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Diagnosis and Treatment of Patients with early and advanced Breast Cancer

Health Literacy and Communication



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Health Literacy

- **Versions 2020-2022:**
Bauerfeind / Maass / Rhiem / Schmidt / Schütz
- **Version 2023:**
Bauerfeind / Rhiem

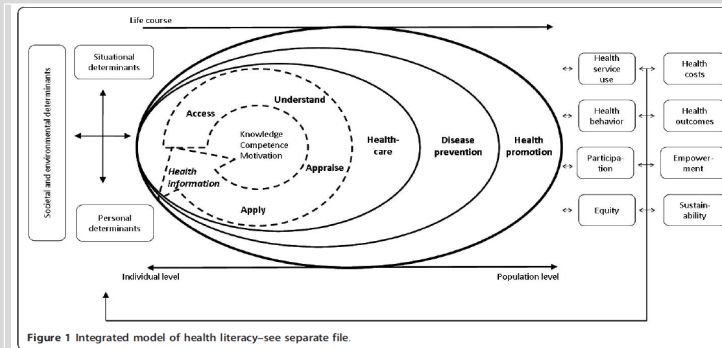
Health Literacy Definition

“Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.”

Sørensen et al., (2012)

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. <https://www.federalregister.gov/documents/2019/06/04/2019-11571/solicitation-for-written-comments-on-an-updated-health-literacy-definition-for-healthy-people-2030>

Health Literacy Model (according to Sørensen)



Competencies

Access: seek, find, obtain health information.

Understand: Understanding the health information received

Appraise: Interpret, select, assess, review health information

Apply: Use health information to make decisions that support and improve health

Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, Brand H. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*. 2012, 12:80

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nicht-heilbaren Krebserkrankung, Lang-version 2.0, 2019, AWMF-Registernummer: 128/001OL, <https://www.leitlinienprogramm-onkologie.de/leitlinien/palliativmedizin/> (abgerufen am: 20.01.2020)

Health Literacy

- The more developed health literacy is, the better a person can **inform** himself or herself about health (e.g. prevention, therapy) in everyday life, **form** an **opinion** and **make self-determined decisions** that maintain or improve the quality of life and health throughout the self-determined course of life.
- However, the extent of health literacy of a person depends not only on his or her individual prerequisites and acquired competencies, but especially on the **professional quality, appropriateness, comprehensibility, form of communication and availability of the information provided.**

1. Simonds SK. Health education as social policy. Health Education Monograph. 1974, 2: 1-25
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Health Literacy

User Participation

Reasons cited for overuse, underuse and misuse in the health care system include the weak position of patients (SVR 2001).

In the context of health literacy, the patient is

- more autonomous **actor and co-designer**
- the one who takes **responsibility** and an **active role** in medical decisions
- the person who extracts the **individually relevant meaning** from professionally offered information and **behaves in accordance with individual ideas about** certain health situations
- the one whose **digital health literacy** (e.g. media literacy, critical judgement) – as well as that of health professionals – should be supported.

SVR - Council of Experts for the Assessment of Developments in the Health Care System

1. Abel T, Sommerhalder K. Gesundheitskompetenz/Health Literacy : Das Konzept und seine Operationalisierung [Health literacy: An introduction to the concept and its measurement]. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz*. 2015;58(9):923–929. doi:10.1007/s00103-015-2198-2
2. Schulz PJ, Nakamoto K. Health literacy and patient empowerment in health communication: the importance of separating conjoined twins. *Patient Educ Couns*. 2013;90(1):4–11. doi:10.1016/j.pec.2012.09.006
3. SVRT- Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen. Kurzfassung des Gutachtens 2018: Bedarfsgerechte Steuerung der Gesundheitsversorgung, S. 48, https://www.svr-gesundheit.de/fileadmin/user_upload/Gutachten/2018/SVR-Gutachten_2018_Kurzfassung.pdf
4. <https://www.svr-gesundheit.de/gutachten/gutachten-2021/>

Health Literacy

Communication

Aim of a physician-patient communication: enable a self-determined decision based on sufficient health competence (Shared Decision Making)

Oxford

LoE	AGO
3a	+

Doctor-patient communication is key for acquiring health competence. It is the basis for successful oncological treatment and support. Core elements are, for example:

- **Non-directive communication** - i.e. those seeking advice have the right to choose their own goals in life, even if they contradict generally accepted, even evidence-based, recommendations after well-founded consideration.
- **Comprehensible communication** - i.e. geared to the level of knowledge, reception habits, competence requirements and preferences of the different patients

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with early-stage breast cancer. *Psycho-Oncology, Journal of the Psychological, Social and Behavioral Dimensions of Cancer*.

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Health Literacy

Basic Principles of Communication

- Communicate information truthfully and empathetically
- Impart medical evidence-based knowledge
- Critical debate of pseudo-scientific recommendations
- Active listening
- Showing empathy
- actively listening and expressing empathy
- Find out if and how the patient wants to be informed about his / her situation
- use understandable language avoiding or explaining technical terms
- Continuously improve understanding through e.g. repetitions, breaks, summary, comprehensible information material
- Encourage asking questions and expressing feelings
- Identifying individual stresses, problems and needs
- Motivating self-determination and personal activities ("empowerment")
- Giving hope for healing and relief
- Offer further assistance (e.g. psycho-oncology, self-help)

1. Bruera E, Willey JS, Palmer JL, et al. Treatment decisions for breast carcinoma: patient preferences and physician perceptions. *Cancer*. 2002;94(7):2076–80.
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nicht-heilbaren Krebserkrankung, Lang-version 2.0, 2019, AWMF-Registernummer: 128/001OL, <https://www.leitlinienprogramm-onkologie.de/leitlinien/palliativmedizin/> (abgerufen am: 20.01.2020)



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Health Literacy

Evidence-based Information

Evidence-based information in health care should be used to answer patients' questions in an understandable way. They are based on the current state of knowledge and are free from influence:

requirement for evidence-based health information as a discrimination against pseudo-scientific recommendations:

- The information on services or products may not be used directly or indirectly for marketing purposes.
- The systematic search corresponds to the questions relevant to the target group.
- The selection of evidence suitable for the research question is justified.
- An undistorted presentation of the results relevant to the patients (e.g. mortality, complaints, complications, health-related QoL) is available.
- The presentation of uncertainties is appropriate in terms of content and language.
- The presentation of results is clearly separated from the derivation of recommendations.
- Consideration of current evidence to communicate figures, risk information and probabilities.
- there must be sufficient time for the decision.
- The possibility that the measure may be refused must not be a reason for withholding information.

1. Positionspapier des Deutschen Netzwerks Evidenzbasierte Medizin EV, Version 2.0 Stand 21.07.2016
2. Ärztliches Zentrum für Qualität in der Medizin (ÄZQ). Handbuch Patientenbeteiligung.
<https://www.aezq.de/mdb/edocs/pdf/schriftenreihe/schriftenreihe33.pdf>. Zugriff 20.01.2020
3. Leitlinie Gesundheitsinformation, URL: <http://www.leitlinie-gesundheitsinformation.de/>. Zugriff 20.01.2020

Health Literacy

Communication

Non-directive and evidence-based doctor-patient communication geared to the current needs, values, problems, resources and preferences of patients has beneficial effects.

	Oxford
	LoE
▪ Reduction of fear	2b
▪ Trust in treating oncologists is increased	2b
▪ Treatment satisfaction is increased	2a
▪ Therapy adherence is increased	2a
▪ Decision making is improved	2a
▪ Mental complaints are improved	2a

1. Littell RD, Kumar A, Einstein MH, et al.: Advanced communication: A critical component of high quality gynecologic cancer care: A Society of Gynecologic Oncology evidence based review and guide. Gynecol Oncol. 2019;155(1):161–169. doi:10.1016/j.ygyno.2019.07.026

Angst, Vertrauen

1. Zwingmann J, Baile WF, Schmier JW, et al. Effects of patient-centered communication on anxiety, negative affect, and trust in physician in delivering a cancer diagnosis: A randomized, experimental study. Cancer 2017;123:3167-3175.
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3. Curtis J, Back A, Ford D, et al. Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: a randomized trial. JAMA.2013;310:2271-2281
4. O. Husson, F. Mols, L.V. van de Poll-Franse The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review Ann Oncol, 22 (2011), pp. 761-772
5. Tulskey, J.A., et al., Enhancing communication between oncologists and patients with a computer-based training program: a

randomized trial. Ann Intern Med, 2011. 155(9): p. 593-601.

Patientenzufriedenheit

1. A. Boissy, A.K. Windover, D. Bokar, M. et al. Communication skills training for physicians improves patient satisfaction J. Gen. Intern. Med., 31 (7) (2016), pp. 755-761
2. Venetis MK, Robinson JD, Turkiewicz KL, Allen M. An evidence base for patient-centered cancer care: a meta-analysis of studies of observed communication between cancer specialists and their patients. Patient Educ Couns. Dezember 2009;77(3):379–83.
3. J.B. Mallinger, J.J. Griggs, C.G. Shields. Patient-centered care and breast cancer survivors' satisfaction with information Patient Educ Couns, 57 (2005), pp. 342-349
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5. Arora, N.K., Interacting with cancer patients: the significance of physicians' communication behavior. Soc Sci Med, 2003. 57(5): p. 791-806.

Adhärenz

1. Miller TA. Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. Patient Educ Couns. 2016;99(7):1079–1086. doi:10.1016/j.pec.2016.01.020
2. Zolnierak, K.B. and M.R. Dimatteo, Physician communication and patient adherence to treatment: a meta-analysis. Med Care, 2009. 47(8): p. 826-34.
3. Kahn, K.L., et al., Patient centered experiences in breast cancer: predicting long-term adherence to tamoxifen use. Med Care, 2007. 45(5): p. 431-9.

Entscheidungsfindung

1. Edwards AG, Naik G, Ahmed H, et al. Personalised risk communication for informed decision making about taking screening tests. Cochrane Database Syst Rev. 2013;2013(2):CD001865. Published 2013 Feb 28. doi:10.1002/14651858.CD001865.pub3

Kommunikationsprobleme

1. Nicolaije KA, Husson O, Ezendam NP, et al. Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: a study from the population-based PROFILES registry. Patient Educ Couns. 2012;88(3):427–435. doi:10.1016/j.pec.2012.05.002

Health Literacy

Communication Training

Qualified training measures can help to promote communicative skills.

communication training for doctors can e.g.

	Oxford
	LoE AGO
	+
▪ Enhance empathy	2a
▪ Extend and enrich communication skills	2a
▪ Increase patient satisfaction (information, support, consideration of concerns)	2b
▪ Improve transmission of information	2b

Förderung kommunikativer Kompetenzen

1. Barth J, Lannen P. Efficacy of communication skills training courses in oncology: a systematic review and meta-analysis. *Ann Oncol.* 2011;22(5):1030–1040. doi:10.1093/annonc/mdq441
2. Bos-van den Hoek DW, Visser LNC, Brown RF, Smets EMA, Henselmans I. Communication skills training for healthcare professionals in oncology over the past decade: a systematic review of reviews. *Curr Opin Support Palliat Care.* 2019;13(1):33-45. doi:10.1097/SPC.0000000000000409

Patientenzufriedenheit

1. Uitterhoeve, R.J., et al., The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. *Eur J Cancer Care (Engl)*, 2010. 19(4): p. 442-57.

Einfühlungsvermögen

1. Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev.* 2018;7(7):CD003751. Published 2018 Jul 24. doi:10.1002/14651858.CD003751.pub4

Training, coaching, OPL

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Health Literacy

Shared Decision Making - Participatory Decision

- Patients want to be integrated actively into decision making and open discussions about prognosis, treatment options, and quality of life
- Doctors should motivate patients to ask questions, demand clarification, express emotions, opinions, and preferences

Oxford		
LoE	GR	AGO
1b	A	
3b	C	+

Definition

1. Beauchamp, T.L. and J.F. Childress, Principles of biomedical ethics. 2001: Oxford University Press, USA.
2. Sieber, W.J. and R.M. Kaplan, Informed adherence: the need for shared medical decision making. Control Clin Trials, 2000. 21(5 Suppl): p. 233s-40s.
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Prognose, Behandlung, QoL

1. Hagerty RG, Butow PN, Ellis PM, Dimitry S, Tattersall MH. Communicating prognosis in cancer care: a systematic review of the literature. Ann Oncol. 2005; 16(7):1005–1053. [PubMed: 15939716]
2. Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. J Clin Oncol. 2005; 23(6):1278–1288. [PubMed: 15718326]
3. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA. 2008; 300(14):1665–1673. [PubMed: 18840840]

Zögern etc.

1. Frosch DL, May SG, Rendle KA, et al.: Authoritarian physicians and patients' fear of being labeled "difficult" among key obstacles to shared decision making. Health Aff (Millwood). 2012; 31(5):1030–1038. [PubMed: 22566443]

Health Literacy

Decision Aids for Patients

	Oxford	
	LoE	AGO
The use of decision support in the physician-patient communication		+
▪ improves knowledge about treatment options	1a	
▪ reduces the decision conflict	1a	
▪ improves the level of information	1a	
▪ increases the feeling about the clarity of personal values	1a	
▪ encourages a more active role in decision-making	2b	
▪ improves risk perception	2b	
▪ improves the match between the chosen option and the patient's values	3a	

Entscheidungshilfen

1. Stacey D, Légaré F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2014;(1):CD001431. Published 2014 Jan 28. doi:10.1002/14651858.CD001431.pub4
2. Krassuski L, Vennedey V, Stock S, Kautz-Freimuth S. Effectiveness of decision aids for female BRCA1 and BRCA2 mutation carriers: a systematic review. *BMC Med Inform Decis Mak*. 2019;19(1):154. Published 2019 Aug 1. doi:10.1186/s12911-019-0872-2
3. Kautz-Freimuth S, Redaelli M, Isselhard A, et al. Evaluation of two evidence-based decision aids for female BRCA1/2 mutation carriers in Germany: study protocol for a randomised controlled parallel-group trial. *Trials*. 2022;23(1):157. Published 2022 Feb 16. doi:10.1186/s13063-022-06081-7

Health Literacy

Decision coaching

Oxford		
LoE	GR	AGO
+		
The use of decision coaching by health professionals based on evidence-based patient information can improve the decision-making process of patients.		
Decision coaching is able to improve		
▪ the knowledge of patients	2a	B
▪ the active role of patients in the process of decision making	2b	B

Aktive Rolle:

1. Berger-Höger B, Liethmann K, Mühlhauser I, et al. Nurse-led coaching of shared decision-making for women with ductal carcinoma in situ in breast care centers: A cluster randomized controlled trial. *Int J Nurs Stud*. 2019;93:141-152. doi:10.1016/j.ijnurstu.2019.01.013
2. Isselhard A, Töpper M, Berger-Höger B, et al. Implementation and evaluation of a nurse-led decision-coaching program for healthy breast cancer susceptibility gene (BRCA1/2) mutation carriers: a study protocol for the randomized controlled EDCP-BRCA study. *Trials*. 2020;21(1):501. Published 2020 Jun 8. doi:10.1186/s13063-020-04431-x
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Allgemein/Wissen:

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