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Diagnosis and Treatment of Patients with early and advanced Breast Cancer

Health Literacy and Communication

Health Literacy



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- **Versions 2020-2024:**
Albert / Bauerfeind / Ditsch / Maass / Rhiem / Schmidt / Schütz
- **Version 2025:**
Friedrich / Heil

Consulting patient advocates of the AGO-Patient-Taskforce:

R. Haidinger, Brustkrebs Deutschland e.V.

B. Welter, mamazone e.V.

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



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Digital Health Literacy

Definition

Digital health literacy is the ability to search for, find, understand and evaluate health-related information in relation to digital applications and digital information services and to apply the acquired knowledge to solve a health problem.

1. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): Psychoonkologische Diagnostik, Beratung und Behandlung von erwachsenen Krebspatient*innen, Langversion 2.1, 2023, AWMF-Registernummer: 032-051OL <https://www.leitlinienprogramm-onkologie.de/leitlinien/psychoonkologie/>; Zugriff am [03.01.2024]



Health Literacy

Patient-centered Communication

Oxford

LoE	AGO
3a	+

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

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

1. Søndergaard SM, The impact of shared decision making on time consumption and clinical decisions. A prospective cohort study. Patient Education and Counseling, Volume 104, 2021.
2. Maes-Carballo M, Shared decision making in breast cancer screening guidelines: a systematic review of their quality and reporting. European Journal of Public Health, Volume 31, August 2021.
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Health Literacy

Basic Principles of Patient-centered Communication

- **Communicate information truthfully and empathetically**
- **Impart medical evidence-based knowledge in lay language**
- **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. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): Psychoonkologische Diagnostik, Beratung und Behandlung von erwachsenen Krebspatient*innen, Langversion 2.1, 2023, AWMF-Registernummer: 032-051OL <https://www.leitlinienprogramm-onkologie.de/leitlinien/psychoonkologie/>; Zugriff am [03.01.2024]

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.

	<u>Oxford</u>
	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

Trust and Fear

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.
2. Elsner, K., Naehrig, D., Halkett, G., & Dhillon, H. M. (2017). Reduced patient anxiety as a result of radiation therapist-led psychosocial support: a systematic review. *Journal of medical radiation sciences*, 64(3), 220–231. doi:10.1002/jmrs.208
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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.

Patient satisfaction

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.
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Adherence

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2. Zolnierok, 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.

Decision making

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

Communication problems

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

	Oxford	
	LoE	AGO
Qualified training measures can help to promote communicative skills.		+
communication training for doctors can e.g.		
▪ Enhance empathy	2a	
▪ Extend and enrich communication skills	2a	
▪ Increase patient satisfaction (information, support, consideration of concerns)	2b	
▪ Improve transmission of information	2b	

Promotion of communicative skills

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

Patienten Satisfaction

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.

Empathy

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

	Oxford		
	LoE	GR	AGO
▪ Patients want to be integrated actively involved into decision making at an early stage and open discussions about prognosis, treatment options, and quality of life	1b	A	
▪ Doctors should motivate patients to ask questions, demand clarification, express emotions, opinions, and preferences	3b	C	+
• Active involvement of caregivers/trusted persons	4	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.
3. Weinstein, J.N., Editorial: The missing piece: Embracing shared decision making to reform health care. 2000, LWW.

Prognosis, Treatment, 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]

4. A Vodermaier 1, C Caspari, J Koehm, S Kahlert, N Ditsch, M Untch: Contextual factors in shared decision making: a randomised controlled trial in women with a strong suspicion of breast cancer. *Randomized Controlled Trial Br J Cancer*. 2009 Feb 24;100(4):590-7. doi: 10.1038/sj.bjc.6604916. Epub 2009 Feb 10.
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Hesitation 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]

Caregivers:

1. Cincidda C, Pizzoli SFM, Ongaro G, Oliveri S, Pravettoni G. Caregiving and Shared Decision Making in Breast and Prostate Cancer Patients: A Systematic Review. *Curr Oncol*. 2023 Jan 6;30(1):803-823. doi: 10.3390/curroncol30010061.
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Decision Aids

Decision aids address

- a wide range of preventive, diagnostic and therapeutic applications
- are offered as brochures, decision charts, videos or computer programs
- contain information on advantages and disadvantages, available options and instructions for individualized decision-making
- are used individually or as components of structured counseling or training.

The minimum quality standards are evidence-based, complete, unbiased and comprehensible.

Medical decision aids do not replace medical advice.

1. Lenz M, Buhse S, Kasper J, Kupfer R, Richter T, Mühlhauser I. Entscheidungshilfen für Patienten Decision Aids for Patients Dtsch Arztebl Int 2012; 109(22-23): 401-8; DOI: 10.3238/arztebl.2012.0401

Health Literacy

Decision Aids for Patients - not breast cancer specific -

	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	

Decision Aids

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. Zdenkowski, Nicholas, Butow P, Tesson S, and Boyle F. "A Systematic Review of Decision Aids for Patients Making a Decision About Treatment for Early Breast Cancer." [In eng]. *Breast (Edinburgh, Scotland)* 26 (2016-4 2016): 31-45. <https://doi.org/doi:> <https://pubmed.ncbi.nlm.nih.gov/27017240/>.
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4. V, Mühlbauer, Berger-Höger B, Albrecht M, Mühlhauser I, and Steckelberg A. "Communicating Prognosis to Women with Early Breast Cancer - Overview of Prediction Tools and the Development and Pilot Testing of a Decision Aid." [In eng]. *BMC health services research* 19, no. 1 (2019-3-15 2019): 171. <https://doi.org/doi:> <https://pubmed.ncbi.nlm.nih.gov/30876414/>.
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6. Salwei ME, Ancker JS, Weinger MB. The decision aid is the easy part: workflow challenges of shared decision making in cancer care. *J Natl Cancer Inst.* 2023 Nov 8;115(11):1271-1277.
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8. Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (IQWiG) HTA-Bericht Behandlungsgespräche: Führt eine gemeinsame Entscheidungsfindung von Arzt und Patient bei der Therapiewahl zu besseren Ergebnissen? Projekt: HT22-01 Version: 1.0 Stand: 04.09.2023 https://www.iqwig.de/presse/pressemitteilungen/pressemitteilungen-detailseite_100418.html Abruf 03012024



Health Literacy

Decision coaching - not breast cancer specific -

	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	

Active Role:

- 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
- Isselhard A, Töpfer 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
- Berger-Höger B, Vitinius F, Fischer H, et al. Nurse-led decision coaching by specialized nurses for healthy BRCA1/2 gene mutation carriers - adaptation and pilot testing of a curriculum for nurses: a qualitative study. *BMC Nurs.* 2022;21(1):42. Published 2022 Feb 10. doi:10.1186/s12912-022-00810-8

Informedness:

- Stacey D, Kryworuchko J, Bennett C, et al. Decision coaching to prepare patients for making health decisions: a systematic review of decision coaching in trials of patient decision aids. *Med Decis Mak.* 2012;32(3):E22–33.
- Stacey D, Kryworuchko J, Belkora J, et al. Coaching and guidance with patient decision aids: a review of theoretical and empirical evidence. *BMC Med Inform Decis Mak.* 2013;13(Suppl 2):S11. <https://doi.org/10.1186/1472-6947-13-S2-S11>.

General:

1. Jull J, Köpke S, Boland L, et al. Decision coaching for people making healthcare decisions. Cochrane Database of Syst Rev. 2021;11(11):CD013385. <https://doi.org/10.1002/14651858.CD013385.pub2>.

Use of eHealth in breast cancer patients

	Oxford		
	LoE	GR	AGO
▪ Use of DiGA to improve quality of life during and after breast cancer therapy	1b	B	+
▪ PRO-based management for reduction of therapy-associated side effects and for improvement of quality of life	1b	A	+
▪ PRO-based management for improvement of survival in metastatic breast cancer	1b	B	+/-

* See current DiGA status / reimbursement

DiGA aktuell: diga.bfarm.de

1. Wolff J, Seidel S, Wuelfing P et al. (2024). App-based support for breast cancer patients to reduce psychological distress during therapy and survivorship – a multicentric randomized controlled trial. *Frontiers in Oncology*,14. <https://doi.org/10.3389/fonc.2024.1354377>
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4. Vollmar HC, Kramer U, Müller H, Griemmert M, Noelle G, Schrappe M. Position Paper of The AG Digital Health DNVF on Digital Health Applications: Framework Conditions For Use in Health Care, Structural Development and Science. *Gesundheitswesen*. 2017 Dec;79(12):1080-1092. doi: 10.1055/s-0043-122233. Epub 2017 Dec 29.; 12/2017
5. Wanchai, A, Anderson EA, and Armer JM. "A Systematic Review of M-Health Apps on Managing Side Effects of Breast Cancer Treatment." [In eng]. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer* 31, no. 1 (2022-12-27 2022): 86. <https://doi.org/doi:10.1007/s00520-022-07464-x>. <https://pubmed.ncbi.nlm.nih.gov/36574048/>
6. Horn A, Jírů-Hillmann S, Widmann J, Montellano FA, Salmen J, Pryss R, Wöckel A, Heuschmann PU. Systematic review on the

effectiveness of mobile health applications on mental health of breast cancer survivors. *Journal of Cancer Survivorship*
<https://doi.org/10.1007/s11764-023-01470-6>

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<https://pubmed.ncbi.nlm.nih.gov/35500200/>.
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9. Luo X, Chen Y, Chen J, Zhang Y, Li M, Xiong C, and Yan J. "Effectiveness of Mobile Health-Based Self-Management Interventions in Breast Cancer Patients: A Meta-Analysis." [In eng]. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer* 30, no. 3 (2022-3 2022): 2853-76. <https://doi.org/doi:>. <https://pubmed.ncbi.nlm.nih.gov/34561732/>.
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<https://doi.org/10.1371/journal.pone.0251276>

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