studies reported that those with higher HL had more self-efficacy, and three out of four studies reported that patients with lower HL had suboptimal beliefs, regarding the management of their condition. While these characteristics are posited in SCT and the TPB models as fundamental to behaviour change, and have been implicated in poorer health outcomes (87, 88), their relationship with HL is limited given the findings from the current review.

### 4.3 Limitations

The findings of the current review must be considered with the following limitations in mind. Only studies written in English were included, and as the majority of these studies were cross-sectional in design, caution must be taken when assuming direct causal relationships. In addition, 13 papers were rated as weak according the EPHPP quality assessment tool. Lastly, given the heterogeneity of the studies included, it was not possible to categorize the results section by self-management characteristics, as the findings were not generalizable to all chronic diseases included.

### 4.4. Conclusions

The literature suggests that there is an association between HL and self-management skills. However, more robust research, particularly studies with interventional components is needed, to understand the direction and magnitude of the relationship between HL and disease-related knowledge, self-efficacy, and beliefs. More importantly, HL researchers should consider utilising HL frameworks (e.g. Passche-Orlow and Wolf), to gain a greater appreciation of the mediating influence of HL on health outcomes. This may serve as a more accurate method of analysis, as the use of multivariate regression techniques risks 'over-adjustment' - given that HL may develop from a range of patient demographics and attributes. Techniques such as structural equation modeling as utilized by Chen et al (52) and Osborn et al (67), or mediational analysis techniques conducted by Wolf et al (71), may provide more accurate representation of the impact of HL on self-management behaviors.

### 4.5. Practice Implications

Low HL can be difficult to detect and it can be embarrassing for patients, leading to further stigma and unwillingness to attend or seek out health services. Previous research found that HL-sensitive interventions resulted in significant improvements in self-care practices, regardless of HL levels. Therefore healthcare professionals should consider adopting HL-sensitive interventions, regardless of their patients' backgrounds. Furthermore, as outcomes from typical education based interventions have been reported as modest or inconclusive, HL must not be solely viewed as a patient issue, but must be addressed holistically by health services, ensuring disease-related knowledge is disseminated efficiently, that discordant beliefs regarding chronic diseases are eliminated, and that self-efficacy levels are improved or maintained. A HL-sensitive approach may foster an environment that promotes patient empowerment, which could ultimately lead to improved adherence to self-management strategies.

## 5. ACKNOWLEDGEMENTS

The authors wish to thank Mundipharma for an unrestricted educational grant.

## 6. CONFLICT OF INTEREST

The authors do not have any conflicts of interest to disclose.

# 7. REFERENCES


1. Ruiz S, Brady TJ, Glasgow RE, Birkel R, Spafford M. Chronic condition self-management surveillance: what is and what should be measured? Prev Chronic Dis. 2014;11.
2. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. J Nurs Scholarsh. 2012;44(2):136-44.
3. Dufour SP, Graham S, Friesen J, Rosenblat M, Rous C, Richardson J. Physiotherapists supporting self-management thorugh health coaching: a mixed methods program evaluation. Physiotherapy Theory and Pracctice. 2014;1:1-10.
4. Fortin M, Haggerty J, Almirall J, Bouhali T, Sasseville M, Lemieux M. Lifestyle factors and multimorbidity: a cross sectional study. BMC Public Health. 2014;14.
5. WHO. World Health Organisation The top 10 causes of death. Factsheet No.310. (Accessed 2014). Available from: http://who.int/mediacentre/factsheets/fs310/en/.
6. WHO. Adherence to long-term therapies - evidence for action (see annex section) 2003 (Accessed 2014). Available from: http://www.who.int/chp/knowledge/publications/adherence_report/en/.
7. Walker JG, Jackson HJ, Littlejohn GO. Models of adjustment to chronic illness: using the example of rheumatoid arthritis. Clin Psychol Rev. 2004;24:461-88.
8. Bodenheimer T. Patient Self-management of Chronic Disease in Primary Care. JAMA. 2002;288(19):2469.

9. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions. Patient Educ Couns. 2002;48:177-87.

10. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011;155:97-107.

11. (NALA) NALA. Health Literacy Policy and Strategy 2002 (Accessed 2015). Available from: https://http://www.nala.ie/sites/default/files/publications/Health literacy policy and strategy - 2002 research report_1.pdf.

12. U.S. Department of Health and Human Services - Office of Disease Prevention and Health Promotion. National Action Plan to Improve Health Literacy Washington2010 (Accessed 2014). Available from: http://www.health.gov/communication/hlactionplan/.

13. WHO. Health Literacy - the Solid Facts 2013 [updated June 2015].

14. Loke YK, Hinz I, Wang X, Rowlands G, Scott D, Salter C. Impact of health literacy in patients with chronic musculoskeletal disease--systematic review. PLoS One. 2012;7(7):e40210.

15. Wu JR, Holmes GM, DeWalt DA, Macabasco-O'Connell A, Bibbins-Domingo K, Ruo B, et al. Low literacy is associated with increased risk of hospitalization and death among individuals with heart failure. J Gen Intern Med. 2013;28(9):1174-80.

16. Eichler K, Wieser S, Brugger U. The costs of limited health literacy: a systematic review. Int J Public Health. 2009;54(5):313-24.

17. Nutbeam D. The evolving concept of health literacy. Soc Sci Med. 2008;67(12):2072-8.

18. Naik AD, Street RL, Castillo D, Abraham NS. Health literacy and decision making styles for complex antithrombotic therapy among older multimorbid adults. Patient Education and Counselling. 2011;85(3):499-504.

19. Mbaezue N, Mayberry R, Gazmararian J, Quarshie A, Ivonye C, Heisler M. The impact of health literacy on self-monitoring of blood glucose in patients with diabetes receiving care in an inner-city hospital. J Natl Med Assoc. 2010;1102(1):5-9.

20. Sorensen K, Van den Brouke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health. 2012;12(80):doi: 10.1186/471-2458-12-80.

21. Passche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. Am J Health Behav. 2007;31(Suppl 1):S19-26.

22. Newman S, Steed L, Mulligan K. Chronic Physical Illness: Self-management and behavioural Interventions. United Kingdom: Open University Press; 2009.

23. Leventhal H, Diefenbach M, Leventhal EA. Illness cognition: using common sense to understand treatment adherence and affect cognition interactions. Cognit Ther Res. 1992;16(2):143-63.

24. Bandura A. Social foundations of thought and action: a social cognitive theory. Englewood Cliffs, NJ: Prentice Hall; 1986.

25. Ajzen I. The theory of planned behavior. Organ Behav Hum Decis Process. 1991;50(2):179-211.

26. Lawn S, Schoo A. Supporting self-management of chronic health conditions: common approaches. Patient Educ Couns. 2010;80(2):205-11.

27. Lorig KR, Holman HR. Self-management education: history, definitions, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1-7.

28. Halm EA, Mora P, Leventhal H. No symptoms, No asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma. Chest. 2006;129(3):573-80.

29. Heisler M, Piette JD, Spencer M, Kieffer E, Vijan S. The relationship between knowledge of recent HbA1C values and diabetes care understanding and self-management. Diabetes Care. 2005;28(4):816-22.

30. Wingham J, Harding G, Britten N, Dalal H. Heart failure patients' attitudes, beliefs, expectations and experiences of self-management strategies: a qualitative synthesis. Chronic illness. 2014;10(2):135-54.

31. Murray CJ, Lopez AD. Measuring the global burden of disease. N Engl J Med. 2013;369(5):448-57.

32. Thomas H, Ciliska D, Dobbins M, Micucci S. A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. Worldviews Evidence-Based Nursing. 2004;1(3):176-84.

33. Deeks JJ, Dinnes J, D'amico R, Sowden AJ, Sakarovitch C, Song F, et al. Evaluating non-randomised intervention studies. Health Technol Assess. 2003;7(27).

34. (PHRU) PHRU. Learning and Development NHS; 2006.

35. Bigos S, Bowyer O, Braen G, al. e. Acute low back problems in adults. Clinical practice guideline no. 14. Rockville MD: Agency for Health Care Policy

and Research, Public Health Service: U.S. Department of Health and Human Services; 1994.

36. Fullen BM, Baxter GD, O'Donovan BGG, Doody C, Daly L, Hurley DA. Doctors' attitudes and beliefs regarding acute low back pain management: a systematic review. Pain. 2008;136:388-96.

37. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J. Development of a brief test to measure functional health literacy. Patient Education and Counselling. 1999;38(1):33-42.

38. Davis TC, Crouch MA, Long SW, Jackson RH, Bates P, George RB, et al. Rapid estimate of literacy levels of adult primary care patients. Fam Med. 1991;23(6):433-5.

39. Parker RM, Baker DW, Williams MV, Nurss J. The test of functional health literacy in adults. J Gen Intern Med. 1995;10(10):537-41.

40. Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, et al. Quick assessment of literacy in primary care: The Newest Vital Sign. The Annals of Family Medicine. 2005;3(6):514-22.

41. Kim SH. Health literacy and functional health status in Korean older adults. J Clin Nurs. 2009;18(16):2337-43.

42. Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. J Gen Intern Med. 2008;23(5):561-6.

43. Federman AD, Wisnivesky JP, Wolf MS, Leventhal H, Halm EA. Inadequate health literacy is associated with suboptimal health beliefs in older asthmatics. J Asthma. 2010;47(6):620-6.

44. Mancuso CA, Rincon M. Impact of health literacy on longitudinal asthma outcomes. J Gen Intern Med. 2006a;21(8):813-7.

45. Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. Chest. 1998a;114:1008-15.

46. Devraj R, Herndon CM, Griffin J. Pain awareness and medication knowledge: a health literacy evaluation. J Pain Palliat Care Pharmacother. 2013;27(1):19-27.

47. Martin RW, McCallops K, Head AJ, Eggebeen AT, Birmingham JD, Tellinghuisen DJ. Influence of patient characteristics on perceived risks and willingness to take a proposed anti-rheumatic drug. Med Decis Making. 2013;13(89).

48. Quinlan P, Price KO, Magid SK, Lyman S, Mandl LA, Stone PW. The relationship among health literacy, health knowledge, and adherence to treatment in patients with rheumatoid arthritis. HSS J. 2013;9(1):42-9.

49. Levinson MR, Leeuwrik T, Oldroyd JC, Staples M. A cohort study of osteoporosis health knowledge and medication use in older adults with minimal trauma fracture. Archives of osteoporosis. 2012;7:87-92.

50. Briggs AM, Jordan JE, Buchbinder R, Burnett AF, O'Sullivan PB, Chua JY, et al. Health literacy and beliefs among a community cohort with and without chronic low back pain. Pain. 2010;150(2):275-83.

51. Sperber N, Hall KS, Allen K, DeVellis BM, Lewis M, Callahan LF. The role of symptoms and self-efficacy in predicting physical activity change among older adults with arthritis. Journal of physical activity & health. 2014;11(3):528-35.

52. Chen AM, Yehle KS, Albert NM, Ferraro KF, Mason HL, Murawski MM, et al. Relationships between health literacy and heart failure knowledge, self-efficacy, and self-care adherence. Res Social Adm Pharm. 2014;10(2):378-86.

53. Hwang B, Moser DK, Dracup K. Knowledge is insufficient for self-care among heart failure patients with psychological distress. Health Psychol. 2014;33(7):588-96.

54. Dennison CR, McEntee ML, Samuel L, Johnson BJ, Rotman S, Kielty A, et al. Adequate health literacy is associated with higher heart failure knowledge and self care confidence in hospitalized patients. J Cardiovasc Nurs. 2011;26(5):359-67.

55. Macabasco-O'Connell A, DeWalt DA, Broucksou KA, Hawk V, Baker DW, Schillinger D, et al. Relationship between literacy, knowledge, self-care behaviours, and heart-failure-related quality of life among patients with heart failure. J Gen Intern Med. 2011;26(9):979-86.

56. Kollipara UK, Jaffer O, Amin A, Toto KH, Nelson LL, Schneider R, et al. Relation of lack of knowledge about dietary sodium to hospital readmission in patients with heart failure. Am J Cardiol. 2008;102(9):1212-5.

57. Morrow DG, Weiner M, Young J, Steinley D, Deer M, Murray MD. Improving medication knowledge among older adults with heart failure: a patient-centred approach to instruction design. The Gerontologist. 2005;45(4):545-52.

58. Giuse NB, Koonce TY, Storrow AB, Kusnoor SV, Ye F. Using health literacy and learning style preferences to optimize the delivery of health information. Journal of health communication. 2012;17 Suppl 3:122-40.

59. Osborn CY, Passche-Orlow MK, Cooper-Bailey S, Wolf MS. The mechanisms linking health literacy to behavior and health status. Am J Health Behav. 2011;35(1):118-28.

60. Pandit AU, Tang JW, Bailey SC, Davis TC, Bocchini MV, Persell SD, et al. Education, literacy, and health: Mediating effects on hypertension knowledge and control. Patient Educ Couns. 2009;75(3):381-5.

61. Persell SD, Osborn CY, Richard R, Skripkauskas S, Wolf MS. Limited health literacy is a barrier to medication reconciliation in ambulatory care. J Gen Intern Med. 2007;22(11):1523-6.

62. Willams MV, Baker DW, Park RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. JAMA Intern Med. 1998b;158(2):166-72.

63. Sanders K, Schnepel L, Smotherman C, Livingood W, Dodani S, Antonios N, et al. Assessing the impact of health literacy on education retention of stroke patients. Prev Chronic Dis. 2014;11:E55.

64. Fang MC, Panguluri P, Machtinger EL, Schillinger D. Language, literacy, and characterization of stroke among patients taking warfarin for stroke prevention: Implications for health communication. Patient Education and Counselling. 2009;75(3):403-10.

65. Eckman MH, Wise R, Leonard AC, Dixon E, Burrows C, Khan F, et al. Impact of health literacy on outcomes and effectiveness of an educational intervention in patients with chronic diseases. Patient Educ Couns. 2012;87(2):143-51.

66. Kripalani S, Henderson LE, Chiu EY, Robertson R, Kolm P, Jacobson TA. Predictors of medication self-management skill in a low-literacy population. J Gen Intern Med. 2006;21(8):852-6.

67. Osborn CY, Cavanaugh K, A. WK, Rothman RL. Self-efficacy links health literacy and numeracy to glycemic control. Journal of Health Communication: International Perspectives. 2010;15(Suppl 2):146-58.

68. Kim S, Love F, Quistberg DA, Shea JA. Association of health literacy with self-management behavior in patients with diabetes. Diabetes Care. 2004;27(12):2980-2.

69. Grubbs V, Gregorich SE, Perez-Stable EJ, Hsu CY. Health literacy and access to kidney transplantation. Clin J Am Soc Nephrol. 2009;4(1):195-200.

70. Wright Nunes JA, Wallston KA, Eden SK, Shintani AK, Ikizler TA, Cavanaugh KL. Associations among perceived and objective disease knowledge and satisfaction with physician communication in patients with chronic kidney disease. Kidney Int. 2011;80(12):1344-51.

71. Wolf MS, Davis TC, Osborn CY, Skripkauskas S, Bennett CL, Makoul G. Literacy, self-efficacy, and HIV medication adherence. Patient Educ Couns. 2007;65(2):253-60.

72. Osborn CY, Davis TC, Bailey SC, Wolf MS. Health literacy in the context of HIV treatment: introducing the Brief Estimate of Health Knowledge and Action (BEHKA)-HIV version. AIDS Behav. 2010;14(1):181-8.

73. Kim SH, Yu X. The mediating effect of self-efficacy on the relationship between health literacy and health status in Korean older adults: a short report. Aging Ment Health. 2010;14(7):870-3.

74. Gazmararian JA, Williams MV, Peel J, Baker DW. Health literacy and knowledge of chronic disease. Patient Educ Couns. 2003;51(3):267-75.

75. Scotland N. Making it easy: a health literacy action plan for Scotland 2014 (Accessed 2014). Available from: http://www.scotland.gov.uk/Resource/0045/00451263.pdf.

76. Department of Health and Children I. Primary Care - A New Direction 2001 (Accessed 2014). Available from: http://www.iasw.ie/attachments/316ea78e-c0b3-4342-8901-d56733b22788.PDF.

77. Kiser K, Jonas D, Warner Z, Scanlon K, Shilliday BB, DeWalt DA. A randomized controlled trial of a literacy-sensitive self-management intervention for chronic obstructive pulmonary disease patients. J Gen Intern Med. 2012;27(2):190-5.

78. Cavanaugh K, Wallston KA, Gebretsadik T, Shintani A, Huizinga MM, Davis D, et al. Addressing literacy and numeracy to improve diabetes care: two randomized controlled trials. Diabetes Care. 2009;32(12):2149-55.

79. Kim KB, Han HR, Huh B, Nguyen T, Lee H, Kim MT. The effect of a community-based self-help multimodal behavioral intervention in Korean American seniors with high blood pressure. Am J Hypertens. 2014;27(9):1199-208.

80. NHS. NHS allocations for 2013-2014 2013-2014 (Accessed 2014). Available from: http://www.england.nhs.uk/allocations-2013-14/.

81. Department for Business Innovation and Skills. Skills Funding Statement 2013-2016 2014 (Accessed 2014). Available from:

https://http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/278529/bis-14-p172a-skills-funding-statement-2013-2016.pdf.

82. Gargon E, Gurung B, Medley N, Altman DG, Blazeby JM, Clarke M, et al. Choosing important health outcomes for comparative effectiveness research: a systematic review. PLoS One. 2014;9(6):e99111.

83. Taggart J, Williams A, Dennis S, Newall A, Shortus T, Zwar N, et al. A systematic review of interventions in primary care to improve health literacy for chronic disease behavioral risk factors. BMC Fam Pract. 2012;13:49.

84. Ray SM, Helmer RS, Stevens AB, Franks AS, Wallace LS. Clinical utility of the chronic obstructive pulmonary disease knowledge questionnaire. Fam Med. 2013;45(3):197-200.

85. Rosneck JS, Hughes J, Gunstad J, Josephson R, Noe DA, Waechter D. Development and psychometric evaluation of a cardiovascular risk and disease management knowledge assessment tool. J Cardiovasc Nurs. 2014;29(3):242-56.

86. Weeks DL, French BF, Davis AD, Towle LA. Development and validation of the Diabetes Knowledge Assessment Test for use in medical rehabilitation. Disabil Rehabil. 2014;15:1-10.

87. Lamé IE, Peters ML, Vlaeyen JWS, Kleef MV, Patjin J. Quality of life in chronic pain is more associated with beliefs about pain, than with pain intensity. Eur J Pain. 2005;9:15-24.

88. Murray J, Fenton G, Honey S, Bara AC, Hill KM, House A. A qualitative synthesis of factors influencing maintenance of lifestyle behaviour change in individuals with high cardiovascular risk. BMC Cardiovasc Disord. 2013;13:48.

# 8. TABLES

Table 1: Components and scoring method of Effective Public Health Practice Project (EPHPP) Quality Assessment Tool

| | STRONG | MODERATE | WEAK |
|---|---|---|---|
| Selection bias and Sample size | Very likely to represent target population and ≥80% participation. | Somewhat likely to represent target population and 60-79% participation. | Not likely to represent target population or <60% participation. |
| Design | Randomized control trials or controlled clinical trials. | Cohort analytical studies, case control studies, or interrupted time series. | Any other method used, or if method is not stated. |
| Confounders (list provided in accompanying document) | Controlled for ≥80%. | Controlled for 60-79%. | Controlled for ≤60%. |
| Blinding | Assessor not aware of participant status, **and** participant not aware of research question. | Assessor not aware of participant status, **or** participant not aware of research question, **or** blinding not described. | Assessor is aware of participant status, **and** participant is aware of research question. |
| Data collection methods | Tools are valid and reliable | Tools are valid but not shown to be reliable. | Tools are not shown to be valid or reliable. |
| Withdrawals and dropouts | Follow-up rate is ≥80%. | Follow-up rate is 60-79%, or question is non-applicable. | Follow-up rate is ≤60%, or withdrawals and dropouts not described. |
| **Calculating overall score:** | Study is rated as STRONG if there are no weak ratings. | Study is rated as MODERATE if there is one weak rating. | Study is rated as WEAK if there are two or more weak ratings. |

Thomas et al, 2004

Table 2. Level of evidence

| Level | Type of evidence |
|---|---|
| A | Generally consistent findings provided by (a systematic review of) multiple high quality studies (STRONGLY rated) |
| B | Generally consistent findings provided by (a systematic review of) multiple moderate quality studies (MODERATELY rated) |
| C | Generally consistent findings provided by (a systematic review of) multiple low quality studies (LOW rated) |
| D | One diagnostic study (either high or low quality), or inconsistent findings from (a systematic review of) multiple studies (LOW rated) |
| E | No diagnostic studies |

The Agency for Health Care Policy and Research (AHCPR) Guidelines.

Table 3: Summary of included studies.

**RESPIRATORY DISEASES**

| Author & Country | Disease & Design | Aims/Hypothesis | Tools/Outcome measures | Results | Quality |
|---|---|---|---|---|---|
| 43. Federman et al, 2010.<br><br>U.S.A.<br><br>Primary Care. | Asthma.<br><br>C/S study.<br><br>n=100. | Understand the relationship between HL & disease beliefs in older, inner-city dwelling adults. | 1. HL: S-TOFHLA.<br><br>2. Beliefs: CSM. | 1. HL scores: 35% (n=35) inadequate, 65% (n=65) marginal or adequate.<br><br>2. Low HL associated with poorer beliefs: no symptoms-no asthma (AOR 2.5, 95% CI 1.0-6.1, p=0.01); that asthma can be cured (AOR 3.3, 95% CI 1.3-8.3, p=0.05); medication works better when not taken regularly (AOR 3.8, 95% CI 1.3-11.2p=0.02). | Moderate |
| 44. Mancuso & Rincon, 2006.<br><br>U.S.A.<br><br>Primary Care. | Asthma.<br><br>C/S study.<br><br>n=175. | Measure the association between HL & patients' assessment of care, desire to be informed about, & participate in treatment. | 1. HL: TOFHLA.<br><br>2. Asthma knowledge (Check your Asthma IQ).<br><br>3. Self-efficacy. | 1. HL scores: 82% (n=143) adequate, 18% (n=32) marginal/inadequate.<br><br>2. HL levels correlated with asthma knowledge (r = 0.39, p<0.0001).<br><br>3. HL levels did not correlated with: self-efficacy (r=0.05, p=0.66). | Moderate |
| 45. Williams et al, 1998a.<br><br>U.S.A.<br><br>Hospital. | Asthma.<br><br>C/S study.<br><br>n=483. | Measure reading ability of asthma patients presenting to the ED or during routine care. | 1. HL: REALM.<br><br>2. Asthma knowledge. | 1. HL scores: 27% (n=130) adequate, 33% (n=158) marginal, 27% (n=130) inadequate, 13% (n=65) essentially illiterate.<br><br>2. Low HL associated with poorer knowledge (adjusted diff. -1.1, CI 95% -1.7, -0.5, p<0.001). | Moderate |

**MUSCULOSKELETAL DISEASES**

| Author & | Disease & | Aims/Hypothesis | Tools/Outcome | Results | Quality |
|---|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| 46. Devraj et al, 2013.<br><br>U.S.A.<br><br>Primary care. | Chronic pain.<br><br>C/S study.<br><br>n=139. | Examine the relationship between patient's HL level, pain awareness, & pain medication knowledge. | 1. HL: NVS.<br><br>2. Knowledge: pain medication. | 1. HL scores: 56.1% (n=78) limited, 43.9 (n=61) adequate.<br><br>2. Low HL associated with poorer medication knowledge (F change (1,70) = 4.48, p=0.038). | Weak |
| 47. Martin et al, 2013<br><br>U.S.A<br><br>Community | RA<br><br>C/S study<br><br>n=1009 | Risk perception could be a unique patient attribute that might be influenced by background factors as well as modified by various formats of a risk presentation in a decision aid. | 1. HL: 3 item literacy questionnaire (Chew et al, 2008)<br><br>2. Beliefs:<br>Risk Perception and willingness to take DMARDS | 1. HL scores: 8.8% (n=89) inadequate.<br><br>2. Low HL associated with increased risk perception (B=0.82, p<0.01) and reduced willingness for taking medication (B=0.86, p<0.01) | Moderate |
| 48. Quinlan et al, 2012.<br><br>U.S.A.<br><br>Primary care | RA.<br><br>C/S study.<br><br>n=125. | Determine if HL is a predictor of health knowledge in RA patients. | 1. HL: TOFHLA.<br><br>2. Arthritis knowledge: AKQ. | 1. HL levels: 3% (n=4) inadequate, 4% (n=5) marginal, 93% (n=116) adequate. Mean (SD) HL scores 90.8 (13.8)<br><br>2. HL and knowledge significantly and independently associated (B=0.266, p=0.002) | Moderate |
| 49. Levinson et al, 2012<br><br>Australia<br><br>Hospital | Osteoporo sis<br><br>Cohort study<br><br>n=60 | To measure HL and osteoporosis knowledge in older adults with MTF. | 1. HL: REALM<br><br>2. Knowledge: disease related (OKAT). | 1. HL scores: 97% (n=58) adequate.<br><br>2. HL not associated with OKAT scores (p= not given). | Weak |
| 50. Briggs et al, 2010. | CLBP. | Explore the relationship between HL & LBP- | 1. HL: S-TOFHLA. | 1.HL scores: All participants had adequate HL. | Strong |

| | | | | | |
|---|---|---|---|---|---|
| Australia.<br><br>Community | C/S study.<br><br>n=117. | disability, & the association between LBP & LBP-related beliefs. | 2. Beliefs: (i) Fear avoidance (FABQ), (ii) Catastrophizing (CSQ), (iii) Beliefs about pain (BBQ). | 2. HL not associated with: (i) Fear avoidance (p=0.43PA; p=0.35work), (ii) catastrophizing (p=0.85), beliefs (p=0.48). | |
| 51. Sperber et al, 2013<br><br>U.S.A<br><br>Primary Care | Osteoarthritis<br><br>RCT.<br><br>n=461 | Explore whether a 12-month telephone-based self-management support intervention yielded differences in outcomes according to HL. | 1. HL: REALM<br><br>2. Self-efficacy: Arthritis self-efficacy scale | 1. HL scores: 70% (n=323) adequate.<br><br>HL not associated with changes in self-efficacy post intervention (p>0.05). | Strong |

**CARDIOVASCULAR DISEASES**

| Author & Country | Disease & Design | Aims/Hypothesis | Tools/Outcome measures | Results | Quality |
|---|---|---|---|---|---|
| 52. Chen et al., 2014.<br><br>U.S.A.<br><br>Primary care. | HF<br><br>C/S study.<br><br>N=63. | To test a model examining relationships between HL, HF knowledge, self-efficacy and self-care.<br><br>*Structural Equation Modeling. | 1. HL: S-TOFHLA<br><br>2. Knowledge: HFKQ.<br><br>3. Self-Efficacy: SCHFI | 1. HL scores: 15.9% (n=10) inadequate, 15.9% (n=10) marginal, 68.2% (n=43) adequate. Mean (SD) HL = 27.4 (9.3).<br><br>2. Low HL significantly associated with knowledge (B=0.46, p<0.05).<br><br>3. HL not associated with self-efficacy ( B=0.19, p>0.05). | Moderate |
| 53. Hwang et al, 2014<br><br>USA | HF<br><br>C/S study<br><br>n=612 | Identify barriers to, and factors promoting self-care among HF patients with high or low knowledge. | 1. HL: S-TOFHLA<br><br>2. Beliefs: Perceived control (CAS-R) | Mean (SD) scores of 4 groups: low knowledge & good self-care = 24.9 (9.1), low knowledge & poor self-care = 25.1 (9.2), high knowledge & good self-care, = 25.6 (8.7), high knowledge & poor self-care 26.4 (8.5).<br><br>Perceived control significant correlation ( r=0.095, p<0.05) | Moderate |

| | | | | | |
|---|---|---|---|---|---|
| | | | Knowledge: HFKS | No significant findings between knowledge/self-care combined in 4 groups. | |
| 54. Dennison et al, 2011.<br><br>U.S.A.<br><br>Hospital. | HF.<br><br>C/S study.<br><br>n=95. | Determine prevalence of inadequate HL, & differences by HL levels in relation to self-care & knowledge. | 1. HL: S-TOFHLA.<br><br>2. Knowledge (DHFKS). | 1. HL scores : 42% (n=40) inadequate, 19% (n=16) marginal, 39% (n=35) adequate.<br><br>2. Low HL associated with lower knowledge (F(2,92)=12.7, p<0.001). | Weak |
| 55. Macabasco et al, 2011.<br><br>U.S.A.<br><br>Hospital. | HF.<br><br>C/S study.<br><br>n=605. | Examine potential mediators of HL development (e.g. knowledge, self-efficacy, self-care behaviors). | 1. HL: S-TOFHLA .<br><br>2. Knowledge.<br><br>3. Self efficacy. | 1. HL scores: 37% (n=225) low, 63% (n=380) adequate. Mean (SD) scores = 24.2 (12.3).<br><br>2. Adequate HL associated with better knowledge: mean 6.6 vs. 5.5 (adjusted diff. 0.63, 95% CI 0.97-0.29 p=0.01).<br><br>3. Higher HL associated with higher self-efficacy: 5.0 vs. 4.1 (adjusted diff. 0.99, 95% CI 1.55-0.43, p=0.01). | Moderate |
| 56. Kollipara et al, 2008.<br><br>U.S.A.<br><br>Hospital. | HF.<br><br>C/S study.<br><br>n=97. | Examine risk factors associated with deficiencies in dietary sodium knowledge in HF patients. | 1. HL: TOFHLA.<br><br>2. Knowledge of dietary sodium (PDSKT). | 1. HL scores: 29% (n=14) inadequate, 71%(n=83) adequate.<br><br>2. Low HL associated with less sodium knowledge (p=0.01). | Moderate |
| 57. Morrow et al, 2005<br><br>U.S.A<br><br>Community | HF<br><br>Cohort study<br><br>n=32 | Investigate whether patient-centred instructions for HF medications increase comprehension and memory for medication information in older adults. | 1. HL: S-TOFHLA<br><br>2. Knowledge: recall of information in medication leaflet | 1. HL scores: 34% (n=11) inadequate.<br>Mean (SD): 26.3 (9.4)<br><br>2. HL predicted recall (B=0.53,p<0.01). | Strong |

| | | | | | |
|---|---|---|---|---|---|
| 58. Guise et al, 2012<br><br>U.S.A<br><br>Hospital | HTN<br><br>RCT<br><br>n=196 | Investigate whether appealing to HL level alone, or in conjunction with preferred learning style enhances educational outcomes | 1. HL: S-TOFHLA<br><br>2. Knowledge: Hypertension Knowledge Test | 1. HL scores: 83.7% (n=164) adequate, 8.7% (n=17) marginal, 7.7% (n=15) inadequate.<br><br>2. HL not associated with improved knowledge in HL only intervention.<br><br>HL sensitive intervention resulted in improved pre versus post-test knowledge scores ($p<0.001$), in comparison to control group ($P>0.05$). | Strong |
| 59. Osborn et al, 2011.<br><br>U.S.A.<br><br>Community. | HTN.<br><br>C/S study.<br><br>n=330. | Examine pathways associated with self-care behaviors (e.g. demographics, knowledge, self-efficacy), & HL.<br><br>*Structural Equation Modeling. | 1. HL: S-TOFHLA.<br><br>2. Knowledge.<br><br>3. Self-efficacy. | HL scores: 30.3% (n=100) inadequate, 69.7% (n=230) marginal/adequate.<br><br>2. Higher HL associated with higher knowledge ( B=0.22, $p<0.001$).<br><br>3. HL not associated with self-efficacy ($p>0.05$). | Weak |
| 60. Pandit et al, 2009.<br><br>U.S.A.<br><br>Primary Care. | HTN.<br><br>C/S study.<br><br>n=330. | Examine if HL mediated the association between education &, HTN knowledge. | 1. HL: S-TOFHLA.<br><br>2. Knowledge. | 1. HL scores: 28.2% (n=93) inadequate, 71.8% (n=237) adequate.<br>2. Low HL associated with poorer HTN knowledge (Adj. diff. -0.89, 95% CI -1.79-0.02, $p<0.001$). | Weak |
| 61. Persell et al, 2007.<br><br>U.S.A.<br><br>Community. | HTN.<br><br>C/S study.<br><br>n=119. | Determine prevalence of medication discrepancies, & whether HL was associated with reconciliation problems. | 1. HL: S-TOFHLA.<br><br>2. Medication knowledge: naming them. | 1. HL scores: 31% (n=37) inadequate, 69% (n=82) adequate.<br><br>2. Low HL associated with having more difficulty naming medications (AOR 2.9, 95%CI 1.3-6.7, $p=0.03$). | Moderate |

| | | | | | |
|---|---|---|---|---|---|
| 63. Sanders et al, 2014<br><br>USA | Stroke<br><br>Prospective C/S study<br><br>n=92 | Examine the relationship of HL to retention of knowledge after recommended stroke education | 1. HL: S-TOFHLA<br><br>2. Knowledge: retention of post stroke education provided in hospital (SPER). | 1. HL scores:% 57.6 (n=53) inadequate. Mean (SD): Inadequate 5.58 (2.06), adequate 7.31 (1.76).<br><br>2. HL associated with poorer recall (adjusted difference 1.87, 95% CI 0.63-3.12, p=0.001) | Strong |
| 64. Fang et al, 2009.<br><br>U.S.A.<br><br>Hospital. | Stroke.<br><br>C/S study.<br><br>n=146. | Assess stroke related HL in patients at risk of stroke, & perceptions of stroke. | 1. HL: S-TOFHLA.<br><br>2. Knowledge: (i) medication knowledge ('why take warfarin'), (ii) definition of stroke & mechanisms ('what is a stroke'). | 1. HL scores: 35.6% (n=52) adequate, 12.3% (n=18) marginal, 52.1% (n=76) inadequate. Mean HL score = 17<br><br>2. Low HL: (i) not associated with warfarin knowledge (OR 2.2, 95%CI 0.8–5.7,p>0.05), (ii) is associated with discordant answers regarding stroke perception (AOR 5.8, 95% CI 2.1-15.6, p<0.001). | Moderate |
| 65. Eckman et al, 2012<br><br>U.S.A.<br><br>Hospital | CVD.<br><br>RCT.<br><br>n=170 | Investigate whether appealing to HL level alone, or in conjunction with preferred learning style enhances educational outcomes | 1. HL: S-TOFHLA<br><br>2. Knowledge: Hypertension Knowledge Test | 1. HL scores: 83.7% (n=164) adequate, 8.7% (n=17) marginal, 7.7% (n=15) inadequate.<br><br>2. HL not associated with improved knowledge in HL only intervention.<br><br>HL sensitive intervention resulted in improved pre versus post-test knowledge scores (p<0.001), in comparison to control group (P>0.05). | Strong |
| 66. Kripalani et al, 2006.<br><br>U.S.A.<br><br>Primary care. | CVD<br><br>C/S study.<br><br>n=152. | Examine the association of HL with medication management capacity in an inner-city medical clinic. | 1. HL: REALM.<br><br>2. Knowledge: Medication regimen complexity (DRUGS). | 1. HL scores: 50.7% (n=70) inadequate, 28.9% (n=44) marginal, 20.4% (n=31) adequate.<br><br>2. Low HL associated with poorer ability to identify medications (AOR 12, 95% CI 0.97-23.75, p<0.001). | Weak |

**DIABETES**

| Author & Country | Disease & Design | Aims/Hypothesis | Tools/Outcome measures | Results | Quality |
|---|---|---|---|---|---|
| 67. Osborn et al, 2010. U.S.A. Primary care. | DM. C/S study. n=383. | Examine the association between HL, numeracy, & diabetes self-efficacy. *Structural Equation Modeling. | 1. HL: REALM. 2. Diabetes self-efficacy: PDSMS. | 1. HL scores: 31% (n=120) ≤9th grade (inadequate), 69% (n=263) ≥9th grade (adequate). 2. HL had direct affect on self-efficacy ( r=0.14, p<0.01). | Weak |
| 68. Kim et al, 2004. U.S.A. Hospital. | DM. Prospective study. n=92. | Assess the association of HL with self-management behaviors, & if diabetes education improves self-management in low HL patients. | 1. HL: S-TOFHLA. 2. Knowledge: DKQ. | 1. HL scores: 77% (n=71) adequate, 23% (n=21) limited. 2. Lower HL associated with lower knowledge (19.9±0.51 vs. 18.0±1.08, p<0.001). | Weak |

**RENAL DISEASES**

| Author & Country | Disease & Design | Aims/Hypothesis | Tools/Outcome measures | Results | Quality |
|---|---|---|---|---|---|
| 69. Grubbs et al, 2009. U.S.A. Hospital. | Kidney disease. C/S study. n=62. | Inadequate HLIT in dialysis population is common & associated with poorer access to kidney transplant wait list. | 1. HL: S-TOFHLA. 2. Knowledge: transplant awareness. | 1. HL scores: 32.3% (n=20) inadequate, 67.7% (n=42) adequate. Mean (SD) HL scores = 25.6 (9.4). 2. HL not associated with preference for transplant (p = 0.7), or certainty about the decision (p = 0.5). | Weak |
| 70. Wright-Nunes et al, | Kidney disease. | Perceived knowledge is low in patients with | 1. HL: REALM. | 1. HL scores: 18% (n=71) <9th grade, 83% (n=328) ≥9th grade. | Moderate |

| | | | | | |
|---|---|---|---|---|---|
| 2011.<br>U.S.A<br>Primary Care | C/S study.<br>n=399. | chronic kidney disease. | 2. Knowledge: of chronic kidney disease. | 2. Low HL (<9th grade) associated with poorer knowledge | |

**HIV**

| Author & Country | Disease & Design | Aims/Hypothesis | Tools/Outcome measures | Results | Quality |
|---|---|---|---|---|---|
| 71. Wolf et al, 2007.<br>U.S.A.<br>Hospital. | HIV.<br>C/S study.<br>n=204. | Investigate whether HIV treatment knowledge, self-efficacy, or both mediate the literacy-adherence relationship | 1. HL: REALM.<br>2. Knowledge (BEHKA - HIV).<br>3. Self-efficacy. | 1. HL scores: 68.6% (n=140) adequate, 20.1% (n=41) marginal, 11.3% (n=23) low.<br>2. Low HL significant predictor of poorer knowledge (AOR 2.4, 95% CI 2.2-2.6).<br>3. Low HL significant predictor of poorer self-efficacy (AOR 5.8 95% CI 2.0-15.7). | Weak |

**MULTIPLE CHRONIC DISEASES**

| Author & Country | Disease & Design | Aims/Hypothesis | Tools/Outcome measures | Results | Quality |
|---|---|---|---|---|---|
| 73. Kim and Yu, 2010.<br>South Korea.<br>Community. | OA, DM, Pulmonary disease, & CVD.<br>C/S study.<br>n=103 | Investigate whether HL is mediated through self-efficacy on influencing the health status in Korean older adults. | 1. HL: Korean TOFHLA.<br>2. Self-efficacy: GSE. | 1. HL scores: mean score (SD) = 5.48 (3.53). Mean (<br>2. HL predicted self-efficacy (B=0.67, SE=0.28, p=0.001). | Weak |
| 74. Gazmararian | DM, HF, Asthma, | Explore the relationship between HL & knowledge | 1. HL: S-TOFHLA. | HL scores: 24% (n=157) inadequate, 11.8% (n=77) marginal, 64.2% (n=419) adequate. | Weak |

| | | | | | |
|---|---|---|---|---|---|
| et al, 2003.<br><br>U.S.A.<br><br>Community. | HTN.<br><br>C/S study.<br><br>n=653. | of chronic disease among medicare managed care patients. | 2. Knowledge. | 2. Patients with low HL were less likely to answer multiple questions related to overall knowledge of condition correctly (p<0.05). | |
| 62. Williams et al, 1998b.<br><br>U.S.A.<br><br>Hospital. | HTN & DM.<br><br>C/S study.<br><br>HTN: n=402.<br><br>DM: n=114. | Examine the relationship between HL & chronic disease (HTN and DM), its relationship with disease knowledge. | 1. HL: TOFHLA.<br><br>2a. HTN knowledge.<br><br>2b. DM knowledge. | 1. HL scores:<br>HTN: 49% (n=196) inadequate, 12% (n=50) marginal, 39% (n=156) adequate.<br>DM: 44% (n=50) inadequate, 11% (n=13) marginal, 51% (n=45) adequate.<br><br>2a. Low HL associated with poorer HTN knowledge (p<0.01).<br><br>2b. Low HL associated with poorer DM knowledge (p<0.05). | Weak |

AKQ: Arthritis Knowledge Questionnaire; BEHKA - HIV: Brief Estimate of Health Knowledge and Action - HIV Version; C/S: Cross-Sectional; CLBP: Chronic Low Back Pain; CSM: Common Sense Model of Self-Regulation; CSQ: Coping Skills Questionnaire; CVD: Cardiovascular Disease; DHKFS: Dutch Heart Failure Knowledge Scale; DKQ: Diabetes Knowledge Questionnaire; DM: Diabetes; DRUGS: Drugs Regimen Unassisted Grading Scale; FABQ: Fear Avoidance Beliefs Questionnaire; GSE: General Self-Efficacy Scale; HC: Healthcare; HF: Heart Failure; HeLMS: The Health Literacy Management Scale; HFKQ: Heart Failure Knowledge Questionnaire; HIV: Human Immunodeficiency Virus; HL: Health Literacy; HTN: Hypertension; LBP: Low Back Pain; NVS: Newest Vital Sign; OA: Osteoarthritis; PDSKT: Parkland Dietary Sodium Knowledge Test; PDSMS: Perceived Diabetes Self-Management Scale; RCT: Randomized Control Trial; REALM: Rapid Estimate of Adult Literacy in Medicine; -S-TOFHLA: Shortened Version -Test of Functional health literacy in Adults; TOFHLA: SCHFI: Self-Care Heart Failure Index; Test of Functional health literacy in Adults.

# 9. FIGURES

Figure 1: Passche Orlow and Wolf (21), health literacy model.

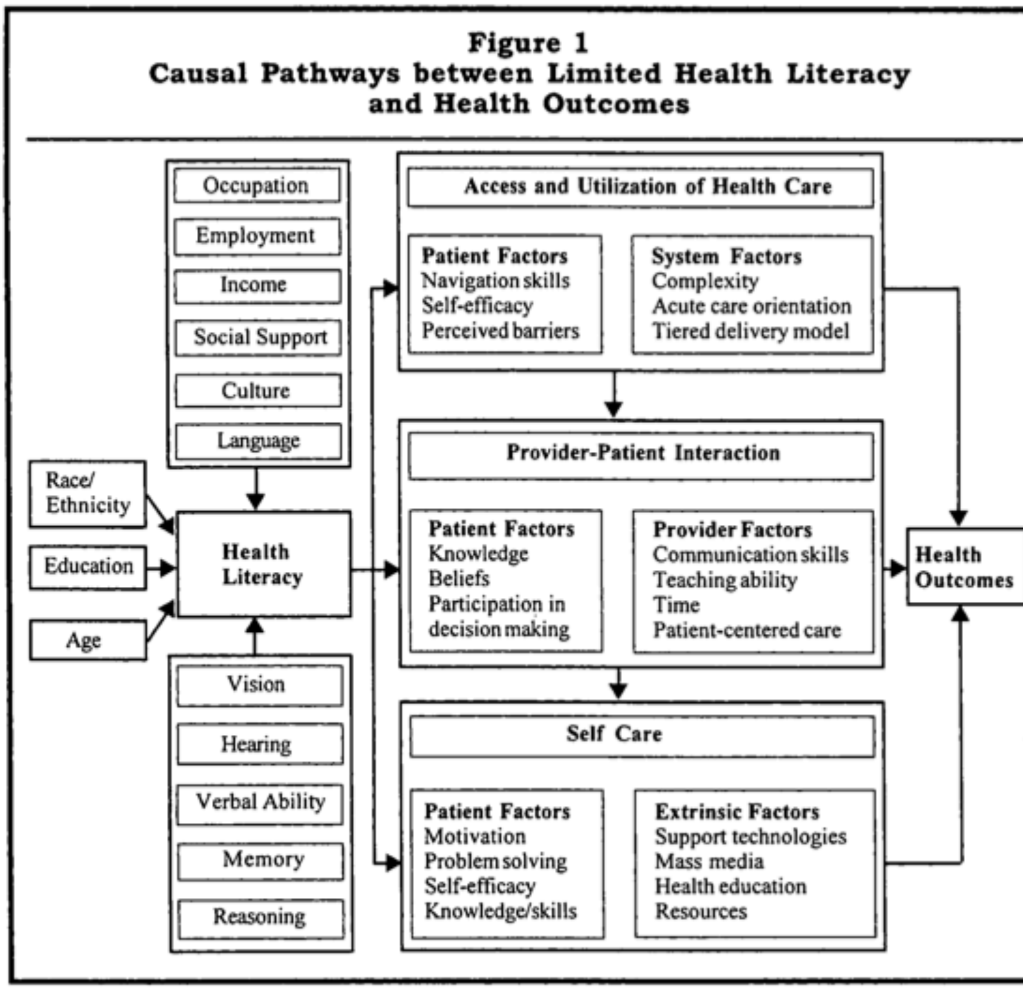
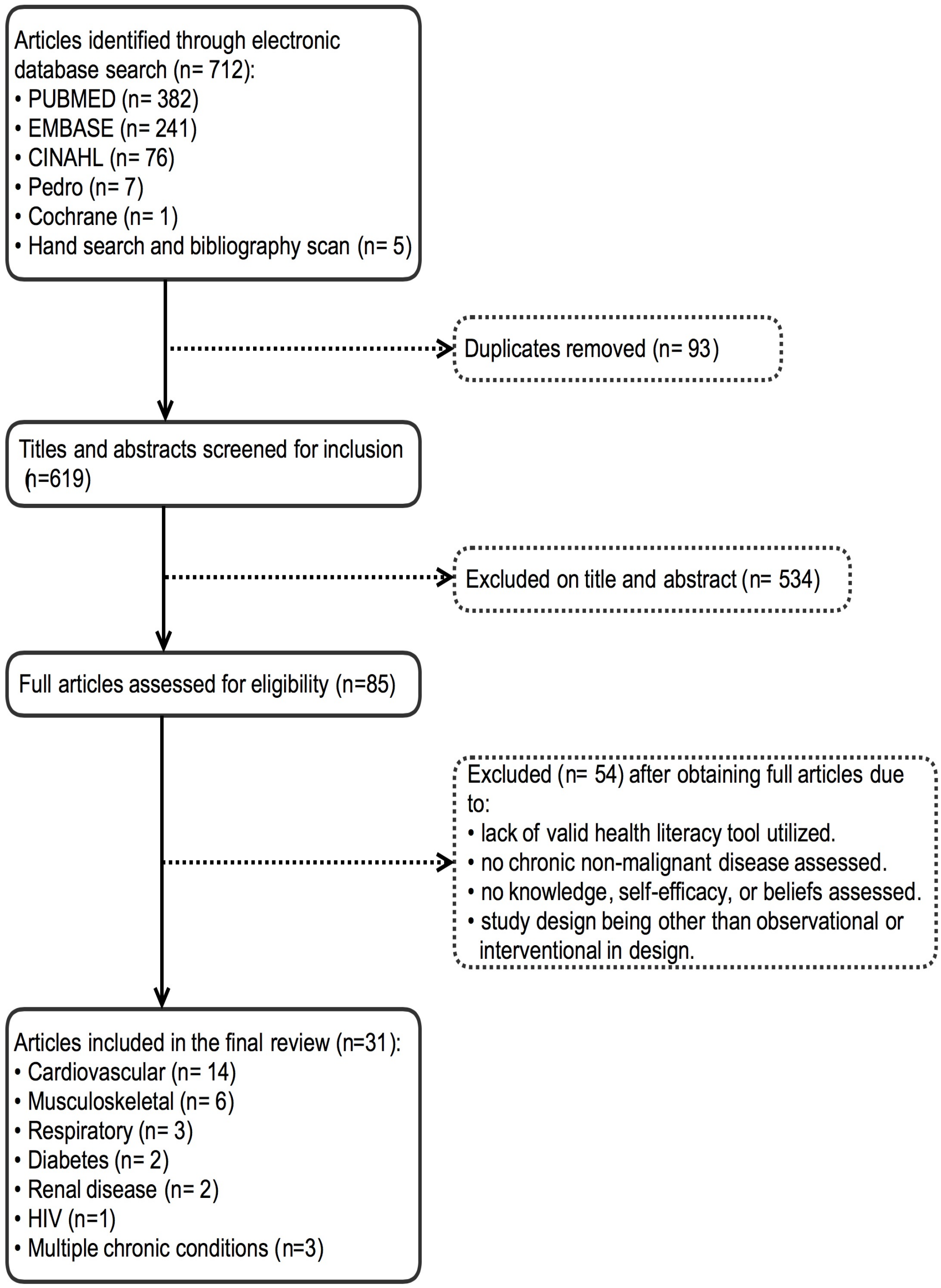


Figure 2: PRISMA flow chart.



# 10. APPENDIX

Search string entered into PUBMED:

(((health literacy) OR "Health Literacy"[Mesh])) AND (((((((("Chronic Pain"[Mesh]) OR "Musculoskeletal Diseases"[Mesh]) OR chronic renal disease) OR "Kidney Diseases"[Mesh]) OR ("Diabetes Mellitus, Type 2"[Mesh] AND "Diabetes Mellitus, Type 1"[Mesh])) OR ("Pulmonary Disease, Chronic Obstructive"[Mesh] AND "Lung Diseases, Obstructive"[Mesh])) OR "Asthma"[Mesh]) OR "Cardiovascular Diseases"[Mesh]) OR "Chronic Disease"[Mesh])