The importance of health literacy on clinical cancer outcomes: a scoping review

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Abstract: A scoping review was conducted to summarize what is known about the associations between health literacy and cancer outcomes and to determine which health literacy measures are most commonly used in cancer health literacy research. Five electronic databases (Ovid Medline, Ovid Embase, PsychInfo, EBSCO CINAHL and ERIC) were searched, yielding 3,591 articles. Of those, 146 met inclusion criteria. Associations between health literacy and preventative cancer behaviours were the most widely examined outcome (N=55, 38%). Post treatment behaviours were the least commonly examined outcome (N=5, 3%). While mixed results were prevalent in the literature, inadequate health literacy was often found to be associated with a myriad of unfavorable health outcomes. A large breadth of health literacy tools was additionally used in the evaluation of health literacy, suggesting that existing measures are inadequate or incomplete, and that no existing measure holistically assess the construct. This review provides a detailed account of the associations between health literacy and cancer in the literature. Health literacy impacts cancer patients' behaviours and health care service use. Future research is required to advance this field, in order to develop best-practices for health literacy evaluation and to produce programs and policies that aim to enhance patient outcomes.

Keywords: Cancer; health literacy; health outcomes; prevention; self-management

Introduction

Health literacy (HL) refers to an individual's ability to access, understand, appraise, and apply health related information (1). According to conservative estimates of the prevalence of low HL in Canada, only less than 12% of people aged 65 and older will not experience HL impairments throughout their lives and this challenge is widely felt across the globe (2,3). Health systems can be complicated to understand, leaving even highly educated individuals vulnerable when navigating their care (2). In

an era of increasingly complex advances in oncology, even the small number of patients with high HL will struggle to understand and act on information about their diagnosis and treatments, leading to higher mortality and morbidity among this population (4). Given that cancer patients also experience immense emotional and psychological distress, further impairing their ability to retain and utilize health information, the challenge of low HL in the context of cancer care is significant and deserves immediate attention (5).

In past decades increased attention has been paid to HL as a factor influencing health behaviors and the use

of preventive health care services (6). Low HL has been reported to be associated with several adverse clinical health outcomes including increased incidence of chronic illness, poorer intermediate disease markers, and less use of preventive health services (7). People with low HL are hospitalized more frequently, are less likely to undergo cancer screening, and more likely to have their cancer detected later (6,8). Although extensive research has been conducted to understand the effects of low HL on various health outcomes, there are no existing scoping reviews that comprehensively summarize the effects of HL in the context of cancer care delivery and clinical cancer-related outcomes. In addition, HL is an evolving concept with several definitions and measures (9). The purpose of this review is to identify and collate evidence on the known associations between HL and clinical cancer outcomes. In this review, clinical cancer outcomes are defined attitudes, knowledge and behaviors likely to affect engagement in cancer prevention, screening, and/or management activities and health care service-related outcomes (e.g., health services utilization, adherence/compliance, cost-related outcomes). A secondary purpose is to determine what HL measures are most commonly used in cancer HL research. We present the following article in accordance with the PRISMA extension for scoping reviews (PRISMA-ScR) reporting checklist (available at http://dx.doi.org/10.21037/ace-20-30).

Methods

A scoping review was conducted to summarize what is known about the association between HL and clinical cancer outcomes in the literature. Five electronic databases (Ovid Medline, Ovid Embase, EBSCO CINAHL PsychInfo, and ERIC) were searched by an information specialist. Ovid Medline, Ovid Embase and EBSCO CINAHL were searched as they broadly cover biomedical/health science literature. PsychInfo was searched to identify HL measurement tools, as it covers a wide range of survey instruments. ERIC was searched to discover additional HL literature, as it covers education related topics. Searches were limited to the English language and articles published between 1990 and March 1, 2020, as valid instruments to measure HL were not widely used until 1992. Database specific search strategies were developed using the following search terms: literacy [MeSH], health literacy [MeSH], computer literacy [MeSH], information literacy [MeSH, functional literacy, conceptual literacy, and numeracy for

HL and cancer, neoplasms [MeSH], oncology [MeSH], tumor, and carcinoma for cancer. See Supplementary file 1 for detailed search strategies.

Citations were uploaded into EndNote for duplicate removal and exported into a spreadsheet. Citations were screened independently by a single reviewer in a two-stage process. Studies that did not meet inclusion criteria were excluded during title and abstract scan or full-text review as required. A small sample of articles (5%, N=180) were screened by two independent reviewers to assess inter-rater reliability and no discrepancies were identified. The literature suggests that a single reviewer process has no impact or a negligible impact on findings when performed by an experienced reviewer, which was the case for the present review (10).

Articles were included if they were English language research studies (observational or experimental), focused on associations between HL and cancer-related outcomes. Articles found in the gray literature were excluded because the focus of this review was on empirical evidence of association. Use of a validated instrument to measure HL was required. The study population included all patients, with or without a cancer diagnosis, across all cancer disease types. Data was extracted from full text articles and study characteristics were summarized using numeric and thematic analyses. Data was extracted using a standardized charting form developed by the reviewers, consisting of ten dimensions: jurisdiction, study purpose, study design, disease site, stage in cancer journey, sample, HL measures, outcomes, associations (results of the study), and authors' conclusion. Inductive thematic coding was conducted to classify clinical cancer outcomes and a numerical summary of HL measures used was additionally performed.

Results

The search yielded 3,591 articles. After duplicate removal and title and abstract scan, the number of eligible articles was reduced to 249. Backward reference searches of 13 systematic reviews identified nine additional articles. Data was extracted from 146 articles (see *Figure 1*).

Numeric summary

Included studies were published in 20 countries, with most published in the US (N=91). Study design varied with a majority using cross sectional surveys (N=86). The top three cancer sites of interest were breast (N=51), cervix (N=25),
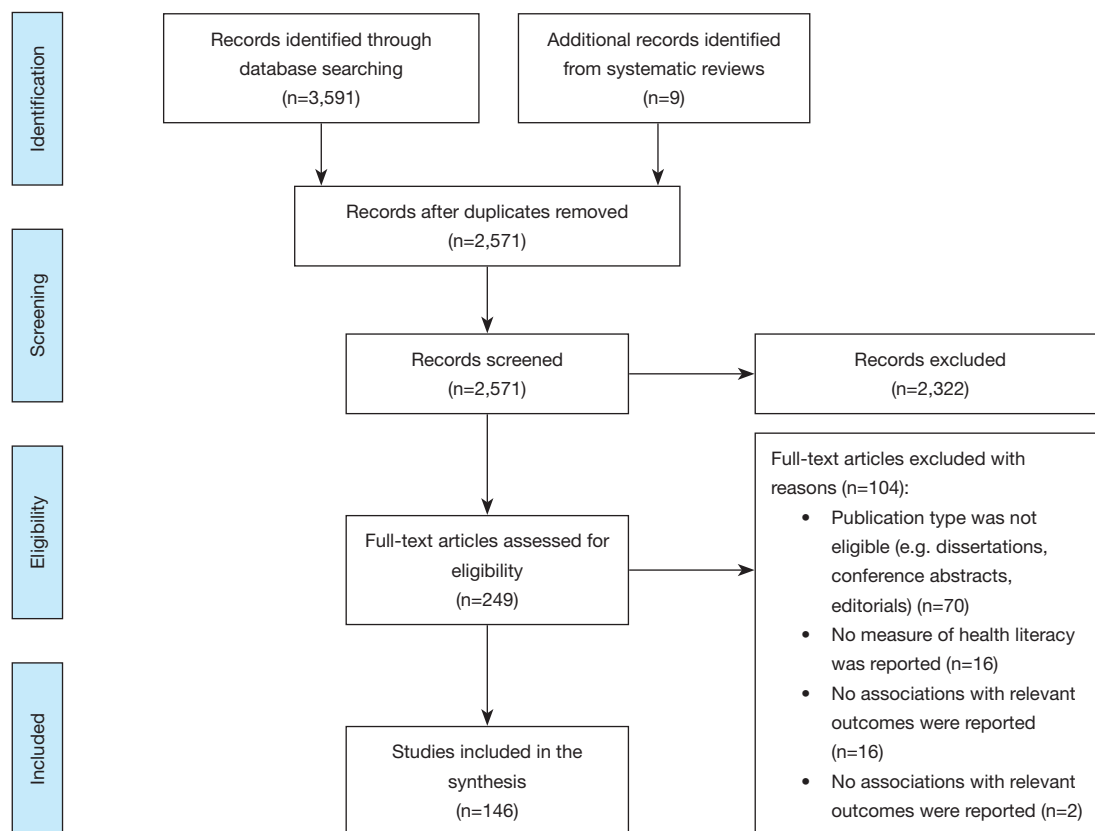
Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. Included studies extend on a previous review conducted by the authors (11).

and colorectal (N=32). The majority of studies focused on cancer in the screening stage (N=58), followed by prevention (N=27), treatment (N=26), survivorship (N=19), and diagnosis (N=4). Characteristics of included studies are summarized in *Table 1*.

Thematic summary

HL assessment tools

Fifty-three HL measures were identified and thirty were validated. Measurement instruments are summarized in *Table 2*. Among these, nineteen measured general HL, nine numeracy, and eight functional HL.

The Rapid Estimate of Adult Literacy in Medicine (REALM) (N=24) and the Test of Functional HL in Adults (TOFHLA) including the abbreviated version (S-TOFHLA) (N=17) were most frequently used. Eighty-one studies examined general HL, 19 examined functional HL and 22 examined numeracy using. The three-item objective numeracy scale (126), which evaluates individuals'

understanding and ability to solve basic probability and related ratio problems (76), was the most frequently used (N=9).

Fifteen studies assessed cancer-specific literacy using eleven measurement tools. Echeverri *et al.* (53) used the Cancer Health Literacy Test as well as the Multidimensional Cancer Literacy Questionnaire. Another study used the Cancer Literacy Scale (45). Three studies assessed screening literacy using the Assessment of Health Literacy in Cancer Screening (38,73,93). The Cancer Message Literacy Test was used in two studies, to assess patients' listening and reading abilities (25) and communication with physicians (142). Three studies assessed breast cancer related literacy (121,122,143). The Cancer Literacy Assessment Tool for breast cancer (B-CLAT) was used in the two studies (122,143) and it was adapted to assess cervical cancer literacy (143). One study used the Assessment of Colon Cancer Literacy measure (28).

Five studies assessed e-HL (12,81,111,117,144). The e-HL Scale was used in all five studies. Twenty-seven studies used other measures of HL: three used

Table 1 Characteristics of Included Studies (N=146)

First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
Nejati (2019) (12)	Iran	Prospective observational study	Multiple myeloma	Survivorship	276 men	eHealth Literacy Scale (eHEALS)	Trust in the healthcare system; patient self-reported communication pattern; perceived involvement in shared decision making
Adams (2013) (13)	Australia	Secondary analysis of population-based survey data (SAHOS[1])	All	NR	2,824	The Newest Vital Sign (NVS)	Perception of the risk of lifestyle behaviors for cancer
Aggarwal (2007) (14)	USA	CSS[2]	Breast, CRC	Screening	264	3 item scale developed by Black et al.	Screening behavior; screening knowledge
Agho (2012) (15)	USA	CSS	CRC	Screening	142	Author developed questionnaire (incorporated instruments developed by Chew et al.)	Screening knowledge
Albright (2018) (16)	USA	CSS	Cervical	Prevention	360	Health Literacy Questionnaire (44 items); NVS	HPV and HPV vaccine knowledge
Almutairi (2018) (17)	Saudi Arabia	CSS	Colorectal (CRC)	Prevention, screening	250	The Short Test of Functional Health Literacy in Adults (S-TOFHLA)	Awareness of CRC and CRC screening
Altsitsiadis (2012) (18)	EU (multi-national)	Secondary analysis of data collected in EPIDERM[3] study (skin cancer patients vs. hospital-based control persons)	Skin	Prevention	3,289	S-TOFHLA	Sunscreen and sunbed use
Anderson (2011) (19)	USA	Mixed methods (CSS + interview)	Breast	Screening	191 (physicians)	3-item Objective Numeracy Scale (by Schwartz et al.)	Physicians' perception of their patients' knowledge and opinions about screening
Heuser (2019) (20)	Germany	Prospective observational study	Breast	Treatment	863	The European Health Literacy Survey (HLS-EU-Q16 Scale)	Multidisciplinary tumour conference attendance; opportunity to partake in shared decision making
April-Sanders (2017) (21)	USA	CSS	Breast	Screening	250	Validated scale developed by Chew et al. (3 items)	Breast cancer worry and perceived risk of breast cancer
Arnold (2012) (22)	USA	Secondary analysis of baseline data collected for RCT	Breast	Screening	975	REALM	Awareness, knowledge, beliefs about CRC screening; screening behavior
Heckman (2019) (23)	USA	CSS	Skin	Prevention	958, adults with heightened risk of skin cancer	Author adapted scale; including 3-item measure by Chew et al. (2004) & 1 reading ability item from Jeppesen et al. (2009)	Prevention; exposure to UV radiation (e.g., indoor tanning, sunburn) and engagement in protective behaviours (e.g., sunscreen use, sunless tanning)
Turkoglu (2019) (24)	Turkey	CSS	Bladder	Treatment	133	The European Health Literacy Survey (HLS-EU-Q47)	Compliance with treatment protocol (complete vs. incomplete) as recorded on hospital records
Bennett (1998) (25)	USA	Mixed methods (CSS + retrospective chart review)	Prostate	Diagnosis	212	REALM	Pathologic stage of prostate cancer
Bennett (2009) (26)	USA	CSS	Breast	Prevention, screening	2,668	The National Assessment of Adult Literacy (NAAL) 2003	Self-rated health status; prevention behavior (intake of mammogram)
McDowell (2019) (27)	USA	CSS	Breast	Survivorship	1,128 women	Set of Brief Screening Questions (SBSQ) by Chew et al.	Quality of life (disease specific measured using the FACT-B)
Boogar (2018) (28)	Iran	CSS	CRC	Screening	366	Assessment of Colon Cancer Literacy (ACCL)	Perceived efficacy, perceived susceptibility; defensive avoidance

Table 1 (continued)

Table 1 (*continued*)

First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
Ousseine (2019) (29)	France	CSS	All, primarily breast	Treatment & survivorship	2,299	FHL: The Functional Communicative and Critical HL scale (FCCHL)	Perceived participation in the process of shared decision making in deriving their treatment plan
						Health Literacy Questionnaire (HLQ)	
						The Single Item Literacy Screener (SILS)	
						Subjective Numeracy Scale (SNS-3)	
Boxell (2012)[4] (30)	UK	Quasi-experimental (pre/post intervention analysis)	Gynecological	NR	451	NVS	Gynecological cancer symptom awareness; barriers to medical help seeking
Brewer (2009) (31)	USA	CSS	Breast	Survivorship	163	REALM	Perception of recurrence risk
Brittain (2016) (32)	USA	Secondary analysis of RCT data	CRC	Screening	817	REALM	Intention for CRC screening tests (FOBT, colonoscopy)
Brown (2011) (33)	USA	CSS	Breast	NR	120 women with personal or family history of breast cancer	HL: REALM	Interpretation of graphical representations of breast cancer risk
						Numeracy: 6-item numeracy scale (combined two validated scales: Woloshin scale + Schapira scale)	
Bynum (2013) (34)	USA	CSS	Cervical	Prevention, screening	145 HIV positive women	The Single Item Literacy Screener (SILS)	Cervical cancer screening knowledge; screening behavior
Chang (2019) (35)	China	CSS	All	Treatment	120	The Short-form Mandarin Health Literacy Scale (s-MHLS)	Perceived participation in the process of shared decision making in deriving their treatment plan
Cho (2008) (36)	USA	CSS	CRC, prostate, breast, cervical	Prevention, screening	489	S-TOFHLA	Screening behavior; health care utilization (ER visits, hospitalization)
Ciampa (2010) (37)	USA	Secondary analysis of population-based survey data (HINTS 2007)[5]	CRC	Screening	4,133	2 items adapted from previously developed scales (subjective/objective numeracy scales; Woloshin *et al.*; Lipkus *et al.*)	Perception of provider communication; CRC screening status
Han (2019) (38)	USA	CSS	Cervical	Screening	560 women	The Assessment of Health Literacy in Cancer Screening (AHLC)	Screening behaviour; self-reported triennial and lifetime pap test use
Thompson (2019) (39)	USA	Secondary analysis of HINTS data	Cervical	Screening	2,992, women	8 HINTS survey questions	Timing of last pap-test
Davis (1996) (40)	USA	CSS	Breast	Screening	445	REALM	Knowledge and attitudes regarding mammography
Davis (2017) (41)	USA	CSS	CRC	Screening	339	REALM	CRC screening knowledge; perceived barriers to screening
Xia (2019) (42)	China	CSS	All	Survivorship	4,589	Set of Brief Screening Questions (SBSQ) by Chew *et al.*	Self-reported quality of life
Jin (2019) (43)	USA	CSS	CRC	Screening	433, Korean Americans	The Brief Health Literacy Screening Tool (BRIEF)	Decisional balance
Haack (2020) (44)	Germany	CSS	Prostate	NR	1,577 men previously diagnosed with PC	Author developed questionnaire by Haack, 2018	Quality of life (i.e., in the last four weeks) and fear of disease progression (e.g., affecting various areas of life)

Table 1 (*continued*)

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First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
Diviani (2012) (45)	Switzerland	Instrument development and validation study	All	NR	639	Cancer Literacy Scale (CLS) 37 items	Attitudes toward cancer screening; health promoting behaviors
Diviani (2014) (46)	Switzerland	CSS	All	Prevention, screening	639	Functional HL: scales by Chew *et al.* / Cancer literacy: CLS-37	Cancer information seeking; intention for screening; screening behaviors
Keim-Malpass (2018) (47)	USA	Prospective observational study	Breast	Treatment	512	Set of Brief Screening Questions (SBSQ) by Chew *et al.*	Initiation of adjuvant endocrine therapy and adherence to the therapy at 2-year follow-up
Dolan (2004) (48)	USA	CSS	CRC	Screening	377 male veterans	REALM	Knowledge, attitudes, beliefs toward CRC cancer and screening
Donelle (2008) (49)	Canada	CSS	CRC	Prevention, screening	140	FHL: S-TOFHLA / Numeracy: 3-item objective numeracy scale; Lipkus scale / Math anxiety: The Abbreviated Math Anxiety Scale (AMAS)	Risk comprehension (comprehension of online CRC screening information)
Donelle (2009) (50)	Canada	CSS	All	Prevention	49	NVS; 3-item objective numeracy scale; Lipkus scale	Comprehension of cancer risk information
Drummond (2019) (51)	Ireland	CSS	All	Prevention	259 men	Set of Brief Screening Questions (SBSQ) by Chew *et al.*	Active and passive cancer information seeking behaviour; preference for receiving cancer information
Ozkaraman (2019) (52)	Turkey	CSS	All	Treatment	111	The European Health Literacy Survey (HLS-EU-Q47)	Quality of life (general wellness, functional difficulties, and symptom control); self-efficacy to manage their chronic illness (measured using the SEMCD)
Echeverri (2018) (53)	USA	Community-based participatory research (CBPR)	All	NR	1,500	Cancer health literacy test (CHLT30)	Willingness to participate in cancer research
Essink-Bot (2016) (54)	The Netherlands	CSS	CRC	Screening	1,500	The Short Assessment of Health Literacy in Dutch (SAHL-D)	Screening decision-relevant knowledge; informed decision making
Fernandez (2016) (55)	USA	CSS	CRC, breast	Prevention, screening	707	Objective HL: TOFHLA / Subjective HL: A single item screener by Chew *et al.*	Health perceptions; screening behaviors
Ferreira (2005)[6] (56)	USA	RCT	CRC	Screening	Intervention: 197; control: 185	REALM	CRC screening behaviors
Fleary (2019) (57)	USA	Secondary analysis of population-based survey data (HINTS)	All	Prevention	1,675	NVS	Cancer prevention beliefs; cancer prevention behaviors
Fleary (2019) (57)	USA	Secondary analysis of HINTS data	All	Prevention	1,675	4 HINTS survey questions	Cancer prevention beliefs & engagement in prevention behaviours (e.g., diet, exercise, smoking)
Fortner (2007) (58)	USA	CSS	Cervical	Screening	103	REALM	Understanding of the Pap smear and colposcopy
Woudstra (2019) (59)	The Netherlands	Prospective observational study	CRC	Screening	407	Comprehension: The Short Assessment of Health Literacy in Dutch (SAHL-D) / Application: The Newest Vital Sign in Dutch (NVS-D) / Numeracy: Four items from the Short Assessment of HL (SAHL)	Knowledge about CRC and CRC screening behaviours; attitudes about participating in CRC; injunctive and descriptive norm; CRC risk perception; decisional conflict and decisional certainty about participating in CRC screening

Table 1 (*continued*)

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First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
Friedman (2009) (60)	USA	Mixed method (survey + interviews/focus groups)	Prostate	Prevention	25	FHL: The Cloze procedure, S-TOFHLA	Understanding and perception of prostate cancer risk (assessed by qualitative interviews)
Gabel (2019) (61)	Denmark	CSS	CRC	Screening	7,142, men eligible for screening	The European Health Literacy Survey (HLS-EU-Q16 Scale)	Knowledge, attitudes and worries about CRC screening
Garbers (2004) (62)	USA	CSS	Cervical	Screening	205	FHL: TOFHLA (Spanish version)	History of Pap test (self-report)
Garbers (2009) (63)	USA	CSS	Breast, cervical	Screening	707	FHL: TOFHLA (Spanish version)	Follow-up adherence after mammography (outcome 1); receipt of Pap test after mammogram (outcome 2); return for annual mammogram (outcome 3)
Goodwin (2018) (64)	Australia	CSS	Prostate	Survivorship	565	The Health Literacy Questionnaire (HLQ)	Quality of life (measured by SF36)
Goto (2019) (65)	Japan	CSS	All	Prevention	1,002	The Communicative and Critical Health Literacy Scale (CCHL)	Screening behaviour; health service utilization including engagement in annual cancer screening
Guerra (2005a) (66)	USA	CSS	CRC	Screening	136	FHL: S-TOFHLA	Knowledge, beliefs, and behaviors related to CRC screening
Guerra (2005b) (67)	USA	CSS	Breast	Screening	96	FHL: S-TOFHLA	Knowledge, beliefs, and behaviors related to breast cancer screening
Hahn (2007) (68)	USA	CSS	Mix (GI, gender-specific, hematologic, other)	Treatment, survivorship	420	Woodcock Language Proficiency Battery	Health related quality of life (HRQL) measurement (measured by FACT-G, SF36, SGUQ[7])
Hahn (2010) (69)	USA	CSS	Mix (GI, gender-specific, hematologic, other)	Treatment, survivorship	97	REALM, Woodcock Language Proficiency Battery, S-TOFHLA	Attitudes towards literacy screening; informed consent comprehension; HRQL
Halbach (2016a) (70)	Germany	Prospective observational study	Breast	Treatment	1,359	The European Health Literacy Survey (HLS-EU-Q16)	Fear of cancer progression
Halbach (2016b) (71)	Germany	Prospective observational study	Breast	Treatment	1,060	The European Health Literacy Survey (HLS-EU-Q16)	Unmet information needs
Halverson (2015) (72)	USA	CSS	Breast, CRC, prostate, lung	Treatment	1,841	4-item questionnaire based on TOFHLA (3 items) and REALM (1 item)	HRQL
Han (2017)[8] (73)	USA	RCT	Breast, cervical	Prevention, screening	560	The Assessment of Health Literacy in Cancer Screening	Uptake of mammogram, Pap test
Kim (2019) (74)	USA	Secondary analysis of population-based survey data (BRFSS)	Breast, cervical	Screening	Breast: 44,241; cervical: 38,956	3 items from population health survey; the Behavioral Risk Factor Surveillance System (BRFSS)	Self-reported breast and cervical cancer screening status (i.e., Have you ever had a mammogram/pap-test?/When was your last mammogram/pap test?)
Hanoch (2014) (75)	USA	CSS	Breast	Prevention	477	Numeracy: The Objective Numeracy Scale; The Subjective Numeracy Scale	Interpretation of inconclusive BRCA1/2 genetic test results
Hanoch (2015) (76)	USA	CSS	Breast	Treatment	476	Numeracy: The Objective Numeracy Scale; The Subjective Numeracy Scale	Preference for shared decision making (treatment related decision)
Harrison (2020) (77)	USA	Retrospective chart review	Head & neck	Survivorship	218, ≥1 year post treatment	Set of Brief Screening Questions (SBSQ) by Chew *et al.*	Physical and social-emotional quality of life (measured using the University of Washington QOL questionnaire)
Hawley (2010) (78)	USA	CSS	Breast	Treatment, survivorship	2,148	3-item questionnaire by Chew *et al.*	Satisfaction with care coordination

Table 1 (*continued*)

Table 1 (*continued*)

First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
Hay (2015) (79)	USA	Secondary analysis of HINTS data	CRC	Prevention	590	HINTS survey questions	"Don't know" responses to perceived risk (DKPR) questions
Heberer (2016) (80)	USA	CSS	Cervical	Screening	1,318	NVS	Use of Pap smear
Heiman (2018) (81)	Germany	CSS	All	Treatment, survivorship	182	eHEALS	Use of internet for information gathering
Hodges (2016) (82)	USA	Secondary analysis of RCT data	CRC	Screening	270	REALM	The impact of an educational intervention on CRC screening knowledge, attitude, intention
Hoffman-Goetz (2009) (83)	USA	Secondary analysis of population-based survey data (HINTS 2003)	All	NR	6,369	Measured by proxy variables (television viewing, internet use, reading newspapers)	Self-reported health status
Shen (2019) (84)	Taiwan	CSS	Breast	Treatment	511	The European Health Literacy Survey (HLS-EU-Q)	Perceived participation in the process of shared decision making in their most recent medical consultation
Husson (2015) (85)	The Netherlands	CSS	CRC	Survivorship	1,743	Set of Brief Screening Questions (SBSQ) by Chew *et al.*	HRQOL (measured by EORTC QLQ-C30)
Jiang (2018) (86)	USA	Secondary analysis of population-based survey data (HINTS)	All	Survivorship	459	HINTS survey questions	Emotional health
Jin (2019) (43)	USA	CSS	CRC	Screening	240	The Brief Health Literacy Screening Tool (developed by Haun *et al.*)	Uptake of CRC screening tests
Jung (2016) (87)	South Korea	CSS	All	Prevention, screening	2,540	Author-developed questionnaire (modified from the Personal Competence of Health Care Scale for Koreans)	Primary prevention: healthy lifestyle and behaviors; secondary prevention: finding cancer early and cancer screening for early treatment
Kadivar (2016) (88)	USA	CSS	Breast	Screening	4,244	FHL: The National Assessment of Adult Literacy (NAAL 2003)	Uptake of mammogram
Kamimura (2016) (89)	USA	CSS	Breast	Prevention, screening	276	16-item questionnaire adapted from Chew *et al.*	Negative perceptions of breast cancer and treatment
Keim-Malpass (2018) (90)	USA	Retrospective chart review	Breast	Treatment	512	SBSQ	Surgical decision for breast cancer
Keller (2009) (91)	Switzerland	CSS	Colon	NR	266	Lipkus expanded numeracy scale	Risk perception of prenatal test results for Down syndrome and results of colon cancer screening tests
Kelly (2007) (92)	USA	CSS	Colon	NR	457	Numeracy: 3-item Objective Numeracy Scale	Perceived colon cancer risk (estimate of personal percentage risk)
Kim (2018) (93)	USA	Secondary analysis of RCT data	Cervical	Screening	560	The assessment of Health Literacy in Cancer Screening (Baker *et al.*)	Cervical cancer knowledge; use of Pap test (screening behavior); decisional balance
King-Marshall (2016) (94)	USA	CSS	CRC	Screening	1,821 (patients); 1,492 (caregivers)	Brief Health Literacy Screening Tool—BRIEF	Knowledge of colonoscopy
Koay (2013) (95)	Australia	CSS	Head and neck, lung	Treatment, survivorship	93	S-TOFHLA Health Literacy Management Scale (HeLMS)	Distress level
Kobayashi (2014) (96)	UK	Secondary analysis of population-based survey data (ELSA[9])	CRC	Screening	3,087	4-item test from the International Adult Literacy Survey	CRC screening (use of FOBT kit)

Table 1 (*continued*)

Table 1 (*continued*)

First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
Kobayashi (2016) (97)	UK	Secondary analysis of HINTS (2013) data	All	NR	2,657 adults with no history of cancer	NVS	Information seeking behavior; cancer fatalism
Koo (2017) (98)	USA	CSS	Prostate	Screening	200	Numeracy: 3-item Objective Numeracy Scale	Perceived risk of prostate cancer mortality (accuracy in interpretation)
Kugbey (2019) (99)	Ghana	CSS	Breast	Treatment	205 women	Author adapted; from the Original Health Literacy Scale (Ishikawa, 2008)	Quality of life (disease specific measured using the FACT-B); anxiety and depression
Lee (2016) (100)	South Korea	CSS	All	Screening	585	CL: Cancer literacy scale by Stein *et al.*	Cancer screening behavior (FOBT, gastrography, sigmoidoscopy/ colonoscopy, PSA screening, ultrasound breast exam)
Lee (2018) (101)	South Korea	CSS	Lung	Treatment	80	FHL: S-TOFHLA	Quality of life (disease-specific QOL measured by FACT-L; general QOL by FACT-G
Li (2018) (102)	USA	Secondary analysis of population-based survey data (The Population Study of Chinese Elderly in Chicago)	Breast, prostate, cervical, CRC	Screening	3,157	REALM (revised version)	Cancer screening behaviors
Lillie (2007) (103)	USA	CSS	Breast	Treatment	163	REALM	Participation in decision making for genomic tests
Lindau (2002) (104)	USA	CSS	Cervical	Prevention, screening	529	REALM Physicians' perceptions of patient literacy level	Cervical cancer screening knowledge
Lindau (2006) (105)	USA	Prospective observational study	Cervical	Screening, diagnosis	68 women with abnormal Pap diagnosis	REALM Physicians' perceptions of patient literacy level; patients' education level	Adherence to follow-up recommendations after abnormal Pap results (assessed by chart abstraction)
Song (2017) (106)	USA	CSS	Prostate	Treatment	142	eHEALS	Partner engagement in decision making for treatment
Mahal (2015) (107)	USA	Prospective observational study	Prostate	Treatment	375	REALM short form	Receipt of salvage androgen deprivation therapy (ADT)
Matsuyama (2011) (108)	USA	CSS	GI, breast, lung and other	Treatment	138	REALM; S-TOFHLA	Information needs [measured by the Toronto Informational Needs Questionnaire (TINQ)]
Mazor (2016) (109)	USA	Mixed methods (survey + audio vignette analysis)	Breast, prostate, CRC	Prevention, screening	433	HL-Listening skill: The Cancer Message Literacy Test (CMLT)-Listening	Pattern of patient questions
McEwan (2014) (110)	Egypt	Qualitative study	Breast	Diagnosis	15 women diagnosed with breast cancer	Explored in interviews	Experiences with diagnosis and treatment delays
Mitsutake (2012) (111)	Japan	CSS	CRC	Screening	2,970	eHealth Literacy: eHEALS	CRC screening knowledge and practice
Mora-Pinzon (2019) (112)	USA	CSS	Breast	Survivorship	1,221	S-TOFHLA	Perceived care coordination (presence of a care coordinator as a covariate)
Morris (2013) (8)	USA	CSS	All	NR	1,013	HL: CMLT-Listening, Reading Numeracy: Lipkus numeracy scale (8 items)	Cancer related attitudes and behaviors

Table 1 (*continued*)

Table 1 (*continued*)

First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
O'Hara (2018) (113)	Australia	CSS	Breast	Screening	317 women from 3 cultural groups (English, Arabic, Italian)	The Health Literacy Questionnaire	Participation in BC screening; barriers to BC screening
Ojinnaka (2015) (114)	USA	CSS	CRC	Screening	456 uninsured adults age >50 years	A single item screener by Chew *et al.*	CRC screening behavior
Orom (2018) (115)	USA	CSS	Colon	NR	1,005	FHL: NVS	DK responses for risk perception questions
Pagán (2012) (116)	USA	CSS	Breast	Screening	722	FHL: S-TOFHLA	Uptake of mammography
Park (2014) (117)	USA	CSS	All	NR	108	eHealth literacy: eHEALS	Information seeking behavior; educational needs about information searching, history of cancer screening tests
Plummer (2017) (118)	Australia	CSS	Breast	Survivorship	36	HLQ	Physical activity (self-report)
Portnoy (2010) (119)	USA	CSS	Breast	Screening	246	Numeracy: 3-item Objective Numeracy Scale Genetic literacy: The Rapid Estimate of Adult Literacy in Genetics (REAL-G)	Knowledge about genetic counseling
Rakhshkhorshid (2018) (120)	Iran	CSS	Breast	Screening	250	HLQ	Knowledge, perceptions, and screening behavior related to breast cancer
Roh (2018) (121)	USA	CSS	Breast	Screening	286	Breast cancer literacy: Breast Cancer Literacy Questionnaire (author developed)	Breast cancer screening (CBE, mammography)
Roman (2014) (122)	USA	Secondary analysis of baseline data of a RCT	Breast, cervical	Screening	514	HL: risk scores using sum of 3 indicators: whether the participant had low cancer literacy (breast or cervical), no knowledge of own family cancer history, and an education less than 12 years CL: BCLAT, CCLAT	Appropriate screening behaviors (annual CBE, annual mammogram for women age >40; Pap smear every 3 years)
Ross (2018) (123)	USA	Secondary analysis of HINTS data	All	NR	3,052	Numeracy: questions in HINTS survey	Cancer information overload; cancer fatalism; cancer prevention knowledge; and cancer worry
Rutherford (2018) (124)	Ireland	CSS	Breast	NR	86	NVS	Accuracy of risk perception
Schapira (2011) (125)	USA	CSS	Breast, cervical, CRC	Screening	359	HL: REALM Numeracy: Lipkus expanded scale	Screening behavior
Schwartz (1997) (126)	USA	CSS	Breast	Screening	287 female veterans	Numeracy: 3-item Objective Numeracy Scale	Accuracy in applying risk reduction information (quantitative information)
Scott (2002) (127)	USA	CSS	Breast, cervical	Prevention, screening	2,722	S-TOFHLA	Self-reported use of clinical preventive health care (mammogram, Pap test, flu vaccination)
Sentell (2013) (128)	USA	Secondary analysis of population-based survey data (California Health Interview Survey 2007)	CRC	Screening	15,888	2 questions in California Health Interview Survey	Compliance of CRC screening guidelines

Table 1 (*continued*)

Table 1 (*continued*)

First author (year)	Jurisdiction	Study design	Cancer type	Stage in cancer journey	Sample size	Measure of HL	Outcomes
Sentell (2015a) (129)	USA	Secondary analysis of population-based survey data (California Health Interview Survey 2007)	Breast, cervical	Screening	Cervical: 15,210; breast: 11,163	2 questions in California Health Interview Survey	Screening behavior
Sentell (2015b) (130)	USA	Secondary analysis of population-based survey data (California Health Interview Survey 2007)	Breast, cervical, CRC	Screening	Cervical: 632; CRC: 488; breast: 326	2 questions in California Health Interview Survey	Screening behavior
Sharp (2002) (131)	USA	CSS	Cervical	Screening, diagnosis	130	REALM	Psychological distress
Smith (2016) (132)	UK	Secondary analysis of RCT data	CRC, screening	Screening	964	Numeracy: a single item measure used in HINTS	CRC screening knowledge; attitudes; defensive processing; intention for screening
Son (2017) (6)	South Korea	CSS	All	Prevention	542	16-item questionnaires developed by Chew *et al.*	Cancer-related knowledge; preventive health behaviors
Tagai (2019) (133)	USA	CSS	Prostate	Treatment	50	3-item scale by Chew *et al.*	Knowledge and perception of GSS
Tang (2017) (134)	China	CSS	Breast	Survivorship	286	Health Literacy Management Scale	Compliance of postoperative functional exercise
Tecu (2012) (135)	USA	Mixed methods (survey + interview)	Cervical	Screening	37	REALM	Perception and beliefs on factors influencing cancer-related behaviors (recognition of symptoms, decision to seek medical help)
Thompson (2019) (39)	USA	Secondary analysis of HINTS data	Cervical	Screening	2,992	Use of proxy variables: selected from the survey data using the domains of the Integrated Model of Health Literacy's definition of HL	Previous experience of Pap test (Pap testing within the last 3 years)
Tobias-Machado (2013) (136)	Brazil	CSS	Prostate	Screening	17,558	Author-developed general epidemiologic questionnaire	Compliance with follow-up recommendations after screening; biopsy results
Turkoglu (2018) (24)	Turkey	CSS	Bladder	Treatment	126	HLS-EU 47	Cystoscopy follow-up compliance
Verkissen (2014) (137)	The Netherlands	CSS	Ovarian	Survivorship	275	3-item questionnaires by Chew *et al.*	Perceived information provision and satisfaction
White (2008) (138)	USA	Secondary analysis of population-based survey data (NAAL)	Breast, cervical, colon, prostate	Prevention, screening	18,100	NAAL	Self-reported use of preventive services (mammogram, Pap smear, prostate cancer screening, CRC screening etc.)
Yılmazel (2018) (139)	Turkey	CSS	Breast	Screening	519	REALM	Mammogram awareness; screening behavior
Zanchetta (2004; 2007) (140,141)	Canada	Qualitative study	Prostate	Prevention	15 men	Explored in interviews	Information seeking strategy

[1], South Australian Health Omnibus Survey; [2], cross-sectional study; [3], a 3-year European Union-funded, a multicenter case control study (skin cancer patients *vs.* hospital-based control patients); [4], intervention: provision of gynecological cancer information leaflets; [5], The Health Information National Trends Survey; [6], intervention: Healthcare provider attended a workshop on CRC screening (provider-directed intervention); [7], The Standard Gamble Utility Questionnaire; [8], intervention: HL intervention including educational brochure, DVD, guidebook and HL skills training; [9], The English Longitudinal Study of Ageing. HL, health literacy; CSS, cross-sectional survey; CRC, colorectal cancer; NR, not reported; RCT, randomized controlled trial; HINTS, Health Information National Trends Survey; FOBT, fecal occult blood test; REALM, Rapid Estimate of Adult Literacy in Medicine; S-TOFHLA, Short Test of Functional Health Literacy in Adults; QOL, quality of life; ELSA, English Longitudinal Study of Ageing; HRQOL, health related quality of life; BC, breast cancer; CBE, clinical breast examination; CL, Cancer Literacy; BCLAT, Breast Cancer Literacy Assessment Tool; CCLAT, Cervical Cancer Literacy Assessment Tool .

Table 2 Identification of Health Literacy Measurement Tools (N=146)

Measurement type	Health literacy category	Assessment tools	References
Validated measurement tools (N=30)	General health literacy; literacy (N=19)	REALM (N=24)	Arnold (2012), Arnold (2016), Arnold (2017), Bennett (1998), Brewer (2009), Brittain (2016), Brown (2011), Davis (1996), Davis (2017), Dolan (2004), Ferreira (2005), Fortner (2007), Hahn (2010), Hodges (2016), Li (2018), Lillie (2007), Lindau (2006), Lindau (2002), Mahal (2015), Matsuyama (2011), Tecu (2012), Schapira (2011), Sharp (2002), Yilmazel (2018)
		3-item questionnaire (SBSQ) developed by Chew *et al.* for subjective HL (N=11)	Altsitsiadis (2012), April-Sanders (2017), Diviani (2014), Hawley (2010), Tagai (2019), Verkissen (2014), Xia (2019), Harrison (2020), McDowell (2019), Drummond (2019), Keim-Malpass (2018) (47)
		Single item screener for subjective HL (by Chew *et al.* (N=2)	Fernandez (2016), Ojinnaka (2015)
		TOFHLA (N=1)	Fernandez (2016)
		S-TOFHLA (N=7)	Cho (2008), Jenkins (2016), Koay (2013), Liu (2011), Matsuyama (2011), Mora-Pinzon (2019), Scott (2002)
		16-item questionnaire by Chew *et al.* (N=2)	Kamimura (2016), Son (2017)
		Brief Health Literacy Screening Tool—BRIEF (4 item) (N=1)	King-Marshall (2016)
		Health Literacy Questionnaire (HLQ) (N=6)	Albright (2018), Goodwin (2018), Kayser (2015), O'Hara (2018), Plummer (2017), Ousseine (2019)
		Health Literacy Management (HeLMS) Scale (N=2)	Koay (2013), Tang (2017)
		International Adult Literacy Scale (N=1)	Kobayashi (2014)
		The New Vital Scale (NVS) (N=4)	Kobayashi (2016), Fleary (2018), Woudstra (2018), Boxell (2012)
		Short Assessment of Health Literacy (SAHL) (N=2)	Essink-Bot (2016), Woudstra (2019)
		European Health Literacy Survey (HLS-EU-Q16) (N=4)	Halbach (2016a,b), Heuser (2019), Gabel (2019)
		HLS-EU-Q47 (N=5)	Shen (2018), Turkoglu (2018), Turkoglu (2019), Hoffmann (2019), Ozkaraman (2019)
		Woodcock language proficiency battery (N=2)	Hahn (2007; 2010)
		The Single Item Literacy Screener (SILS) (N=2)	Bynum (2013), Ousseine (2019)
		Iranian Health Literacy Questionnaire (IHLQ) (N=1)	Rakhshkhorshid (2018)
		NAAL (National Assessment of Adult Literacy) (N=2)	Bennett (2009), White (2008)
		4-item questionnaire based on TOFHLA and REALM (N=1)	Halverson (2015)

Table 2 (*continued*)

Table 2 (*continued*)

Measurement type	Health literacy category	Assessment tools	References
		Health Literacy Management (HeLMS) Scale (N=2)	Koay (2013), Tang (2017)
	Functional Health Literacy (N=8)	Test of Functional Health Literacy in Adults (TOFHLA) (N=3)	Donelle (2008), Garbers (2004; 2009)
		Short Test of Functional Health Literacy in Adults (S-TOFHLA) (N=6)	Friedman (2009), Almutairi (2018), Guerra (2005a,b), Lee (2018), Pagán (2012)
		The New Vital Scale (NVS) (N=3)	Adams (2013), Orom (2018), Woudstra (2019)
		3 item scale by Chew *et al.* (N=2)	Diviani (2014), Husson (2015)
		NAAL (National Assessment of Adult Literacy) (N=1)	Kadivar (2016)
		The Communicative and Critical Health Literacy Scale (CCHL) (N=2)	Goto (2019), Ousseine (2019)
		The Short-form Mandarin Health Literacy Scale (s-MHLS) (N=1)	Chang (2019)
		The Cloze Procedure (N=1)	Friedman (2009)
	Numeracy (N=9)	NVS (N=1)	Donelle (2009)
		S-TOFHLA (N=1)	Hahn (2010)
		6 item scales combined Woloshin and Schapira (N=1)	Brown (2011)
		2 items included in HINTS survey (adapted from previously validated scale: Woloshin *et al*.; Lipkus *et al.*) (N=1)	Ciampa (2010)
		3 item numeracy scale developed by Black *et al.* (N=1)	Aggarwal (2007)
		3 item Objective Numeracy Scale (N=9)	Anderson (2011), Donelle (2008, 2009), Hanoch (2014,2015), Koo (2017), Kelly (2007), Portnoy(2010), Schwartz (1997)
		Lipkus Numeracy Scale (8-item) (N=3)	Donelle (2008, 2009), Morris (2013)
		Lipkus expanded numeracy scale (11 items) (N=2)	Keller (2009), Schapira (2011)
		Subjective Numeracy Scale (SNS) (N=3)	Hanoch (2014, 2015), Ousseine (2019)

Table 2 (*continued*)

Table 2 (*continued*)

Measurement type	Health literacy category	Assessment tools	References
Cancer-specific literacy measurement tools (N=9)	Cancer literacy (N=4)	Cancer Health Literacy Test (CHLT 30) (N=1)	Echeverri (2018)
		Multidimensional Cancer Literacy Questionnaire (author developed) (N=1)	Echeverri (2018)
		Cancer Literacy scale (developed by Steiner *et al.* 2007) (N=1)	Lee (2016)
		Cancer Literacy Scale (37 items, author developed) (N=1)	Diviani (2012)
		Cancer Message Literacy Test-Listening (CMLT-L) (N=2)	Mazor (2016), Morris (2013)
		CMLT-Reading (N=1)	Morris (2013), Jenkins (2016)
	Breast cancer literacy (N=2)	Breast Cancer literacy questionnaire (author developed) (N=1)	Roh (2018)
		Breast Cancer Literacy Assessment Tool (Breast-CLAT) (N=2)	Roman (2014), Zambrana (2015)
	Colon cancer literacy (N=1)	Assessment of Colon Cancer Literacy (ACCL) (N=1)	Boogar (2018)
	Cervical cancer literacy (N=1)	Cervical Cancer Literacy Assessment Tool (C-CLAT) (N=1)	Zambrana (2015)
	Cancer screening literacy (N=1)	The Assessment of Health literacy in Cancer screening (author developed) (N=3)	Han (2017), Kim (2018), Han (2019)
e-Health literacy measures (N=1)	E-Health Literacy (N=1)	The eHealth Literacy Scale (eHEALS) (N=5)	Heiman (2018), Song (2017), Mitsutake (2012), Hyejin (2014), Nejati (2019)
Other measures (N=6)	Variable Dimensions of Health Literacy (N=6)	Explored in interview (N=3)	McEwan (2014), Zanchetta (2004;2007)
		Indirect measurement (use of proxy variables) (N=4)	Hoffman-Goetz (2009), Lindau (2002;2006), Thompson (2019)
		Combination of author-developed questionnaire and validated instruments (N=3)	Haack (2018), Haack (2020), Dia (2019)
		HL risk score (N=1)	Roman (2014)
		Author developed questionnaire (N=5)	Agho (2012), Jung (2016), Tobias-Machando (2013), Heckman (2019), Kugbey (2019)
		Questions from population-based survey (HINTS, CHIS, BRFSS) (N=10)	Hay (2015), Jiang (2018), Ross (2018), Sentell (2013; 2015a), Smith (2016), Thompson (2019), Kim (2019), Fleary (2019)

questionnaires combining a self-developed questionnaire and a validated HL instrument (44,145), and four used an indirect measurement of HL. Of the four, two used proxy measures (e.g., education, provider's subjective assessment), in addition to objective measures (104,105). The other two studies used proxy variable data (e.g., education, television/internet use) extracted from the Health Information National Trends Survey (HINTS) in the US (39,83). Questions from population-based surveys were leveraged to collect sample specific data in ten studies. Among these, six used HINTS questions in their assessments of HL (39,57,79,86,123,132). One study used HL risks scores as an explanatory variable (122). Health risks scores were the sum of three indicators: low cancer literacy, no knowledge of family cancer history, and education less than 12 completed years (122). Five studies used author-developed questionnaires to measure HL (15,23,87,99,136). Three qualitative studies explored participants' functional HL (110,140,141).

Clinical cancer-related outcomes

Outcomes were analyzed thematically and nine outcome categories were identified: preventive behaviors (N=55); cancer-related knowledge, awareness, attitudes, and beliefs (N=39); risk perception (N=9); information seeking (N=9); decision-making for cancer care (N=12); quality of life (QOL) (N=11); health status (N=6); post-treatment health behaviors (N=5); and provider-patient communication (N=6). Other outcomes included willingness to participate in cancer research (N=1) and trust in the healthcare system (N=1). Study outcomes are summarized in *Table 3*.

Preventive behaviors (N=55)

Cancer screening behaviors (N=42), were the most examined outcome. Eleven studies examined colorectal cancer (CRC) (17,22,28,56,79,82,97,114,128,146,147), (N=7) breast cancer (67,88,113,116,120,121,139) and (N=8) cervical cancer screening behaviors (34,38,39,62,80,93,105,142). Fourteen studies examined screening for 2 or more cancer types (14,36,46,55,63,73,74,102,122,125,127,129,130,138). Four studies examined general cancer screening (65,87,100,117). Most studies reported that individuals with adequate HL are more likely to participate in screening (N=30).

Six studies reported no significant association between HL and screening outcomes (14,63,66,113,117,125). One study found that adherence to breast and cervical cancer screening follow-up was similar regardless of the women's functional HL status (63). Mixed results were reported in

six studies (34,74,88,91,122,130). One study reported that HIV positive women with low HL were more likely to comply with cervical cancer screening recommendations, suggesting an inverse association with HL (P=0.02). However, the same women were less likely to meet annual screening recommendations in the long-term (P=0.05) (34). Alternate findings suggest that barriers to accessing health services, which are greater for those with inadequate HL (91), as well as the influence of ethnicity and language preference acculturation (88) may impact individuals' uptake of screening services.

The association between HL and other preventative behaviours (e.g., fruit/vegetable consumption, exercise, smoking) was explored in eight studies (6,13,18,23,26,46,57,79). Six studies reported a positive association between higher levels of HL and engagement in preventative health behaviours. Adams *et al.* (13) reported that inadequate functional HL was associated with increased odds of reporting lifestyle risk factors (e.g., smoking, obesity, alcohol consumption). A structural equation model revealed that functional HL had a significant mediation effect on the path from socioeconomic status to perceptions of lifestyle risk factors (P<0.001) (13).

Two studies examining skin cancer prevention behaviours reported mixed findings, where HL was positively associated with health-promoting behaviours (e.g., sunscreen use), as well as non-health promoting behaviours (e.g., incidental UV exposure, sunless tanning) (P<0.05) (18,23). Fleary *et al.* (57) reported that HL was not a significant predictor for cancer prevention behaviors, although HL was positively associated with cancer prevention beliefs.

Two studies examined compliance with post-screening follow-up recommendations. The first found that that education and physician-estimated literacy level were significant predictors of duration of time to follow-up (P=0.005), whereas objective HL level was not (P=0.25) (105). The second reported that men with low HL were less likely to comply with follow-up recommendations after prostate specific antigen testing (P<0.0001) (136). A greater proportion of these men also had a higher probability of experiencing locally advanced prostate cancer (P<0.005) (136).

Three studies examined associations between HL and time to notice symptoms/seek medical help (25,110,135). One found that low-income men with low HL were more likely to present with more advanced stage prostate cancer when first seeking medical attention (P=0.02) (25). In a qualitative study exploring women's experiences with diagnosis and treatment delays for breast cancer, even when

Table 3 Associations between health literacy and related outcomes (N=146)

Outcomes category	Outcomes	Associations with health literacy				Qualitative evidence
		Positive (+)	Negative (−)	No association (0)	Mixed results	
Preventative behaviours (N=44)	Cancer screening behavior	Arnold (2012), Boogar (2018)[26], Ciampa (2010), Diviani (2014), Fernandez (2016), Ferreira (2005), Garbers (2004), Guerra (2005b), Han (2017), Heberer (2017), Jin (2019)[27], Jung (2016), Kim (2018), Kobayashi (2014), Lee (2016)[28], Li (2016), Mazor (2014), Ojinnaka (2015), Pagán (2012), Rakhshkhorshid (2018), Roh (2018), Sentell (2013; 2015a), Thompson (2019), Cho (2008), Scott (2002), White (2008), Goto (2019), Han (2019)	–	Aggarwal (2007), Garbers (2009), Guerra (2005a), Park (2014), Schapira (2011), O'Hara (2018)[29]	Bynum (2013): +/–, Fernandez (2016): +/–, Kadivar (2016): +/–, Roman (2014): +/0, Sentell (2015b): +/0, Kim (2019): +/0	–
	Compliance with post-screening follow-up recommendations	Tobias-Machado (2013), Lindau (2006)	–	–	–	–
	"Don't know" responses to risk perception questions	–	Hay (2015)[30]	Orom (2018)[31]	–	–
	Time to notice symptoms/seek a medical help	–	Tecu (2012), Bennett (1998)[32]	–	–	McEwan (2014)
	Other preventive behaviors	Adams (2013), Altsitsiadis (2012), Son (2017), Bennett (2009)[33], Diviani (2012), Jung (2016)	–	Fleary (2018), Fleary (2019)	Heckman (2019): +/–	–
Cancer-related knowledge, awareness, attitudes, and beliefs (N=36)	Cancer-related knowledge, awareness, attitudes	Agho (2012), Albright (2018), Aggarwal (2007), Almutairi (2018), Arnold (2012), Davis (1996; 2017), Diviani (2012), Dolan (2004), Fortner (2007), Guerra (2005b), Hanoch (2014), King-Marshall (2016), Kim (2018)[34], Lindau (2002), Mitsutake (2012), Morris (2013), Rakhshkhorshid (2018), Yılmazel (2018), Portnoy (2010), Smith (2016), Tagai (2019), Gabel (2019)	Kamimura (2016)[35], Halbach (2016a)[36]	Guerra (2005a), Bynum (2013), Hodges (2016), April-Sanders (2017)	Ross (2018): +/0, Boxell (2012): +/0	Friedman (2009)
	Cancer prevention beliefs	Fleary (2018), Fleary (2019)	–	–	–	–
	Cancer fatalism and disease progression	–	Morris (2013)[37]	–	Haack (2020): +/–	–

Table 3 (*continued*)

Table 3 (*continued*)

Outcomes category	Outcomes	Associations with health literacy				
		Positive (+)	Negative (−)	No association (0)	Mixed results	Qualitative evidence
	Intention for cancer Screening	Diviani (2014)	–	Brittain (2016)	–	–
	Physicians' perception of patients' attitudes of cancer screening	–	Anderson (2011)	–	–	–
Risk perception (N=8)	Comprehension of cancer risk information	Brewer (2009), Brown (2011), Donelle (2008; 2009), Rutherford (2018), Keller (2009), Schwartz (1997)	–	–	–	–
	Estimate of personal risk of developing cancer	–	Kelly (2007)	–	–	–
	Perception of cancer risk	–	Kim (2018)	–	–	–
Information seeking (N=8)	Information seeking behavior	Diviani (2014)[38], Heiman (2018), Kobayashi (2016)	–	–	Drennan (2019): +/0	–
	Information needs	Park (2014)	Halbach (2016b)[39] Matsuyama (2011)[40]	–	–	–
	Patterns of information seeking strategy	–	–	–	–	Zanchetta (2004; 2007)
Decision making for cancer care (N=7)	Informed decision making for screening	Essink-Bot (2016), Lillie (2007), Dia (2019)	–	–	–	–
	Active participation in decision making for treatment	Hanoch (2015), Lixin (2017), Shen (2018), Chang (2019), Heuser (2019), Nejati (2019)	–	–	–	–
	Decision for salvage ADT	–	Mahal (2015)[41]	–	–	–
	Decision for surgical/medical treatment of breast cancer	–	–	Keim-Malpass (2018) (47)	Keim-Malpass (2018) (90): +/0	–
Quality of Life (N=6)	Quality of life	Goodwin (2018), Halverson (2015), Husson (2015), Lee (2018), Kugbey (2019), Xia (2019)	Bales (2019)[42]	Hahn (2007; 2010)	Ozkaraman (2019): +/−, Harrison (2020): +/0	–
Health status (N=5)	Self-reported health status	Hoffman-Goetz (2009), Haack (2020)	–	–	–	–
	Emotional health	Jiang (2018)[43]	Kugbey (2019)[44]	–	–	–
	Psychological distress	–	Sharp (2002)[45]	–	Koay (2013)[46]: −/0	–

Table 3 (*continued*)

Table 3 (*continued*)

Outcomes category	Outcomes	Associations with health literacy				
		Positive (+)	Negative (−)	No association (0)	Mixed results	Qualitative evidence
Post-treatment health behavior (N=3)	Level of physical activity	Plummer (2017)	–	–	–	–
	Post-operative functional exercise compliance	Tang (2017)	–	–	–	–
	Treatment follow-up compliance	Turkoglu (2018), Turkoglu (2019)	–	Keim-Malpass (2018) (47)	–	–
Provider-patient communication (N=3)	Perception of provider-patient communication	–	–	–	Ciampa (2010): +/−, Ousseine (2019): +/0	–
	Perception of care coordination	Hawley (2010)	Mora-Pinzon (2019)	–	–	–
	Perception and satisfaction with information provision	Verkissen (2014)	–	–	–	–
	Patterns of patient question asking	Nejati (2019)	–	–	–	Mazor (2016)
Other outcomes (N=2)	Willingness to participate in cancer research	Echeverri (2018)	–	–	–	–
	Trust in the healthcare system	Nejati (2019)	–	–	–	–

[26], mediating effect of HL; [27], mediating effect of HL; [28], mediating effect of HL; [29], indirect effect of HL; [29], indirect effect of HL was alluded to; [30], undesirable outcomes; [31], undesirable outcomes; indirect effect of HL; [32], undesirable outcomes; [33], mediating effect of HL; [34], indirect effect of HL; [35], negatively worded outcome (negative perceptions of breast cancer treatment); [36], negatively worded outcome (fear of cancer progression); [37], negatively worded outcome; [38], association with cancer literacy and cancer information seeking; [39], negative outcomes (unmet information needs); [40], HL measures not associated with information needs; addition of education level to the prediction model revealed that education is associated with information needs; [41], outcome is a use of salvage ADT (not a desirable outcome); [42], moderating effect of HL; [43], mediating effect of HL; [44], undesirable outcomes (anxiety and depression); [45], negatively worded outcome (level of psychological distress); [46], negatively worded outcome (level of psychological distress).

women had adequate knowledge about breast cancer risk factors, they did not think they were at risk of cancer, which caused diagnostic delays (110). Tecu *et al.* (20) reported similar findings, however, they reported no statistically significant correlation association between HL and cervical cancer patient's time to notice symptoms or time to decide to seek a medical help (135).

Two studies explored the relationship between HL and patients' "Don't Know" responses to risk perception questions. The first study reported that greater odds of "Don't Know" responses were associated with lower knowledge of cancer prevention and screening strategies, lower health information seeking and lower numeracy (79), while the second conducted a path analysis and found no direct effects of HL (115).

Cancer-related knowledge, awareness, attitudes and beliefs

Thirty-nine studies reported relationships of HL with cancer-related knowledge, awareness, attitudes, and beliefs. Among these 26 studies reported positive associations with the outcomes and four reported negative associations (8,19,70,89). Three examined negatively worded variables as outcomes [e.g., negative perception of breast cancer treatment (89), fear of cancer progression (70), cancer fatalism (8)], so the inverse relations reported in these studies are considered positive. The last study reporting a significant negative association found that physicians' numeracy level was negatively associated with their predictions of patients' agreement to undergo regular mammography (P=0.012), implying that physicians with low numeracy tend to be more susceptible to biases and heuristics under uncertainty (19).

Four studies found no significant associations with the outcomes (21,34,66,82). One study reported no significant association between HL and cancer knowledge but found that women with lower HL were less likely to report having had a pap test within the past year (χ^2=3.94, P=0.05) (34). Three studies reported mixed results (30,44,123). One found that the effectiveness of an educational intervention was moderated by HL, with smaller increases in symptom awareness, and smaller decreases in barriers to medical help seeking among female participants with lower HL (30). Another found that participants with low numeracy, expressed by discomfort with medical statistics, were more likely to report information overload, display fatalistic attitudes, lack cancer prevention knowledge, and worry about cancer more frequently (123). Other measures of

perceived numeracy which measured understanding and use of health statistics were not associated with fatalism [odds ratio (OR) 1.22, 95% confidence interval (CI): 0.95–1.59, P=0.12], prevention knowledge (OR 1.11, 95% CI: 0.82–1.50, P=0.49), or high frequency of worry (OR 1.39, 95% CI: 0.95–1.80, P=0.59) (123). Two studies examined associations between HL and screening intention. One study reported a positive association (46), whereas the other study reported non-significant associations with fecal occult blood test intention (P=0.34) or colonoscopy intention (P=0.09) (32).

Friedman *et al.* (60) explored African American men's understanding and misperceptions about prostate cancer risks and found that despite adequate HL levels, participant's limited understanding and misperceptions were revealed during interviews and focus groups.

Risk perception

Nine studies examined perception of cancer risks (30,32,49,50,91-93,124,126). Most (N=7) explored how HL (numeracy) is associated with comprehension of cancer risk information. Although most reported positive correlations between HL and the outcomes, more complex findings were reported in the following two studies. Keller *et al.* (91) identified a significant (P<0.001) three-way interaction between format, risk level, and numeracy. Authors found that high-numerate participants could accurately interpret levels of risk presented in three different formats, while low-numerate participants could not observe differences between low-and high-risk scenarios in any format (91). Another study reported a negative association between HL and participant's estimated risk of colon cancer, such that individuals with higher numeracy were likely to estimate lower personal percentage likelihood of developing colon cancer in their lifetime (92).

Information seeking

Nine studies examined information seeking outcomes that included the identification of unmet informational needs (71,108,117), information seeking (81,140,141), and odds of searching for cancer specific information (46,51,97). Four studies reported positive associations with HL (46,81,96,117). One reported that lower HL was associated with higher unmet needs (71). Another study found no significant association between HL and information needs, although education attainment was a significant predictor of information need (108).

Two qualitative studies examined patterns of information

seeking strategies among patients with varying HL levels (140,141). Findings indicated that patients with high HL were more likely to consult a broad informational network for prostate cancer related information and support, while those with low HL were less likely to communicate their personal experience to individuals other than their urologist (140,141).

Decision making for cancer care

Twelve studies examined decision making for cancer care. Three examined decision making for screening (43,54,103), and nine explored treatment-related decision-making (12,20,35,47,76,84,90,107,144). Among these, six reported positive relationships between HL and the outcomes (12,20,35,76,84,144).

One study examined how the e-HL of partners of men with prostate cancer affects their involvement in treatment decision-making. The study found that partners' e-HL was positively associated with active engagement in seeking a second opinion, awareness of treatment options, and use of a large social network for gathering information for treatment decision making (144). Lillie *et al.* (103) reported positive associations between breast cancer patients' HL and their information-processing styles and preferences for active participation in the decisions regarding genomic tests. Women with higher HL indicated greater information retention, higher desire for medical information, and preferred more active participation in medical decision-making (103).

Three studies discussed how patients' HL affects their decision for treatment options. The first found that the odds of undergoing early salvage androgen deprivation therapy, which is characteristic of undesirable effects, was greater among men with low HL and high prostate-specific antigen anxiety (107). Additionally, a study found that patients with low perceived HL were significantly less likely to undergo breast reconstruction following mastectomy (P=0.007), although no significant associations were found between HL and surgical treatment choice (P=0.89) (90). Keim-Malpass *et al.* (47) reported similar findings, such that a patient's decision to begin adjuvant endocrine therapy for breast cancer treatment did not differ significantly across HL levels (P=0.426).

QOL

Eleven studies explored correlations between HL and QOL (27,42,52,64,68,69,72,77,85,99,100). Two studies found no significant differences in health related QOL between low and high literacy groups (68,69). Six studies reported positive effects of HL on the outcomes and two reported mixed results. In one study, HL acted as a moderating variable, such that breast cancer patients with lower levels of HL experienced significantly higher increases in their QOL when subject to cancer care coordination (27). Another study found that HL was positively associated with self-reported increases in general health, and negatively associated with self-reported symptoms and self-efficacy (P<0.001) (139).

Health status

Six studies examined self-reported health status including emotional and psychological health (44,83,86,95,99,131). Among these, three reported positive relations between HL and outcomes (44,83,131). One reported mixed results, such that poor HL measured by HeLMS was associated with high distress, while HL measured by the S-TOFHLA did not have a significant association with the distress level (P=0.74) (95). O'Hara *et al.* (113) examined the relationship between HL, emotional health, and mobile-based patient provider communication (MBPPC). HL was found to be positively associated with both MBPPC (β=0.09, P<0.05) and emotional health (β=0.12, P<0.05), while MBPPC was not significantly associated with emotional health. The Sobel test was conducted to support the mediation effect of HL (z=2.538, P<0.05) (86).

Post-treatment behaviours

Five studies examined post-treatment health behaviors, including self-reported level of physical activity among breast cancer survivors (118), post-operative functional exercise compliance among breast cancer patients (134), cystoscopy follow-up compliance among bladder cancer patients (24), and adherence to adjunctive endocrine therapy at 2-year follow-up (47). Four studies reported positive correlations between HL and the outcomes (24,118,134), while one reported non-significant results (47).

Provider-patient communication

Six studies explored associations between HL and outcomes in this category (12,78,112,137,142,146). One study reported that ovarian cancer survivors with low HL were more likely to report that they preferred receiving less information about medical tests and were less likely to be satisfied with information provided by their health care providers (137). Mixed results were found where low subjective numeracy was associated with perceiving

low-quality provider communication, yet the association was reversed for objective numeracy (P<0.05) (146). The authors suggest that the mixed results can be explained by a discrepancy between confidence in numeracy skills and actual ability (146).

The third study found that patients with lower HL listening scores asked providers for personalized information while participants with higher scores asked a greater variety of risk/benefits questions. The authors suggest that this may imply that patients with lower HL listening skills have greater difficulty understanding information provided to them by their health care providers (142). Similarly, another study found that patients with higher HL scores were more likely to provide their oncologist with more information and asks more questions in comparison to lower HL counterparts (12).

Perception of care coordination was examined in two studies and one reported a positive association between HL and the outcome (78) and the other reported a negative association (P<0.001) (112). The latter result indicates that the use of a designated care coordinator may have a stronger influence on perceived care coordination in patients with lower HL (112).

Other outcomes

One study examined willingness to participate in cancer research and found that participants with higher HL were more likely to participate (53). Another study explored the relationship between e-HL and trust in the healthcare system (12). It was reported that individuals with higher HL have more trust in the healthcare system, which in turn increases their likelihood of participating in shared decision making (12).

One of two studies reported HL as an outcome found that membership in a prostate cancer support group was partially associated with HL, such that members of the support group were more likely to have greater knowledge about cancer, increased likelihood of having read guidelines relating to their diagnosis, and increased competency for health service navigation in comparison to non-support group member patients (145). The second found that the relationship between cancer-specific literacy and family communication varies, suggesting that family communication plays a role in health education and healthcare decision-making (143).

Six studies did not report direct associations between HL and relevant outcomes (147-152); however, findings suggest meaningful implications surrounding HL and

cancer. For instance, Jenkins *et al.* (149) found that the experience of cancer diagnosis and treatment did not in itself impart greater health and cancer specific literacy, and Woudstra (152) identified eight decision-making stages and ten main HL skills for informed decision making in CRC screening. Additional findings are summarized in *Table 4*.

Discussion

The review identified associations between HL and clinical cancer-related outcomes. Among the outcome categories identified, Preventive Behaviors were most widely examined. The majority of studies reported positive associations between HL and clinical cancer related outcomes, suggesting that higher levels of HL are associated with a greater likelihood of experiencing favorable outcomes. The results show that inadequate HL is associated with: lower uptake of screening and preventative behaviours (22,43,116), longer lag time in symptom identification and medical help seeking (25,110), less knowledge of cancer and its prevention and treatment (40,48,120), impairments in risk perception (30,32,49), greater un-met informational needs (71), less information seeking behaviours (140,141), lower perceived QOL (27,85,99,100), less compliance with post-screening or post-treatment follow-up (24,134), and lower perceived quality and involvement in patient-provider communications (12,78,137). Implications of these associations are significant both for patients and the health care system at large. Individuals with low HL may present to the cancer system at more advanced stages of their disease or lack the skills required to self-manage their illness, leading to higher mortality and morbidity and greater care costs due to repeat emergency room visits and hospitalizations (11).

Mixed and contradictory findings were however also reported among the studies included in the review. Conflicting results may suggest implications surrounding measurement approaches for HL. Studies discussed that measurement instruments such as the REALM and TOFHLA may not be comprehensive measures of the broad range of skills and capabilities captured in the concept of HL (32,36). Experts agree that existing measures of HL are inadequate or incomplete, and that no existing measure holistically assess HL (55). This could explain the high between-study variability identified in the present review with respect to the tools and instruments used to assess HL.

Due to shortcomings of existing HL measures, the use of proxy measures or subjective assessment of HL was

Table 4 Summary of additional findings (N=8)

First author (year)/ Jurisdiction	Study purpose	Study design	Cancer type/stage in cancer journey	Sample	Measure of health literacy (HL)	Intervention (if applicable)	Outcomes	Study results
Haack (2018)/ Germany	To describe whether prostate cancer support group (PCSG) members' HL differs from those of men with PC who never visited support groups	Cross-sectional survey (CSS)	Prostate; treatment, survivorship	576	PC knowledge test; Health Education Impact Questionnaire (heiQ)	n/a	HL is the outcome (assessed by PC knowledge and heiQ); PCSG membership is the explanatory variable	PCSG membership was partially associated with PC knowledge and competencies for health service navigation
Zambrana (2015)/ USA	To examine the associations of socio-demographic factors, family communication, and cancer	Analysis of baseline data from an RCT	Breast, cervical; prevention	156 African American (AA), Arab and Latina women	Cancer Literacy Assessment Tool for breast cancer (B-CLAT); Cervical Cancer Literacy Assessment Tool (C-CLAT)	n/a	Breast/cervical cancer literacy is the outcome; family communication score is the explanatory variable	Among AA women, cervical cancer literacy was positively associated with family communication (but not with breast cancer literacy). Among Latinas, who were the least educated and had the lowest literacy scores, family communication was inversely related to breast cancer literacy (but not with cervical cancer literacy)
Arnold (2016)/ USA	To evaluate if FOBT rates could be sustained over 3 years	A three arm, quasi-experimental study	Colorectal cancer (CRC); screening	961 low-income adults aged 50–85 years	Rapid Estimate of Adult Literacy in Medicine (REALM)	Enhanced usual care; literacy-informed education; education+ nurse support	Completion of three annual FOBT	Return of three FOBT kits over the 3-year period was achieved by 4.7% in enhanced care arm, 11.4% in education arm, and 13.6% in the nurse support arm
Arnold (2017)/ USA	To compare the effectiveness of a HL-directed intervention designed to increase knowledge, beliefs, barriers, self-efficacy and behavior associated with CRC screening with FOBT among patients in predominantly rural community clinics	A three arm, quasi-experimental study	CRC; screening	428 low-income adults aged 50–85 years	REALM	Enhanced usual care Literacy-informed education; education+ nurse support	Knowledge, beliefs, barriers to FOBT; Self-efficacy to complete FOBT	There was significant improvement across all groups with the number of patients reporting they had been given information /education on CRC testing, and completed an FOBT with significant improvement in having a doctor recommendation in all groups except usual care
Liu (2011)/USA	To determine the degree of attitudes after reading the information; how the negative attitudes differ by race; and how the negative attitudes are associated with intention for screening	Quasi-experimental study (pre/post analysis)	CRC; screening	42 adults age ≥50 years	Short Test of Functional Health Literacy in Adults (S-TOFHLA)	Negative attitudes about CRC screening	Information about CRC screening	No participants had strong feelings of fear and embarrassment regardless of ethnicity and adherence to screening guidelines. Non-adherent Caucasians had higher anxiety than adherent Caucasians. The degree of negativity was not associated with intention to get screened in non-adherent participants

Table 4 (*continued*)

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First author (year)/ Jurisdiction	Study purpose	Study design	Cancer type/stage in cancer journey	Sample	Measure of health literacy (HL)	Intervention (if applicable)	Outcomes	Study results
Jenkins (2016)/ USA	To examine how the Test of Functional Health Literacy in Adults (TOFHLA) correlates with the CMLT or how cancer survivorship may influence an individual's health literacy	CSS	All; survivorship	104 (43 cancer survivors; 61 cancer free)	S-TOFHLA; Cancer Message Literacy Test (CMLT)-r	n/a	Correlations of TOFHLA and CMLT	CMLT-r and S-TOFHLA scores were significantly correlated. Correlation analysis of CMLT-r and S-TOFHLA scores was significant for cancer free (r=0.308, P=0.045), but not for survivors (P=0.233)
Kayser (2015)/ Denmark	To explore whether the scores of and verbal responses of Health Literacy Questionnaire (HLQ) can be used to identify individuals in need of information and support and to reveal differences in perception and understanding in health-related situations within couples	Mixed methods (survey + interviews)	Prostate; NR	8	HLQ	n/a	n/a	No consistent relation between HLQ scores and the reported experiences and reflections of the participants. Three themes emerged which related to six of the HLQ domains, i.e., involvement of spouses and other people around the men; support from and interaction with healthcare professionals; and use of the Internet for information retrieval. Couples with the largest couple differences in HLQ scores, responses revealed discrepancies in how the men and their spouses perceived their situation
Woudstra (2018)/ The Netherlands	To explore how individuals make a decision about CRC screening and which skills are needed for IDM in CRC screening and to integrate these findings within a conceptual framework	Qualitative study	CRC; screening	17 experts; 22 individuals	NVS	n/a	n/a	The HL skills identified from the focus groups include the abilities in accessing, understanding, deriving meaning, appraising information, communicating, weighing up pros and cons, using information, following instructions and translating decisions into actual participation. Eight decision making stages are: receiving invitation; recognizing decision; structuring decision options; delegating decision; evaluating options based on facts and or feeling; making a decision; participating or not; and interpreting results

attempted in some studies, which may account for some of the conflicting outcomes reported. Several reports of mixed results were highlighted in studies that assessed both subjective and objective measures of HL (55,105,146). It is important to note, however, that it is unknown the extent to which proxy variables, subjective assessments, or self-reported HL may under or overestimate an individual's actual HL level. For instance, literacy experts suggest that patients may attempt to hide their limited HL due to shame or social stigma (70). Individuals may also have a biased understanding of their own ability and skills related to health behaviors and health-related decision-making, which is then captured in their self-report data (37). Caution is therefore needed when interpreting HL results.

While this review was the first of its kind to summarize the effects of HL in the context of cancer care and clinical cancer-related outcomes, it is not without its limitations. A majority of studies included in the review employ a cross-sectional design, which does not allow for generalizability of findings or inferring causality between variables. Generalizability of findings is also limited across cancer stage and cancer type, as studies were largely focused on screening and prevention outcomes for patients with breast, cervical and CRC. The review was additionally limited to studies published in the English language and did not include articles published in the grey literature which may have led to the exclusion of relevant documents. Due to heterogeneity in the definition of HL in the literature, the search terms used in the present study to identify critical HL skills and capabilities may not have fully captured the construct. Another major limitation is that most data was based on participant self-report and therefore may be subject to social desirability and recall biases. Although this review presents supporting evidence for the association between HL and clinical cancer outcomes, more research is needed to explore these associations. As breadth of evidence is the focus of this review, methodological quality of the included studies was not assessed.

Conclusions

This review provides a detailed account of the associations between HL and clinical cancer in the literature. While a majority of studies reported a positive association between adequate levels of HL and favorable cancer-related outcomes, inconsistent results remain apparent. A high degree of variability in HL measurement tools is noteworthy and may account for some inconsistency in

results. The findings of this review can be used to advance the field of cancer HL research by providing a clearer picture of the mechanics of HL and its impact on cancer health behaviours and preventative health care service use. Continued research in this area is critical as the promotion of HL among cancer patients has the potential to improve clinical outcomes and maintain good health.

Footnote

Reporting Checklist: The authors have completed the PRISMA extension for scoping reviews (PRISMA-ScR) reporting checklist. Available at http://dx.doi.org/10.21037/ace-20-30

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at http://dx.doi.org/10.21037/ace-20-30). The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolve.

References

1. Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health 2012;12:80.
2. Kickbusch I, Pelikan JM, Apfel F, et al. Health literacy: the solid facts. Copenhagen, Denmark: World Health Organization Regional Office for Europe, 2013.

3. Murray TS, Hagey J, Willms D, et al. Health Literacy in Canada: A Healthy Understanding. Canadian Council on Learning, 2008.

4. Institute of Medicine (US) Committee on Health Literacy, Nielsen-Bohlman L, Panzer AM, Kindig DA. editors. Health Literacy: A Prescription to End Confusion. Washington (DC): National Academies Press (US), 2004.

5. Koay K, Schofield P, Jefford M. Importance of health literacy in oncology. Asia Pac J Clin Oncol 2012;8:14-23.

6. Son YJ, Kim SH, Kim GY, et al. Associations between Health Literacy, Cancer-Related Knowledge, and Preventive Health Behaviors in Community-Dwelling Korean Adults. J Health Commun 2017;22:999-1006.

7. Berkman ND, Sheridan SL, Donahue KE, et al. Health literacy interventions and outcomes: an updated systematic review. Evid Rep Technol Assess (Full Rep) 2011;(199):1-941.

8. Morris NS, Field TS, Wagner JL, et al. The association between health literacy and cancer-related attitudes, behaviors, and knowledge. J Health Commun 2013;18:223-41.

9. Hernandez LM. Measures of Health Literacy: Workshop Summary. Washington, DC: National Academies Press, 2009.

10. Waffenschmidt S, Knelangen M, Sieben W, et al. Single screening versus conventional double screening for study selection in systematic reviews: a methodological systematic review. BMC Med Res Methodol 2019;19:132.

11. Papadakos JK, Hasan SM, Barnsley J, et al. Health literacy and cancer self-management behaviors: A scoping review. Cancer 2018;124:4202-10.

12. Nejati B, Lin CC, Aaronson NK, et al. Determinants of satisfactory patient communication and shared decision making in patients with multiple myeloma. Psychooncology 2019;28:1490-7.

13. Adams RJ, Piantadosi C, Ettridge K, et al. Functional health literacy mediates the relationship between socio-economic status, perceptions and lifestyle behaviors related to cancer risk in an Australian population. Patient Educ Couns 2013;91:206-12.

14. Aggarwal A, Speckman JL, Paasche-Orlow MK, et al. The role of numeracy on cancer screening among urban women. Am J Health Behav 2007;31 Suppl 1:S57-68.

15. Agho AO, Parker S, Rivers PA, et al. Health literacy and colorectal cancer knowledge and awareness among African-American males. Int J Health Promot Educ 2012;50:10-9.

16. Albright AE, Allen RS. HPV Misconceptions Among College Students: The Role of Health Literacy. J Community Health 2018;43:1192-200.

17. Almutairi KM, Alonazi WB, Alodhayani A, et al. A Cross-Sectional Assessment of Literacy and Awareness, Attitudes, and Beliefs About Colorectal Cancer and Its Screening in Riyadh Region. J Cancer Educ 2018;33:660-7.

18. Altsitsiadis E, Undheim T, de Vries E, et al. Health literacy, sunscreen and sunbed use: an uneasy association. Br J Dermatol 2012;167 Suppl 2:14-21.

19. Anderson BL, Schulkin J. Physicians' perceptions of patients' knowledge and opinions regarding breast cancer: Associations with patient education and physician numeracy. Breast Care 2011;6:285-8.

20. Heuser C, Diekmann A, Kowalski C, et al. Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach. BMC Cancer 2019;19:330.

21. April-Sanders A, Oskar S, Shelton RC, et al. Predictors of Breast Cancer Worry in a Hispanic and Predominantly Immigrant Mammography Screening Population. Womens Health Issues 2017;27:237-44.

22. Arnold CL, Rademaker A, Bailey SC, et al. Literacy barriers to colorectal cancer screening in community clinics. J Health Commun 2012;17 Suppl 3:252-64.

23. Heckman CJ, Auerbach MV, Darlow S, et al. Association of Skin Cancer Risk and Protective Behaviors with Health Literacy Among Young Adults in the USA. Int J Behav Med 2019;26:372-9.

24. Turkoglu AR, Demirci H, Coban S, et al. Evaluation of the relationship between compliance with the follow-up and treatment protocol and health literacy in bladder tumor patients. Aging Male 2019;22:266-71.

25. Bennett CL, Ferreira MR, Davis TC, et al. Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. J Clin Oncol 1998;16:3101-4.

26. Bennett IM, Chen J, Soroui JS, et al. The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. Ann Fam Med 2009;7:204-11.

27. McDowell BD, Klemp J, Blaes A, et al. The association between cancer care coordination and quality of life is stronger for breast cancer patients with lower health literacy: A Greater Plains Collaborative study. Support Care Cancer 2020;28:887-95.

28. Boogar IR, Talepasand S, Norouzi H, et al. The prediction of colorectal cancer screening based on the extended parallel process model: Moderating the role of health literacy and cancer-related empowerment. Int J Cancer Manag 2018;11:e62539.

29. Ousseine YM, Durand MA, Bouhnik AD, et al. Multiple

health literacy dimensions are associated with physicians' efforts to achieve shared decision-making. Patient Educ Couns 2019;102:1949-56.

30. Boxell EM, Smith SG, Morris M, et al. Increasing awareness of gynecological cancer symptoms and reducing barriers to medical help seeking: does health literacy play a role? J Health Commun 2012;17 Suppl 3:265-79.

31. Brewer NT, Tzeng JP, Lillie SE, et al. Health literacy and cancer risk perception: Implications for genomic risk communication. Med Decis Making 2009;29:157-66.

32. Brittain K, Christy SM, Rawl SM. African American patients' intent to screen for colorectal cancer: Do cultural factors, health literacy, knowledge, age and gender matter? J Health Care Poor Underserved 2016;27:51-67.

33. Brown SM, Culver JO, Osann KE, et al. Health literacy, numeracy, and interpretation of graphical breast cancer risk estimates. Patient Educ Couns 2011;83:92-8.

34. Bynum SA, Wigfall LT, Brandt HM, et al. Assessing the influence of health literacy on HIV-positive women's cervical cancer prevention knowledge and behaviors. J Cancer Educ 2013;28:352-6.

35. Chang HL, Li FS, Lin CF. Factors Influencing Implementation Of Shared Medical Decision Making In Patients With Cancer. Patient Prefer Adherence 2019;13:1995-2005.

36. Cho YI, Lee SY, Arozullah AM, et al. Effects of health literacy on health status and health service utilization amongst the elderly. Soc Sci Med 2008;66:1809-16.

37. Ciampa P, Osborn C, Peterson N, et al. Impact of low numeracy on colorectal cancer screening utilization: results from the 2007 health information national trends survey (HINTS). J Gen Intern Med 2010;25:S303.

38. Han HR, Kim K, Cudjoe J, et al. Familiarity, Navigation, and Comprehension: Key Dimensions of Health Literacy in Pap Test Use among Korean American Women. J Health Commun 2019;24:585-91.

39. Thompson EL, Wheldon CW, Vamos CA, et al. How Is Health Literacy Related to Pap Testing Among US Women? J Cancer Educ 2019;34:789-95.

40. Davis TC, Arnold C, Berkel H, et al. Knowledge and attitude on screening mammography among low-literate, low-income women. Cancer 1996;78:1912-20.

41. Davis TC, Morris J, Rademaker A, et al. Barriers and Facilitators to Colorectal Cancer Screening Among Rural Women in Community Clinics by Heath Literacy. J Womens Health Issues Care 2017;6:1000292.

42. Xia J, Wu P, Deng Q, et al. Relationship between health literacy and quality of life among cancer survivors in China: a cross-sectional study. BMJ Open 2019;9:e028458.

43. Jin SW, Lee Y, Dia DA. Analyzing paths from online health information seeking to colorectal cancer screening using health literacy skills frame and cognitive mediation model. Patient Educ Couns 2019;102:416-23.

44. Haack M, Kramer S, Seidel G, et al. Quality of life and fear of disease progression are associated with aspects of health literacy in men with prostate cancer from Germany. Support Care Cancer 2020;28:2283-92.

45. Diviani N, Schulz PJ. First insights on the validity of the concept of Cancer Literacy: A test in a sample of Ticino (Switzerland) residents. Patient Educ Couns 2012;87:152-9.

46. Diviani N, Schulz PJ. Association between Cancer Literacy and Cancer-Related Behaviour: Evidence from Ticino, Switzerland. J Public Health Res 2014;3:295.

47. Keim-Malpass J, Doede A, Showalter SL. Does patient health literacy impact adherence to adjuvant endocrine therapy in breast cancer patients? Patient Prefer Adherence 2018;13:47-51.

48. Dolan NC, Ferreira MR, Davis TC, et al. Colorectal cancer screening knowledge, attitudes, and beliefs among veterans: does literacy make a difference? J Clin Oncol 2004;22:2617-22.

49. Donelle L, Arocha JF, Hoffman-Goetz L. Health literacy and numeracy: key factors in cancer risk comprehension. Chronic Dis Can 2008;29:1-8.

50. Donelle L, Hoffman-Goetz L, Gatobu S, et al. Comprehension of Internet-based numeric cancer information by older adults. Inform Health Soc Care 2009;34:209-24.

51. Drummond FJ, Reidy M, von Wagner C, et al. Health Literacy Influences Men's Active and Passive Cancer Information Seeking. Health Lit Res Pract 2019;3:e147-60.

52. Ozkaraman A, Uzgor F, Dugum O, et al. The Effect of Health Literacy on Self-Efficacy and Quality of Life among Turkish Cancer Patients. J Pak Med Assoc 2019;69:995-9.

53. Echeverri M, Anderson D, Nápoles AM, et al. Cancer Health Literacy and Willingness to Participate in Cancer Research and Donate Bio-Specimens. Int J Environ Res Public Health 2018;15:2091.

54. Essink-Bot ML, Dekker E, Timmermans DRM, et al. Knowledge and Informed Decision-Making about Population-Based Colorectal Cancer Screening Participation in Groups with Low and Adequate Health Literacy. Gastroenterol Res Pract 2016;2016:7292369.

55. Fernandez DM, Larson JL, Zikmund-Fisher BJ. Associations between health literacy and preventive health

behaviors among older adults: findings from the health and retirement study. BMC Public Health 2016;16:596.

56. Ferreira MR, Dolan NC, Fitzgibbon ML, et al. Health care provider-directed intervention to increase colorectal cancer screening among veterans: results of a randomized controlled trial. J Clin Oncol 2005;23:1548-54.

57. Fleary SA, Paasche-Orlow MK, Joseph P, et al. The Relationship Between Health Literacy, Cancer Prevention Beliefs, and Cancer Prevention Behaviors. J Cancer Educ 2019;34:958-65.

58. Fortner KB, Zite NB, Wallace LS. In my own words: Misunderstanding of pap smears and colposcopy among Appalachian women. J Low Genit Tract Dis 2007;11:251-7.

59. Woudstra AJ, Smets EM, Dekker E, et al. Development and pilot-testing of a colorectal cancer screening decision aid for individuals with varying health literacy levels. Patient Educ Couns 2019;102:1847-58.

60. Friedman DB, Corwin SJ, Dominick GM, et al. African American men's understanding and perceptions about prostate cancer: Why multiple dimensions of health literacy are important in cancer communication. J Community Health 2009;34:449-60.

61. Gabel P, Larsen MB, Edwards A, et al. Knowledge, attitudes, and worries among different health literacy groups before receiving first invitation to colorectal cancer screening: Cross-sectional study. Prev Med Rep 2019;14:100876.

62. Garbers S, Chiasson MA. Inadequate functional health literacy in Spanish as a barrier to cervical cancer screening among immigrant Latinas in New York City. Prev Chronic Dis 2004;1:A07.

63. Garbers S, Schmitt K, Rappa AM, et al. Functional health literacy in Spanish-speaking Latinas seeking breast cancer screening through the National Breast and Cervical Cancer Screening Program. Int J Womens Health 2010;1:21-9.

64. Goodwin BC, March S, Zajdlewicz L, et al. Health literacy and the health status of men with prostate cancer. Psychooncology 2018;27:2374-81.

65. Goto E, Ishikawa H, Okuhara T, et al. Relationship of health literacy with utilization of health-care services in a general Japanese population. Prev Med Rep 2019;14:100811.

66. Guerra CE, Dominguez F, Shea JA. Literacy and knowledge, attitudes, and behavior about colorectal cancer screening. J Health Commun 2005;10:651-63.

67. Guerra CE, Krumholz M, Shea JA. Literacy and knowledge, attitudes and behavior about mammography in Latinas. J Health Care Poor Underserved 2005;16:152-66.

68. Hahn EA, Cella D, Dobrez DG, et al. The impact of literacy on health-related quality of life measurement and outcomes in cancer outpatients. Qual Life Res 2007;16:495-507.

69. Hahn EA, Garcia SF, Du H, et al. Patient attitudes and preferences regarding literacy screening in ambulatory cancer care clinics. Patient Relat Outcome Meas 2010;1:19-27.

70. Halbach SM, Enders A, Kowalski C, et al. Health literacy and fear of cancer progression in elderly women newly diagnosed with breast cancer-A longitudinal analysis. Patient Educ Couns 2016;99:855-62.

71. Halbach SM, Ernstmann N, Kowalski C, et al. Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. Patient Educ Couns 2016;99:1511-8.

72. Halverson JL, Martinez-Donate AP, Palta M, et al. Health Literacy and Health-Related Quality of Life Among a Population-Based Sample of Cancer Patients. J Health Commun 2015;20:1320-9.

73. Han HR, Song Y, Kim M, et al. Breast and Cervical Cancer Screening Literacy Among Korean American Women: A Community Health Worker-Led Intervention. Am J Public Health 2017;107:159-65.

74. Kim K, Han HR. The Association Between Health Literacy and Breast and Cervical Cancer Screening Behaviors: Findings From the Behavioral Risk Factor Surveillance System. Nurs Res 2019;68:177-88.

75. Hanoch Y, Miron-Shatz T, Rolison JJ, et al. Understanding of BRCA1/2 genetic tests results: The importance of objective and subjective numeracy. Psychooncology 2014;23:1142-8.

76. Hanoch Y, Miron-Shatz T, Rolison JJ, et al. Shared decision making in patients at risk of cancer: the role of domain and numeracy. Health Expect 2015;18:2799-810.

77. Nilsen ML, Moskovitz J, Lyu L, et al. Health literacy: Impact on quality of life in head and neck cancer survivors. Laryngoscope 2020;130:2354-9.

78. Hawley ST, Janz NK, Lillie SE, et al. Perceptions of care coordination in a population-based sample of diverse breast cancer patients. Patient Educ Couns 2010;81:S34-S40.

79. Hay JL, Orom H, Kiviniemi MT, et al. "I don't know" my cancer risk: exploring deficits in cancer knowledge and information-seeking skills to explain an often-overlooked participant response. Med Decis Making 2015;35:436-45.

80. Heberer MA, Komenaka IK, Nodora JN, et al. Factors associated with cervical cancer screening in a safety net

population. World J Clin Oncol 2016;7:406-13.

81. Heiman H, Keinki C, Huebner J. EHealth literacy in patients with cancer and their usage of web-based information. J Cancer Res Clin Oncol 2018;144:1843-50.

82. Hodges NL, Shoben AB, Paskett ED, et al. Impact of a literacy-sensitive intervention on CRC screening knowledge, attitudes, and intention to screen. J Community Support Oncol 2016;14:420-6.

83. Hoffman-Goetz L, Meissner HI, Thomson MD. Literacy and cancer anxiety as predictors of health status: An exploratory study. J Cancer Educ 2009;24:218-24.

84. Shen HN, Lin CC, Hoffmann T, et al. The relationship between health literacy and perceived shared decision making in patients with breast cancer. Patient Educ Couns 2019;102:360-6.

85. Husson O, Mols F, Fransen MP, et al. Low subjective health literacy is associated with adverse health behaviors and worse health-related quality of life among colorectal cancer survivors: Results from the profiles registry. Psychooncology 2015;24:478-86.

86. Jiang S, Hong YA. Mobile-based patient-provider communication in cancer survivors: The roles of health literacy and patient activation. Psychooncology 2018;27:886-91.

87. Jung SM, Jo HS, Oh HW. Internal Motivation, Perceived Health Competency, and Health Literacy in Primary and Secondary Cancer Prevention. Asian Pac J Cancer Prev 2016;17:5127-32.

88. Kadivar H, Kenzik KM, Dewalt DA, et al. The association of english functional health literacy and the receipt of mammography among hispanic women compared to non-hispanic u.s.-born white women. PLoS One 2016;11:e0164307.

89. Kamimura A, Chernenko A, Nourian M, et al. The Role of Health Literacy in Reducing Negative Perceptions of Breast Health and Treatment Among Uninsured Primary Care Patients. J Community Health 2016;41:858-63.

90. Keim-Malpass J, Doede A, Camacho F, et al. Impact of patient health literacy on surgical treatment of breast cancer. Breast J 2018;24:633-6.

91. Keller C, Siegrist M. Effect of risk communication formats on risk perception depending on numeracy. Med Decis Making 2009;29:483-90.

92. Kelly KM, Graves KD, Harper FWK, et al. Assessing perceptions of cancer risk: Does mode of assessment or numeracy matter? Cancer Detect Prev 2007;31:465-73.

93. Kim K, Xue QL, Walton-Moss B, et al. Decisional balance and self-efficacy mediate the association among provider advice, health literacy and cervical cancer screening. Eur J Oncol Nurs 2018;32:55-62.

94. King-Marshall EC, Mueller N, Dailey A, et al. "It is just another test they want to do": Patient and caregiver understanding of the colonoscopy procedure. Patient Educ Couns 2016;99:651-8.

95. Koay K, Schofield P, Gough K, et al. Suboptimal health literacy in patients with lung cancer or head and neck cancer. Support Care Cancer 2013;21:2237-45.

96. Kobayashi LC, Wardle J, von Wagner C. Limited health literacy is a barrier to colorectal cancer screening in England: evidence from the English Longitudinal Study of Ageing. Prev Med 2014;61:100-5.

97. Kobayashi LC, Smith SG. Cancer Fatalism, Literacy, and Cancer Information Seeking in the American Public. Health Educ Behav 2016;43:461-70.

98. Koo K, Brackett CD, Eisenberg EH, et al. Impact of numeracy on understanding of prostate cancer risk reduction in PSA screening. PLoS One 2017;12:e0190357.

99. Kugbey N, Meyer-Weitz A, Oppong Asante K. Access to health information, health literacy and health-related quality of life among women living with breast cancer: Depression and anxiety as mediators. Patient Educ Couns 2019;102:1357-63.

100. Lee HY, Rhee TG, Kim NK. Cancer literacy as a mediator for cancer screening behaviour in Korean adults. Health Soc Care Community 2016;24:e34-42.

101. Lee SH, Lee KH, Chang SJ. Do health literacy and self-care behaviours affect quality of life in older persons with lung cancer receiving chemotherapy? Int J Nurs Pract 2018;24:e12691.

102. Li CC, Matthews AK, Dong X. The Influence of Health Literacy and Acculturation on Cancer Screening Behaviors Among Older Chinese Americans. Gerontol Geriatr Med 2018;4:2333721418778193.

103. Lillie SE, Brewer NT, O'Neill SC, et al. Retention and use of breast cancer recurrence risk information from genomic tests: the role of health literacy. Cancer Epidemiol Biomarkers Prev 2007;16:249-55.

104. Lindau ST, Tomori C, Lyons T, et al. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. Am J Obstet Gynecol 2002;186:938-43.

105. Lindau ST, Basu A, Leitsch SA. Health literacy as a predictor of follow-up after an abnormal pap smear: A prospective study. J Gen Intern Med 2006;21:829-34.

106. Song L, Tatum K, Greene G, et al. eHealth Literacy and Partner Involvement in Treatment Decision Making for

Men With Newly Diagnosed Localized Prostate Cancer. Oncol Nurs Forum 2017;44:225-33.

107. Mahal BA, Chen MH, Bennett CL, et al. High PSA anxiety and low health literacy skills: Drivers of early use of salvage ADT amongmen with biochemically recurrent prostate cancer after radiotherapy? Ann Oncol 2015;26:1390-5.

108. Matsuyama RK, Wilson-Genderson M, Kuhn L, et al. Education level, not health literacy, associated with information needs for patients with cancer. Patient Educ Couns 2011;85:e229-36.

109. Mazor KM, Rubin DL, Roblin DW, et al. Health literacy-listening skill and patient questions following cancer prevention and screening discussions. Health Expect 2016;19:920-34.

110. McEwan J, Underwood C, Corbex M. Injustice! that is the cause: A qualitative study of the social, economic, and structural determinants of late diagnosis and treatment of breast cancer in Egypt. Cancer Nurs 2014;37:468-75.

111. Mitsutake S, Shibata A, Ishii K, et al. Association of eHealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. J Med Internet Res 2012;14:e153.

112. Mora-Pinzon MC, Chrischilles EA, Greenlee RT, et al. Variation in coordination of care reported by breast cancer patients according to health literacy. Support Care Cancer 2019;27:857-65.

113. O'Hara J, McPhee C, Dodson S, et al. Barriers to Breast Cancer Screening among Diverse Cultural Groups in Melbourne, Australia. Int J Environ Res Public Health 2018;15:1677.

114. Ojinnaka CO, Bolin JN, McClellan DA, et al. The role of health literacy and communication habits on previous colorectal cancer screening among low-income and uninsured patients. Prev Med Rep 2015;2:158-63.

115. Orom H, Schofield E, Kiviniemi MT, et al. Low Health Literacy and Health Information Avoidance but Not Satisficing Help Explain "Don't Know" Responses to Questions Assessing Perceived Risk. Med Decis Making 2018;38:1006-17.

116. Pagán JA, Brown C, Asch D, et al. Health literacy and breast cancer screening among Mexican American women in South Texas. J Cancer Educ 2012;27:132-7.

117. Park H, Moon M, Baeg JH. Association of eHealth literacy with cancer information seeking and prior experience with cancer screening. Comput Inform Nurs 2014;32:458-63.

118. Plummer LC, Chalmers KA. Health literacy and physical activity in women diagnosed with breast cancer.

Psychooncology 2017;26:1478-83.

119. Portnoy DB, Roter D, Erby LH. The role of numeracy on client knowledge in BRCA genetic counseling. Patient Educ Couns 2010;81:131-6.

120. Rakhshkhorshid M, Navaee M, Nouri N, et al. The Association of Health Literacy with Breast Cancer Knowledge, Perception and Screening Behavior. Eur J Breast Health 2018;14:144-7.

121. Roh S, Burnette CE, Lee YS, et al. Breast cancer literacy and health beliefs related to breast cancer screening among American Indian women. Soc Work Health Care 2018;57:465-82.

122. Roman L, Meghea C, Ford S, et al. Individual, provider, and system risk factors for breast and cervical cancer screening among underserved Black, Latina, and Arab women. J Womens Health (Larchmt) 2014;23:57-64.

123. Ross K, Stoler J, Carcioppolo N. The relationship between low perceived numeracy and cancer knowledge, beliefs, and affect. PLoS One 2018;13:e0198992.

124. Rutherford EJ, Kelly J, Lehane EA, et al. Health literacy and the perception of risk in a breast cancer family history clinic. Surgeon 2018;16:82-8.

125. Schapira MM, Neuner J, Fletcher KE, et al. The relationship of health numeracy to cancer screening. J Cancer Educ 2011;26:103-10.

126. Schwartz LM, Woloshin S, Black WC, et al. The role of numeracy in understanding the benefit of screening mammography. Ann Intern Med 1997;127:966-72.

127. Scott TL, Gazmararian JA, Williams MV, et al. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. Medical Care 2002;40:395-404.

128. Sentell T, Braun KL, Davis J, et al. Colorectal cancer screening: low health literacy and limited English proficiency among Asians and Whites in California. J Health Commun 2013;18:242-55.

129. Sentell T, Braun KL, Davis J, et al. Health literacy and meeting breast and cervical cancer screening guidelines among Asians and whites in California. Springerplus 2015;4:432.

130. Sentell TL, Tsoh JY, Davis T, et al. Low health literacy and cancer screening among Chinese Americans in California: A cross-sectional analysis. BMJ Open 2015;5:e006104.

131. Sharp LK, Zurawski JM, Roland PY, et al. Health literacy, cervical cancer risk factors, and distress in low-income African-American women seeking colposcopy. Ethn Dis 2002;12:541-6.

132. Smith SG, Kobayashi LC, Wolf MS, et al. The

associations between objective numeracy and colorectal cancer screening knowledge, attitudes and defensive processing in a deprived community sample. J Health Psychol 2016;21:1665-75.

133. Tagai EK, Miller SM, Kutikov A, et al. Prostate Cancer Patients' Understanding of the Gleason Scoring System: Implications for Shared Decision-Making. J Cancer Educ 2019;34:441-5.

134. Tang W, Li Z, Tang C, et al. Health literacy and functional exercise adherence in postoperative breast cancer patients. Patient Prefer Adherence 2017;11:781-6.

135. Tecu N, Potter P. Relationship of health literacy with women's cervical cancer knowledge and health behaviors. Journal of Gynecologic Oncology Nursing 2012;22:16-39.

136. Tobias-Machado M, Carvalhal GF, Freitas CH Jr, et al. Association between literacy, compliance with prostate cancer screening, and cancer aggressiveness: results from a Brazilian screening study. Int Braz J Urol 2013;39:328-34.

137. Verkissen MN, Ezendam NPM, Fransen MP, et al. The role of health literacy in perceived information provision and satisfaction among women with ovarian tumors: A study from the population-based PROFILES registry. Patient Educ Couns 2014;95:421-8.

138. White S, Chen J, Atchison R. Relationship of preventive health practices and health literacy: a national study. Am J Health Behav 2008;32:227-42.

139. Yılmazel G. Health Literacy, Mammogram Awareness and Screening Among Tertiary Hospital Women Patients. J Cancer Educ 2018;33:89-94.

140. Zanchetta MS. Understanding functional health literacy in experiences with prostate cancer: Older men as consumers of health information. Online Brazilian Journal of Nursing 2004;3:4-15.

141. Zanchetta MS, Perreault M, Kaszap M, et al. Patterns in information strategies used by older men to understand and deal with prostate cancer: An application of the modelisation qualitative research design. Int J Nurs Stud 2007;44:961-72.

142. Mazor KM, Williams AE, Roblin DW, et al. Health literacy and pap testing in insured women. J Cancer Educ 2014;29:698-701.

143. Zambrana RE, Meghea C, Talley C, et al. Association between Family Communication and Health Literacy among Underserved Racial/Ethnic Women. J Health Care Poor Underserved 2015;26:391-405.

144. Song L, Tatum K, Greene G, et al. eHealth Literacy and Partner Involvement in Treatment Decision Making for Men With Newly Diagnosed Localized Prostate Cancer. Oncol Nurs Forum 2017;44:225-33.

145. Haack M, Kofahl C, Kramer S, et al. Participation in a prostate cancer support group and health literacy. Psychooncology 2018;27:2473-81.

146. Ciampa PJ, Osborn CY, Peterson NB, et al. Patient numeracy, perceptions of provider communication, and colorectal cancer screening utilization. J Health Commun 2010;15 Suppl 3:157-68.

147. Arnold CL, Rademaker A, Wolf M, et al. Final Results of a 3-Year Literacy-Informed Intervention to Promote Annual Fecal Occult Blood Test Screening. J Community Health 2016;41:724-31.

148. Arnold CL, Rademaker A, Liu D, et al. Changes in Colorectal Cancer Screening Knowledge, Behavior, Beliefs, Self-Efficacy, and Barriers among Community Health Clinic Patients after a Health Literacy Intervention. J Community Med Health Educ 2017;7:497.

149. Jenkins WD, Zahnd W, Spenner A, et al. Comparison of Cancer-specific and General Health Literacy Assessments in an Educated Population: Correlations and Modifying Factors. J Cancer Educ 2016;31:268-71.

150. Liu CJ, Fleck T, Goldfarb J, et al. Attitudes to colorectal cancer screening after reading the prevention information. J Cancer Educ 2011;26:701-7.

151. Kayser L, Hansen-Nord NS, Osborne RH, et al. Responses and relationship dynamics of men and their spouses during active surveillance for prostate cancer: health literacy as an inquiry framework. BMC Public Health 2015;15:741.

152. Woudstra AJ, Timmermans DRM, Uiters E, et al. Health literacy skills for informed decision making in colorectal cancer screening: Perceptions of screening invitees and experts. Health Expect 2018;21:636-46.

Supplementary file 1 Search strategy

Ovid Medline and EMBASE combined search

No.	Term	Hits
1	exp/Health Literacy/ or Information literacy/ or Computer literacy/ or literacy/	22,576
2	Health literacy.mp	19,221
3	Numeracy.mp	2,557
4	((Functional or conceptual) adj literacy).tw.	69
5	OR/ 1-4	30,768
6	Neoplasms/	429,545
7	Oncology nursing/ or Medical oncology/ or Radiation oncology/ or Psycho-oncology/ or oncology.mp	368,212
8	Carcinoma/	133,392
9	Tumor.mp	3,997,242
10	Cancer.mp	4,649,851
11	OR/ 6-10	7,006,230
12	5 AND 11	2,577
13	Limit 12 to (English language and yr = "1990-current")	2,512
	Ovid Medline	899
	Embase	1,613

Ovid PsychInfo search

No.	Term	Hits
1	exp Health Literacy/ or exp Literacy/	15,913
2	exp Information literacy	257
3	((Functional or conceptual) adj literacy).tw.	112
4	exp Neoplasms/	45,746
5	exp Oncology/	3,864
6	Cancer.mp.	54,699
7	Tumor.mp.	10,633
8	Carcinoma.mp	1,515
9	OR/ 1-3	16,129
10	OR/ 4-8	68,203
11	9 AND 10	291
12	Limit 11 to (English language and yr = "1990-current")	291

EBSCO CINAHL search

Search ID	Search terms	Search options	Hits
S1	(MH "Literacy") OR (MH "Information Literacy") OR (MH "Health Literacy") OR (MH "Computer Literacy")	Search modes—Boolean/Phrase	11,715
S2	TX health literacy	Search modes—Boolean/Phrase	5,614
S3	(MH "Neoplasms") OR "cancer"	Search modes—Boolean/Phrase	349,475
S4	TX tumour OR TX tumor	Search modes—Boolean/Phrase	439,793
S5	(MH "Oncology") OR "oncology"	Search modes—Boolean/Phrase	41,514
S6	(MH "Carcinoma")	Search modes—Boolean/Phrase	6,894
S7	S1 OR S2	Search modes—Boolean/Phrase	13,388
S8	OR/ S3-S6	Search modes—Boolean/Phrase	549,487
S9	S7 AND S8	Limiters—Published Date: 19900101-20190401; English Language, Human	439
		Search modes- Boolean/Phrase	

ProQuest ERIC search

Search terms	Hits
(((cancer OR tumor OR neoplasm OR oncology) AND la.exact("English")) AND (health literacy) OR (computer literacy) OR (information literacy) Or literacy) AND la.exact ("English")))	49
Additional limit – Date: After January 01 1990	