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A review of clinical trials of advance care planning interventions adapted for limited health literacy

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Abstract

Objectives. Advance care planning is vital for ensuring individuals receive end-of-life care that is consistent with their care preferences and improves patient quality of life and satisfaction with care; however, only 11% of Americans have discussed advance care planning with a healthcare provider. Individuals with limited health literacy are even less likely to participate in advance care planning due to difficulty comprehending complex health information. The purpose of this review was to identify randomized controlled trials designed to address the effects of limited health literacy on advance care planning, evaluate the quality of these studies, and summarize evaluation data to inform future studies.

Methods. This systematic review examined randomized controlled trials published from January 1997 to July 2020 using the PubMed, CINAHL, PsycINFO, and Scopus databases. Data were extracted and two reviewers independently evaluated the quality of studies using the Joanna Briggs Institute Critical Appraisal Tool.

Results. The database search yielded 253 studies and five studies were included in the final review. Studies were conducted in mostly White patients in outpatient clinics in the United States. Researchers wrote text at lower reading levels, added images to materials, and created videos to enhance communication. Health literacy interventions increased participant knowledge, preference for comfort care, engagement, and care documentation; however, several methodological issues were identified, including baseline differences in treatment and control groups, issues with blinding, lack of valid and reliable outcome measures, and inappropriate statistical analyses.

Significance of results. More high-quality intervention studies that address the effects of limited health literacy on advance care planning in diverse populations and settings are needed. Future intervention studies should use reliable and valid instruments to measure advance care planning outcomes. Clinicians should use materials appropriate for their patients' health literacy levels to address their advance care planning needs.

Background

Advance care planning (ACP) is vital for ensuring individuals receive end-of-life care that is consistent with their care preferences (Kermel-Schiffman and Werner, 2017; Gazarian et al., 2019). A multidisciplinary Delphi panel defined ACP as a "process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" (Sudore et al., 2017b, p. 826). ACP has been shown to improve patient quality of life, promote patient-centered end-of-life care, and help identify potentially avoidable hospitalizations (Kermel-Schiffman and Werner, 2017; Jimenez et al., 2018; Hickman et al., 2019).

Despite the benefits of ACP, only 11% of Americans have actually discussed ACP with a healthcare provider (Hamel et al., 2017). Limited health literacy (LHL) has been identified as a significant barrier to ACP (Sudore et al., 2018a; Nouri et al., 2019). LHL is defined as the limited ability to attain, comprehend, and communicate basic health information (Nielsen-Bohlman et al., 2004). Individuals with LHL often lack knowledge about potentially life-saving but invasive treatment options, including cardiopulmonary resuscitation and ventilators (Eneanya et al., 2018), which is necessary to make decisions about their future care preferences. To ensure that individuals with LHL can participate in ACP, highly effective interventions tailored to mitigate the effects of LHL, such as redesigning health information materials using simple language, are needed.

While ACP interventions developed for individuals with LHL have been tested in randomized controlled trials (RCTs), to our knowledge there are no published reviews that systematically evaluate the quality of these RCTs. Therefore, this review will rigorously evaluate the quality of RCTs to test ACP interventions adapted for individuals with LHL using the

Joanna Briggs Institute (JBI) Critical Appraisal Checklist (Tufanaru et al., 2020). Accordingly, the specific aims of this integrative review are to (1) identify RCTs designed to address the effects of LHL on ACP, (2) use the JBI Critical Appraisal Tool to evaluate the quality of each study, and (3) summarize the evaluation data to inform future research in this area.

Methods

Search strategy and inclusion criteria

A review protocol was developed based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009). A literature search was conducted using the PubMed, CINAHL, PsycINFO, and Scopus databases using selected keyword search terms (see Table 1). Inclusion criteria for the studies in this review were (1) peer-reviewed, (2) written in English, (3) sampled patients ages 18 years and older, (4) RCTs, (e) assessed ACP outcome measures and baseline health literacy measures, and (f) published between January 1997 and July 2020.

Screening process and data extraction

Two independent reviewers (MH and MM) identified relevant studies (see Figure 1). After removing duplicates from the database search, one reviewer (MH) screened records for eligibility criteria. In a second step, both reviewers assessed full-text articles for eligibility. Discrepancies were discussed until consensus was reached. Reviewers used a standardized form to extract information from each article, including year of publication, study purpose, sample characteristics, research methods, measurement tools, and study results.

Evaluation of study quality

RCTs were independently evaluated by the same two reviewers using the JBI Critical Appraisal Checklist. The JBI Critical Appraisal Checklist is a peer-reviewed tool that helps researchers rigorously evaluate whether individual studies should be incorporated into a review (Tufanaru et al., 2020). It assesses the methodological quality of a study and determines whether that study has addressed the prospect of bias in its methodology (Tufanaru et al., 2020). The checklist consists of 13 questions that assess randomization methods ($n = 1$); concealment of treatment and control group allocation ($n = 1$); similarities between baseline treatment and control groups ($n = 1$); blinding strategies ($n = 3$); care received for treatment and control groups ($n = 1$); follow-up description and analysis ($n = 1$); data analysis ($n = 2$); outcome measurement ($n = 2$); and trial design ($n = 1$) (Tufanaru et al., 2020). The reviewers assessed whether each study addressed each of the 13 questions in the checklist by coding the question as either “Yes,” “No,” “Unclear,” or “Not Applicable.” A consensus was reached, and the total number of questions answered with a “Yes” were then tabulated and percentages were then calculated to score the quality of the studies.

Results

Description of studies

The database search yielded 253 articles after elimination of duplicates. 203 irrelevant papers were excluded based on titles or abstracts. The 50 remaining papers then went on to the full-text review. Of these, five met eligibility criteria and were included in the final review (see Figure 1).

As shown in Table 2, all studies were conducted in outpatient clinics in the United States. Four studies were conducted in urban cities in the coastal United States (Sudore et al., 2007, 2017a, 2018b; Volandes et al., 2009), and one was conducted in a rural clinic in the Southern United States (Volandes et al., 2011). The five studies included in this review were conducted by two research groups (three studies were from the Sudore group and two were from the Volandes group). The two groups used two different measures of health literacy and both tested interventions they developed. Three studies used the Short Form Test of Functional Literacy in Adults (s-TOFHLA; Baker et al., 1999) to categorize participants into limited or adequate health literacy groups (Sudore et al., 2007, 2017a, 2018b), and two studies used the Rapid Assessment of Adult Literacy in Medicine (REALM) tool (Davis et al., 1993) to categorize participants into low, marginal, or adequate health literacy groups (Volandes et al., 2009, 2011). The percentage of participants with LHL, defined as a score of ≤ 22 on the s-TOFHLA and defined as low or marginal literacy with a score ≤ 60 on the REALM, ranged from 20% to 53% across the five studies.

Sample sizes varied greatly among studies. Intervention group sizes ranged from 33 to 481 participants and control group sizes ranged from 43 to 505 participants. A majority of the participants in all five studies identified as White (Volandes et al., 2009, 2011; Sudore et al., 2017a, 2018b). In three studies, the mean age for participants was greater than 65 years (Volandes et al., 2009, 2011; Sudore et al., 2017a). All but one study, which was conducted in a population of veterans (Sudore et al., 2017a), had greater than 50% female participants. Two studies included Spanish-speaking participants (Sudore et al., 2007, 2018b).

All studies required participants to have a primary care provider at the study clinic and excluded individuals who were cognitively impaired. Two studies required participants to have two

Table 1. Keyword search query table

Search Terms	Database	Number of Articles
(“Terminal Care”[Mesh] OR “Living Wills”[Mesh]OR Advance Care Planning[Mesh] OR “Advance Directives”[Mesh] OR “advance care planning” OR “ACP” OR “advance directives”) AND (“Health Literacy”[Mesh] OR “health literacy” OR “literacy”)	PubMed	100
(((MM “Health Literacy”) OR “health literacy” OR “literacy”)) AND (((MM “Advance Care Planning”) OR (MM “Advance Directives”) OR “ACP” OR “advance directive*” OR “living will” OR “power of attorney” OR “end of life”)))	CINAHL	82
(((MM “Health Literacy”) OR “health literacy” OR “literacy”)) AND (((MM “Advance Care Planning”) OR (MM “Advance Directives”) OR “ACP” OR “advance directive*” OR “living will” OR “power of attorney” OR “end of life”)))	PsycInfo	100
(TITLE-ABS-KEY (“health literacy” OR “literacy”) AND TITLE-ABS-KEY (“ACP” OR “advance directive*” OR “living will” OR “power of attorney” OR “Advance care planning” OR “end of life”))	Scopus	153

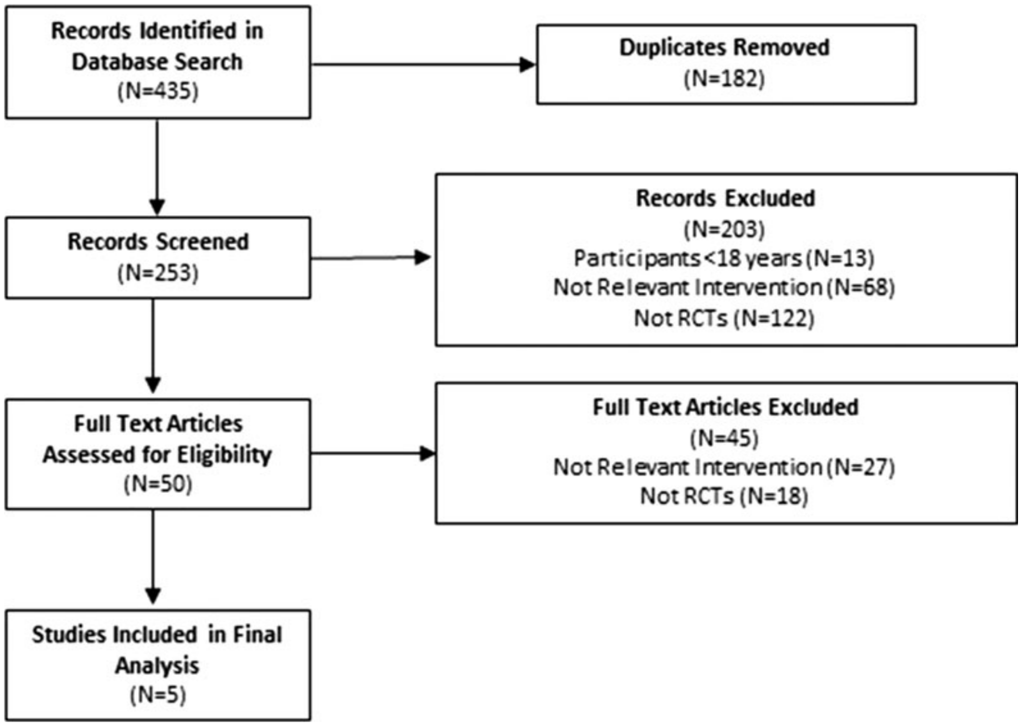

Fig. 1. PRISMA flow diagram. Note: RCT, randomized controlled trial.

Table 2. Summary of the literature review (*N* = 5)

Author (Year), Location	Number of Subjects	Intervention and Control Description	Outcome Measures	Findings (*p*-value)
1. Sudore et al. (2007), San Francisco, CA, outpatient clinic	50+ yrs healthy adults, 40% LHL[a] 103 intervention 102 control	I: Easy-to-read AD C: Standard California AD	AD Knowledge Scale[b](1 time) AD Completion[b] (baseline and 6 mos.) ACP Discussion[b] (baseline and 6 mos.)	Nonsignificant (0.30) Significant increase (0.03) Nonsignificant (NR)
2. Sudore et al. (2017a), San Francisco, CA, outpatient clinic	60+ yrs. Veterans with >1 comorbidity, 20% LHL[a] 205 intervention 209 control	I: Easy-to-read AD, interactive website (end-of-life conversation), and AD action plan C: Easy-to-read AD	AD Completion[c](9 mos.) ACP Discussions[c] (9 mos.) ACP Engagement Survey[c] (1 wk., 3 and 6 mos.)	Significant increase (0.04) Nonsignificant (0.13) Significant increase (<0.001)
3. Sudore et al. (2018b), San Francisco, CA, outpatient clinic	55+ yrs. adults with >1 comorbidity, 39% LHL[a] 481 intervention 505 control	I: Easy-to-read AD, interactive website (end-of-life conversation), and AD action plan C: Easy-to-read AD	AD Completion[c] (15 mos.) ACP Discussions[c] (15 mos.) ACP Engagement Survey[c] (1 wk., 3, 6, and 12 mos.)	Significant increase (<0.001) Nonsignificant (0.10) Significant increase (<0.001)
4. Volandes et al. (2009), Boston, MA, outpatient clinic	65+ yrs. healthy adults, 30% LHL[d] 94 intervention 106 control	I: Verbal description of dementia and video of dementia patient C: Verbal description of dementia	Preference for Comfort Care[b] (6 wks.) Dementia Knowledge[e] (1 time)	Significant increase (0.003) Significant increase (<0.001)
5. Volandes et al. (2011), Greensburg, LA, outpatient clinic	65+ yrs. healthy adults, 53% LHL[d] 33 intervention 43 control	I: Verbal description of dementia and video of dementia patient C: Verbal description of dementia	Preference for Comfort Care[b] (1 time)	Significant increase (0.047)

Notes: yr(s)., years; LHL, Limited Health Literacy; I, Intervention; C, Control; AD, Advance Directive; ACP, Advance Care Planning; mo(s)., month(s), wk(s)., week(s); NR, not reported.
[a] Short Test of Functional Health Literacy in Adults (S-TOFHLA; Baker et al., 1999).
[b] Chi-Square Test.
[c] Mixed Effects Logistic or Linear Regression.
[d] Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1993).
[e] Independent Sample *t*-Test.

or more comorbidities (Sudore et al., 2017a, 2018b), and three studies required participants to own a telephone (Sudore et al., 2007, 2017a, 2018b).

Several intervention types designed to mitigate the effects of LHL on ACP were tested (see Table 2). Approaches to addressing LHL included writing text at lower reading levels, adding images to improve communication, and designing materials with an appropriate layout to enhance readability. One study tested an easy-to-read advance directive intervention, which provided individuals with an advance directive written at a fifth-grade reading level and included pictures that helped explain the text (Sudore et al., 2007). Two studies with the same first author tested an interactive website intervention that included video stories to enhance an easy-to-read advance directive (Sudore et al., 2017a, 2018b). Two studies with the same first author tested a short video intervention for improving participants' comprehension of their disease and care options (Volandes et al., 2009, 2011).

Of the five studies, four included longitudinal data collection that ranged from one week to 15 months after interventions (Sudore et al., 2007, 2017a, 2018b; Volandes et al., 2009). Outcome measures included patient knowledge ($n = 2$), care preferences ($n = 2$), certainty of care preferences ($n = 1$), ACP engagement ($n = 2$), and ACP documentation ($n = 3$).

Reported findings

Of the two studies that measured knowledge, one specifically measured participants' knowledge of advance directives (Sudore et al., 2007) and the other measured participants' knowledge of dementia (Volandes et al., 2009). Although advance directive knowledge significantly improved for both the control and intervention groups, there was no significant post-intervention difference between the groups (Sudore et al., 2007). In contrast, post-intervention dementia knowledge scores were significantly higher for the intervention group compared with the control group ($p < 0.001$) (Volandes et al., 2009).

The two studies that measured patient care preferences found that participants had a higher preference for comfort care than aggressive end-of-life care after the intervention ($p < 0.05$) (Volandes et al., 2009, 2011). The one study that measured certainty of care preference found that participants in the intervention group were more certain about their care preferences immediately after the intervention ($p < 0.0001$) (Volandes et al., 2009), and less likely to change their care preferences over a six-week period compared with the control group ($p < 0.001$) (Volandes et al., 2009).

ACP engagement scores were significantly higher after the intervention compared with the control in both studies that measured ACP engagement ($p < 0.001$) (Sudore et al., 2017a, 2018b). In addition, all three studies that reported ACP documentation outcomes found a significant increase in advance directive completion for the intervention group compared with the control group ($p < 0.05$), but not a significant difference in ACP care provider discussions between groups (Sudore et al., 2007, 2017a, 2018b).

JBI critical appraisal of RCTs

All studies were coded with a "Yes" for at least half of the checklist questions and two were coded with a "Yes" for more than two-thirds of the checklist questions (see Table 3). The most common

Table 3. JBI critical appraisal of RCTs

	Sudore et al. (2007)	Sudore et al. (2017a)	Sudore et al. (2018b)	Volandes et al. (2009)	Volandes et al. (2011)	Criteria met *N* (%)
1. Was true randomization used for assignment of participants to treatment groups?	Y	Y	Y	Y	Y	5 (100)
2. Was allocation to treatment groups concealed?	Y	Y	Y	Y	UC	4 (80)
3. Were treatment groups similar at the baseline?	N	Y	N	N	Y	2 (40)
4. Were participants blind to treatment assignment?	N	N	N	N	N	0 (0)
5. Were those delivering treatment blind to treatment assignment?	N	N	N	N	N	0 (0)
6. Were outcomes assessors blind to treatment assignment?	N	Y	Y	N	N	2 (40)
7. Were treatment groups treated identically other than the intervention of interest?	Y	Y	Y	Y	Y	5 (100)
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Y	Y	Y	Y	N/A	4 (100)[a]
9. Were participants analyzed in the groups to which they were randomized?	Y	Y	Y	N	Y	4 (80)
10. Were outcomes measured in the same way for treatment groups?	Y	Y	Y	Y	Y	5 (100)
11. Were outcomes measured in a reliable way?	UC	UC	UC	UC	UC	0 (0)
12. Was appropriate statistical analysis used?	N	N	Y	Y	UC	2 (40)
13. Was the trial design appropriate, and any deviations from the standard RCT design accounted for in the conduct and analysis of the trial?	Y	Y	Y	Y	Y	5 (100)
Total number of criteria met (% of criteria met)	7 (53.5)	9 (69.2)	9 (69.2)	7 (53.5)	6 (50)[b]	37 (56.9)

Notes: RCT, Randomized Controlled Trial; Y, Yes; N, No; N/A, Not Applicable; UC, Unclear. Adapted from the Joanna Briggs Institute (JBI). JBI Manual for Evidence Synthesis: 2020.

[a] *N*: Calculated using 4 articles instead of 5.

[b] *N*: Calculated using 12 criteria instead of 13.

methodological issues identified included baseline differences in treatment and control groups, issues with blinding, suboptimal reporting of outcome measure psychometric data, and inappropriate statistical analyses.

Baseline differences between the treatment and control groups

Intervention and control groups in three of the five RCTs were not similar at baseline (see Table 3). There were significant differences in age (Sudore et al., 2007), previous ACP documentation (Sudore et al., 2018a), and dementia diagnosis and relationship to someone with dementia (Volandes et al., 2009). One study corrected for their dissimilarity in the analyses (Sudore et al., 2018b); however, because groups were not similar prior to correction, selection bias cannot be ruled out even in that study.

Blinding to treatment assignment

Participants and those delivering treatments were not blinded to treatment assignment for any of the five RCTS. To minimize potential biases resulting from nonblinding, two studies stated that they blinded participants to the study hypothesis (Sudore et al., 2017a, 2018b).

Psychometric properties of outcome measures

The psychometric properties of the outcome measures were not consistently reported among the studies. Validity and reliability of outcome measures were not reported in two studies (Volandes et al., 2009, 2011). One study evaluated internal consistency reliability by calculating Kuder–Richardson reliability coefficients for subscales of an advance directive knowledge survey, but did not report those reliabilities (Sudore et al., 2007). This same study also used factor analysis to explain variance in scales, but did not report results of the factor analysis (Sudore et al., 2007). Two studies provided appropriate references for validity and reliability measures for their main outcome measure, the ACP Engagement Survey; however, the authors did not report the validity and reliability data in the paper (Sudore et al., 2017a, 2018b), rather, these data were reported in the study protocols (Sudore et al., 2015, 2016).

Appropriateness of statistical analyses

Appropriate statistical analyses and reporting of findings were not performed in two of the five studies. One study did not report unadjusted results for logistic regression analysis of ACP documentation completion rates between groups (Sudore et al., 2017a). This study also reported a significant p-value ($p = 0.047$), but a nonsignificant confidence interval [CI = 1.0–15.1], for the ACP documentation rates between control and experimental groups (Sudore et al., 2017a). One study also failed to report standard deviations or factor analysis results for the advance directive knowledge survey used (Sudore et al., 2007).

Discussion

This literature review identified RCTs designed to mitigate the effects of LHL on ACP and evaluated the quality of these studies. We found only five studies that met our eligibility criteria, which were conducted mainly by two research groups. Intervention approaches included rewriting text at lower reading levels, adding images to materials, creating videos to enhance communication, and designing materials to enhance readability. Interventions identified aimed at increasing participant knowledge, preference for comfort care, engagement, and care documentation. Determining which interventions are most effective for mitigating the effects of LHL on ACP is difficult due to heterogeneity in ACP intervention approaches and outcome measures; however, we conclude that employing multiple methods to address LHL, such as introducing both an easy-to-read advance directive and an interactive website (Sudore et al., 2017a, 2018b), might be an advantageous approach for improving ACP outcomes in individuals with LHL.

Although we identified several interventions that significantly improved ACP outcomes, we found a lack of diversity in study settings and participants' race, ethnicity, and age among all five studies. For instance, all studies focused on middle-aged and older adults, despite literature that suggests that ACP is a process that supports adults at any age with discussing and planning future healthcare decisions (Weathers et al., 2016; Sudore et al., 2017b; de Vries et al., 2019). All studies were conducted during outpatient visits, which is an ideal time for providers to discuss end-of-life preferences because individuals are generally stable and not acutely ill during these visits (Houben et al., 2014); however, implementing ACP interventions in outpatient clinics might be problematic since many historically underrepresented populations, including Black and Latinx Americans, lack access to health care (Manuel, 2018; Rhee et al., 2019). Additionally, studies were only conducted in settings on the East Coast, West Coast, and Southern United States, thus limiting generalizability to persons living in other regions of the United States or other countries.

We identified several methodological issues among the reviewed RCTs, including issues with baseline differences between the treatment and control groups, blinding, outcome measure reliability and validity, and statistical analyses. Three studies reported differences between the treatment and control groups at baseline (Sudore et al., 2007, 2018a; Volandes et al., 2009), which might be due to issues with randomization methods or adequacy of sample size. Blinding issues were also identified in all studies; however, these issues are inherent to many behavioral interventions due to ethical concerns with using a placebo or nonequivalent comparator (Edmond et al., 2019). To minimize bias, two studies blinded participants to the study hypothesis (Sudore et al., 2017a, 2018b). Blinding the study hypothesis allows researchers to provide participants with an explanation of the intervention being offered, while concealing the intent of the study (Edmond et al., 2019).

There were also concerns with the lack of reporting of reliability and validity data for the measures used in the studies. Complete reliability and validity data were not reported for outcome measures in all RCTs, which is a concern since suboptimal psychometric rigor is a threat to internal validity (Heale and Twycross, 2015); however, since the concept of ACP has expanded over the past decade and there is currently a lack of consensus on outcomes that define successful ACP (Sudore et al., 2017b), there may be a dearth of psychometrically evaluated tools available to measure ACP outcomes, such as knowledge or patient care preference. Additionally, journal restrictions or previous protocol publication might have prevented authors from publishing reliability and validity data in their papers.

Our findings have implications for clinicians. Since individuals with LHL often have difficulty comprehending important concepts discussed during ACP (Institute of Medicine, 2015; Eneanya et al., 2018; Ladin et al., 2018), clinicians might need to employ different methods and invest more time into ACP interventions for this patient population. For instance, a clinician might promote the use of an interactive website or easy-to-ready advance directive prior to a clinic visit so that an individual may ask questions during their visit, or the clinician may reinforce concepts introduced. Additionally, there is evidence that engagement in ACP increases over time (Sudore et al., 2017a, 2018b), suggesting that ACP is not a one-time occurrence, but rather a process that involves behavior change. Therefore, clinicians should evaluate the ACP needs of their patients frequently, such as during routine care visits and other medical appointments.

There are also several research implications of this review. First, since all studies in this review were performed in outpatient clinics, there is a need to determine the effectiveness of these interventions in different settings, such as nursing homes, assisted living facilities, and long-term care facilities. Determining the efficacy of these interventions in nonclinical settings is important because clinician time constraints and barriers to healthcare access might prevent ACP interventions during a clinic visit. Second, researchers should use reliable and validated instruments for ACP outcomes to encourage comparison of findings across studies and ensure that constructs are appropriately measured (Sudore et al., 2017b). Finally, it is important to note that a majority of the interventions identified in this review were created and implemented by physicians, which might have limited the representativeness of approaches and their associated frameworks for addressing the effects of LHL on ACP.

There were several limitations of this review. First, because we only reviewed papers in English, we might have missed studies that were written in other languages. Second, including only RCTs prevented inclusion of findings from quasi-experimental studies. Finally, the eligibility criteria of this review prevented the inclusion of ACP interventions that did not directly measure participant's health literacy.

This review highlights the need for more valid evaluations of interventions that address the effects of LHL on ACP. Although the studies in this review implemented approaches tailored for individuals with LHL, interventions were not implemented exclusively in populations with LHL. Our findings suggest that interventions included in this review improved ACP outcomes, regardless of health literacy levels.

Since study settings were limited to outpatient clinics, future studies should be performed in alternative settings and locations, such as community settings and in the Midwestern U.S., since environmental context might affect the efficacy of interventions. Additionally, future intervention studies should continue to include historically underrepresented populations, including Latinx or Black populations, since LHL rates remain especially high (RTI International, 2011) and ACP participation remains low, among these groups (Hong et al., 2018). When implementing ACP interventions that address LHL in these populations, it is necessary to consider the contributing social determinants of health that many of these underrepresented populations experience, including inequities in educational opportunities, lack of culturally appropriate health information, and racism (Stormacq et al., 2019; Muvuka et al., 2020). Since social determinants of health affect health literacy, we should also consider how they affect ACP interventions designed to mitigate the effects of LHL. Future research should assess the relationships among social determinants of health, health literacy, and ACP outcomes to improve ACP interventions for individuals with LHL.

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