

Health Literacy of Caregivers Scale – Cancer (HLCS-C)

46 items

Count	Orig Item #	Domain/item
Domain 1. Proactivity and determination to seek information (4 items)		
<i>Stem: Please indicate how strongly you <u>disagree</u> or <u>agree</u> with the following statements by filling in the response that best describes you now.</i>		
1	41	I regularly search for up to date information about the cancer
2	49	I keep searching until I find information that I understand
3	56	I look for new opportunities to get information about the cancer
4	62	To help the person I care for, I actively search for information about cancer

Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 2. Adequate information about cancer and cancer management (4 items)

Stem: Please indicate how strongly you disagree or agree with the following statements by filling in the response that best describes you now.

5	16	I have all the information I need to help look after the health of the person I care for
6	18	I have enough information to understand the potential side effects of treatment
7	26	I know how to manage the side-effects of treatment
8	34	I feel I have good information about the cancer

Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 3. Supported by healthcare providers to understand information (5 items)

Stem: Please indicate how strongly you disagree or agree with the following statements by filling in the response that best describes you now.

9	3	<i>At least one healthcare provider has helped me understand information about cancer (drop if need to reduce items)</i>
10	35	Healthcare providers include me in discussions to help me understand information about cancer
11	43	At least one healthcare provider makes sure I understand enough information about the cancer
12	50	Healthcare providers have helped me understand information about treatments
13	67	<i>Healthcare providers have helped me understand supports and services available for the person I care for (revised item, not yet tested)</i>

Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 4. Social support (4 items)

Stem: Please indicate how strongly you disagree or agree with the following statements by filling in the response that best describes you now.

14	4	I have at least one person who understands and supports me
15	12	I have strong support from at least one family member or friend
16	28	If I need help, I have at least one person I can rely on
17	36	I have at least one family member or friend who can help me understand health information

Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 5. Cancer-related communication with the care recipient (4 items)

Stem: Please indicate how strongly you disagree or agree with the following statements by filling in the response that best describes you now.

18	13	I have honest talks with the person I care for about how the cancer may impact on the future
19	45	To help make decisions, I discuss all of the healthcare options with the person I care for
20	52	I have honest talks with the person I care for about the cancer information given to us by healthcare providers

21	58	After appointments, I discuss the information given by healthcare providers with the person I care for
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Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 6. Understanding care recipient needs and preferences (6 items)

Stem: Please indicate how strongly you disagree or agree with the following statements by filling in the response that best describes you now.

22	6	I understand how much information about the cancer, the person I am caring for wants to know
23	14	<i>I always know when to let the person I am caring for do things for themselves in their own time (revised wording, not yet tested)</i>
24	38	I know what the person I care for can and cannot do physically during treatment
25	53	I know how much help to give the person I care for
26	59	<i>I always understand the needs of the person I care for (revised wording, not yet tested)</i>
27	64	I know which everyday activities the person I care for can do

Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 7. Self-care (5 items)

Stem: Please indicate how strongly you disagree or agree with the following statements by filling in the response that best describes you now.

28	23	I make sure I get enough rest
29	47	I spend quite a lot of time actively managing my own health
30	54	I make plans for what I need to do to be healthy
31	63	I make sure I see healthcare providers for my own health
32	68	Despite other things in my life, I make sure I regularly exercise

Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 8. Understanding the healthcare system (6 items)

Stem: Please indicate how strongly you disagree or agree with the following statements by

filling in the response that best describes you now.

33	8	I know who can provide the right healthcare for the person I care for
34	24	I understand what healthcare services the person I care for is entitled to
35	40	I know where to find the right healthcare for the person I care for
36	48	<i>I know the right place to get the healthcare the person I care for needs (drop if need to reduce items)</i>
37	55	<i>I know how to make healthcare appointments for the person I care for (drop if need to reduce items)</i>
38	65	I know how to find healthcare providers who can help the person I care for

Response options: 4-point Likert format (strongly agree, agree, disagree, or strongly disagree)

Domain 9. Processing health information (4 items)

Stem: Please indicate how easy or difficult the following tasks are for you to do now.

39	78	Find out if the information that I have received is reliable
40	80	Decide where the trustworthy places are to get information about cancer
41	82	Work out which sources have information that is relevant for the person I care for
42	85	Decide which health information is relevant for the person I care for

Response options: 5-point Likert difficulty level (cannot do, very difficult, quite difficult, quite easy, or very easy)

Domain 10. Active engagement with healthcare providers (4 items)

Stem: Please indicate how easy or difficult the following tasks are for you to do now.

43	75	Have good discussions with healthcare providers about the health of the person I care for
44	77	Ask a healthcare provider to explain things to me
45	79	Discuss things about the cancer with healthcare providers until I understand all I need to

46	86	Ask questions if I don't understand the information given to me by healthcare providers
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Response options: 5-point Likert difficulty level (cannot do, very difficult, quite difficult, quite easy, or very easy)

Psychometric properties of the revised domains and items from the HLCS-C

Domain #/Item #	Domain/item	Difficulty (95% CI)	Factor loading (95% CI)	R ²	Ceiling effect (%)
Domain 1. Proactivity and determination to seek information (4 items)					
41	I regularly search for up to date information about the cancer	0.49 (0.44-0.55)	0.88 (0.85-0.90)	0.77	30 (10.1%)
49	I keep searching until I find information that I understand	0.33 (0.28-0.39)	0.86 (0.82-0.89)	0.74	41 (13.8%)
56	I look for new opportunities to get information about the cancer	0.40 (0.35-0.46)	0.90 (0.88-0.93)	0.82	35 (11.8%)
62	To help the person I care for, I actively search for information about cancer	0.42 (0.37-0.48)	0.98 (0.97-0.99)	0.97	35 (11.8%)
CFA Model Fit - $\chi^2_{\text{WLSMV}} = 1.645$, $p = 0.4393$, CFI = 1.00, TLI = 1.00, RMSEA = 0.00, WRMR = 0.147. Composite reliability = 0.92 (0.90-0.94)					
Domain 2. Adequate information about cancer and cancer management (4 items)					
16	I have all the information I need to help look after the health of the person I care for	0.25 (0.21-0.26)	0.77 (0.70-0.83)	0.59	43 (14.5%)
18	I have enough information to understand the potential side effects of treatment	0.21 (0.17-0.26)	0.86 (0.80-0.92)	0.73	62 (20.9%)
26	I know how to manage the side-effects of treatment	0.35 (0.30-0.41)	0.73 (0.66-0.80)	0.54	34 (11.4%)
34	I feel I have good information about the cancer	0.15 (0.12-0.20)	0.80 (0.73-0.87)	0.65	63 (21.2%)
CFA Model Fit - $\chi^2_{\text{WLSMV}} = 1.296$, $p = 0.5230$, CFI = 1.000, TLI = 1.002, RMSEA = 0.00, WRMR = 0.188. Composite reliability = 0.81 (0.78-0.84)					
Domain 3. Supported by healthcare providers to understand information (5 items)					
3	At least one healthcare provider has helped me understand information about cancer	0.167 (0.13-0.21)	0.67 (0.60-0.74)	0.45	84 (28.3%)

35	Healthcare providers include me in discussions to help me understand information about cancer	0.25 (0.20-0.30)	0.87 (0.84-0.91)	0.76	64 (21.5%)
43	At least one healthcare provider makes sure I understand enough information about the cancer	0.28 (0.23-0.34)	0.90 (0.87-0.93)	0.81	48 (16.2%)
50	Healthcare providers have helped me understand information about treatments	0.20 (0.15-0.24)	0.92 (0.89-0.95)	0.85	53 (17.8%)
67	Healthcare providers have helped me understand supports and services available for the person I care for	0.32 (0.27-0.38)	0.85 (0.81-0.89)	0.72	49 (16.5%)

CFA Model Fit - $\chi^2_{\text{WLSMV}} = 7.250$, $p = 0.203$, CFI = 1.00, TLI = 1.00, RMSEA = 0.039, WRMR = 0.322. Composite reliability = 0.89 (0.86-0.91)

Domain 4. Social support (4 items)

4	I have at least one person who understands and supports me	0.16 (0.12-0.21)	0.79 (0.74-0.84)	0.63	85 (28.6%)
12	I have strong support from at least one family member or friend	0.16 (0.12-0.20)	0.91 (0.87-0.95)	0.83	111 (37.4%)
28	If I need help, I have at least one person I can rely on	0.19 (0.15-0.24)	0.89 (0.85-0.92)	0.79	83 (27.9%)
36	I have at least one family member or friend who can help me understand health information	0.30 (0.25-0.35)	0.73 (0.67-0.79)	0.53	67 (22.6%)

CFA Model Fit - $\chi^2_{\text{WLSMV}} = 8.861$, $p = 0.0119$, CFI = 0.997, TLI = 0.991, RMSEA = 0.107, WRMR = 0.458. Composite reliability = 0.86 (0.83-0.88)

Domain 5. Cancer-related communication with the care recipient (4 items)

13	I have honest talks with the person I care for about how the cancer may impact on the future	0.22 (0.17-0.27)	0.66 (0.59-0.73)	0.44	97 (32.7%)
45	To help make decisions, I discuss all of the healthcare options with the person I care for	0.13 (0.10-0.18)	0.86 (0.82-0.91)	0.74	106 (35.7%)
52	I have honest talks with the person I care for about the cancer information given to us by healthcare providers	0.14 (0.10-0.18)	0.92 (0.88-0.96)	0.85	93 (31.3%)

58	After appointments, I discuss the information given by healthcare providers with the person I care for	0.11 (0.08-0.15)	0.89 (0.84-0.94)	0.79	93 (31.3%)
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CFA Model Fit - $\chi^2_{\text{WLSMV}} = 5.223$, $p = 0.0734$, CFI = 0.999, TLI = 0.996, RMSEA = 0.074, WRMR = 0.321. Composite reliability = 0.85 (0.82-0.87)

Domain 6. Understanding care recipient needs and preferences (6 items)

6	I understand how much information about the cancer, the person I am caring for wants to know	0.13 (0.09-0.16)	0.71 (0.64-0.77)	0.51	87 (29.3%)
14	I always know when to let the person I am caring for do things for themselves in their own time.	0.03 (0.02-0.06)	0.64 (0.57-0.72)	0.42	110 (37.0%)
38	I know what the person I care for can and cannot do physically during treatment	0.06 (0.04-0.10)	0.88 (0.83-0.93)	0.77	100 (33.7%)
53	I know how much help to give the person I care for	0.11 (0.08-0.15)	0.88 (0.84-0.92)	0.77	77 (25.9%)
59	I always understand the needs of the person I care for	0.04 (0.02-0.07)	0.85 (0.80-0.89)	0.71	83 (27.9%)
64	I know which everyday activities the person I care for can do	0.05 (0.03-0.09)	0.84 (0.80-0.88)	0.71	87 (29.3%)

CFA Model Fit - $\chi^2_{\text{WLSMV}} = 10.689$, $p = 0.0579$, CFI = 0.995, TLI = 0.991, RMSEA = 0.076, WRMR = 0.62. Composite reliability = 0.78 (0.73-0.83)

Domain 7. Self-care (5 items)

23	I make sure I get enough rest	0.27 (0.22-0.32)	0.71 (0.64-0.78)	0.50	53 (17.8%)
47	I spend quite a lot of time actively managing my own health	0.43 (0.38-0.49)	0.87 (0.83-0.91)	0.76	37 (12.5%)
54	I make plans for what I need to do to be healthy	0.28 (0.23-0.34)	0.89 (0.85-0.92)	0.79	41 (13.8%)
63	I make sure I see healthcare providers for my own health	0.20 (0.16-0.25)	0.68 (0.61-0.75)	0.47	60 (20.2%)

68	Despite other things in my life, I make sure I regularly exercise	0.35 (0.29-0.40)	0.80 (0.76-0.85)	0.65	53 (17.8)
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CFA Model Fit - $\chi^2_{\text{WLSMV}} = 11.795$, $p = 0.0377$, CFI = 0.997, TLI = 0.994, RMSEA = 0.068, WRMR = 0.379. Composite reliability = 0.84 (0.82-0.87)

Domain 8. Understanding the healthcare system (6 items)

8	I know who can provide the right healthcare for the person I care for	0.19 (0.15-0.23)	0.77 (0.72-0.81)	0.60	73 (24.6%)
24	I understand what healthcare services the person I care for is entitled to	0.35 (0.29-0.40)	0.75 (0.70-0.81)	0.57	40 (13.5%)
40	I know where to find the right healthcare for the person I care for	0.19 (0.15-0.24)	0.91 (0.88-0.94)	0.83	58 (19.5%)
48	I know the right place to get the healthcare the person I care for needs	0.15 (0.12-0.20)	0.92 (0.89-0.94)	0.84	65 (21.9%)
55	I know how to make healthcare appointments for the person I care for	0.10 (0.07-0.14)	0.76 (0.71-0.81)	0.58	94 (31.6%)
65	I know how to find healthcare providers who can help the person I care for	0.17 (0.13-0.21)	0.92 (0.90-0.95)	0.86	77 (25.9%)

CFA Model Fit - $\chi^2_{\text{WLSMV}} = 23.046$, $p = 0.0061$, CFI = 0.997, TLI = 0.996, RMSEA = 0.072, WRMR = 0.532. Composite reliability = 0.84 (0.82-0.87)

Domain 9. Capacity to process health information (4 items)

78	Find out if the information that I have received is reliable	0.40 (0.35-0.46)	0.87 (0.83-0.90)	0.76	37 (12.5%)
80	Decide where the trustworthy places are to get information about cancer	0.38 (0.32-0.43)	0.95 (0.93-0.96)	0.90	50 (16.8%)
82	Work out which sources have information that is relevant for the person I care for	0.37 (0.32-0.43)	0.94 (0.92-0.96)	0.88	37 (12.5%)
85	Decide which health information is relevant for the person I care for	0.34 (0.29-0.39)	0.87 (0.83-0.90)	0.75	39 (13.1%)

CFA Model Fit - $\chi^2_{\text{WLSMV}} = 2.286$, $p = 0.3189$, CFI = 1.00, TLI = 1.00, RMSEA = 0.022, WRMR = 0.159. Composite reliability = 0.92 (0.90-0.93)

Domain 10. Active engagement with healthcare providers (4 items)

75	Have good discussions with healthcare providers about the health of the person I care for	0.31 (0.26-0.37)	0.91 (0.89-0.93)	0.83	45 (15.2%)
77	Ask a healthcare provider to explain things to me	0.21 (0.16-0.26)	0.91 (0.88-0.94)	0.82	60 (20.2%)
79	Discuss things about the cancer with healthcare providers until I understand all I need to	0.30 (0.25-0.36)	0.95 (0.93-0.97)	0.91	51 (17.2%)
86	Ask questions if I don't understand the information given to me by healthcare providers	0.21 (0.16-0.26)	0.86 (0.84-0.88)	0.74	63 (21.2%)

CFA Model Fit - $\chi^2_{\text{WLSMV}} = 1.887$, $p = 0.3892$, CFI = 1.000, TLI = 1.000, RMSEA = 0.000, WRMR = 0.142. Composite reliability = 0.92 (0.90-0.93)

CI = Confidence Interval

نسخه فارسی مقیاس سواد سلامت مراقبین

ابعد	ردیف	کاملاً مخالف	مخالف	موافق	کاملاً موافق
فعال بودن و عزم راسخ برای جستجوی اطلاعات	۱				مرتباً مطالب به روز در مورد سرطان را جستجو می‌کنم.
	۲				به جستجو ادامه می‌دهم تا زمانی که اطلاعاتی پیدا کنم که برایم قابل درک باشد.
	۳				به دنبال فرصت‌های جدیدی برای به دست آوردن اطلاعات در مورد سرطان هستم.
	۴				برای کمک به شخصی که از او مراقبت می‌کنم، با جدیت مطالبی را در مورد سرطان جستجو می‌کنم.
اطلاعات کافی در مورد سرطان و مدیریت سرطان	۵				تمام اطلاعات لازم برای کمک به مراقبت از سلامت شخصی که از او مراقبت می‌کنم را دارم.
	۶				اطلاعات کافی برای درک عوارض جانبی احتمالی درمان‌های سرطان را دارم.
	۷				می‌دانم چگونه عوارض جانبی درمان سرطان را مدیریت کنم.
	۸				احساس می‌کنم اطلاعات خوبی در مورد سرطان دارم.
درک اطلاعات سلامت توسط دهندگان مراقبت‌های بهداشتی	۹				حداقل یک ارائه دهنده خدمات سلامت به من کمک کرده‌است تا مطالب مربوط به سرطان را درک کنم.
	۱۰				ارائه دهندگان خدمات سلامت من را در بحث‌ها شرکت می‌دهند تا به من در درک اطلاعات در مورد سرطان کمک کنند.
	۱۱				حداقل یک ارائه دهنده خدمات سلامت مطمئن است که من اطلاعات کافی در مورد سرطان را درک می‌کنم.
	۱۲				ارائه دهندگان خدمات سلامت به من کمک کرده‌اند تا مطالب مربوط به درمان‌ها را بفهمم.
	۱۳				ارائه دهندگان خدمات سلامت به من کمک کرده‌اند تا حمایت‌ها و خدماتی که برای شخصی که از او مراقبت می‌کنم در دسترس است را درک کنم.
	۱۴				حداقل یک نفر را دارم که مرا درک می‌کند و حمایت می‌کند.

				۱۵	حداقل یک عضو خانواده یا یک دوست دارم که از وی حمایت کافی دریافت کنم.	
				۱۶	اگر به کمک نیاز داشته باشم، حداقل یک نفر را دارم که به او تکیه کنم.	
				۱۷	حداقل یک عضو خانواده یا یک دوست دارم که می تواند به من در درک اطلاعات مرتبط با سلامتی کمک کند.	
				۱۸	با فردی که از او مراقبت می کنم صادقانه درباره ی تأثیر سرطان بر آینده ی او گفت و گو می کنم.	ارتباط با گیرنده مراقبت در رابطه با سرطان
				۱۹	برای کمک به تصمیم گیری ها، همه گزینه های خدمات سلامتی را با شخصی که از او مراقبت می کنم در میان می گذارم.	
				۲۰	با شخصی که از او مراقبت می کنم، صادقانه درمورد مطالب مربوط به سرطان که ارائه دهندگان خدمات سلامت به ما می دهند صحبت می کنم.	
				۲۱	پس از ویزیت، اطلاعات ارائه شده توسط ارائه دهندگان مراقبت های بهداشتی را با شخصی که از او مراقبت می کنم در میان می گذارم.	
کاملاً موافق	موافق	مخالف	کاملاً مخالف	رتبه		درک نیازها و ترجیحات دریافت کننده مراقبت
				۲۲	می دانم شخصی که از او مراقبت می کنم چقدر نیاز و تمایل دارد که درباره ی سرطان بداند.	
				۲۳	همیشه می دانم چه زمانی به شخصی که از او مراقبت می کنم اجازه دهم تا به دلخواه خود، کارهای خودش را انجام دهد.	
				۲۴	می دانم شخصی که از او مراقبت می کنم قادر است در طول درمان، چه فعالیت های فیزیکی را انجام دهد و چه فعالیت هایی را قادر نیست.	
				۲۵	می دانم چقدر باید به شخصی که از او مراقبت می کنم کمک کنم.	
				۲۶	همیشه نیازهای شخصی که از او مراقبت می کنم را می فهمم.	
				۲۷	می دانم شخصی که از او مراقبت می کنم، کدام فعالیت های روزمره را می تواند انجام دهد.	
				۲۸	اطمینان حاصل می کنم که در طول مراقبت به اندازه ی کافی استراحت میکنم.	خود مراقبتی
				۲۹	زمان زیادی را فعالانه صرف سلامتی خود می کنم.	
				۳۰	من برای آنچه که باید انجام دهم تا سالم باشم برنامه ریزی می کنم.	
				۳۱	من اطمینان حاصل می کنم که برای سلامتی خودم به ارائه دهندگان مراقبت های بهداشتی مراجعه کنم.	
				۳۲	با وجود مشغله های زندگی، مطمئن می شوم که به طور منظم ورزش می کنم.	
				۳۳	می دانم چه کسی می تواند خدمات سلامتی صحیح برای شخصی که از او مراقبت می کنم را ارائه دهد.	شناخت سیستم مراقبت های بهداشتی
				۳۴	می دانم شخصی که از او مراقبت می کنم حق دریافت چه خدمات سلامتی را دارد.	
				۳۵	می دانم کجا می توانم خدمات سلامت مناسب برای شخصی که از او مراقبت می کنم را پیدا کنم.	

					۳۶	مکان مناسب برای دریافت خدمات سلامتی از فردی که از او مراقبت می‌کنم را می‌شناسم.
					۳۷	می‌دانم چگونه در مورد فردی که از او مراقبت می‌کنم با ارائه دهندگان خدمات سلامت قرار ویزیت بگذارم.
					۳۸	می‌دانم چگونه ارائه دهندگان خدمات سلامتی را پیدا کنم که می‌توانند به فردی که از او مراقبت می‌کنم کمک کنند.
					ردیف	
					۳۹	می‌توانم تشخیص دهم که آیا اطلاعاتی که دریافت کرده‌ام قابل اعتماد است یا خیر.
					۴۰	می‌توانم تصمیم بگیرم که مکان‌های قابل اعتماد برای دستیابی به اطلاعات در مورد سرطان کجا هست.
					۴۱	من می‌توانم بفهمم کدام منابع، اطلاعاتی دارند که برای شخصی که از او مراقبت می‌کنم مناسب است.
					ردیف	
					۴۲	می‌توانم تصمیم بگیرم که کدام مطالب سلامت مرتبط با شخصی است که از او مراقبت می‌کنم.
					۴۳	می‌توانم بحث‌های خوبی با ارائه دهندگان خدمات سلامت در مورد سلامت فردی که از او مراقبت می‌کنم داشته باشم.
					۴۴	می‌توانم از یک ارائه دهنده خدمات سلامت بخواهم که مطالبی را به من توضیح دهد.
					۴۵	می‌توانم در مورد سرطان با ارائه دهندگان خدمات سلامت صحبت کنم تا هرچه که نیاز دارم را بفهمم.
					۴۶	اگر اطلاعاتی که ارائه دهندگان خدمات سلامت به من ارائه داده‌اند را متوجه نشوم، سؤال می‌پرسم.

بزرگداشت اطلاعات سلامت

تعامل فعال با ارائه دهندگان مراقبت‌های بهداشتی