

# Communication and Shared Decision Making

*Pamela Katz and Joseph D. Tariman*

- I. Shared decision making (SDM): historical background
  - A. 1950s to 1970s post–World War II: model of care delivery for patient–physician relationship was predominantly patriarchal (McKinstry, 1992).
    1. Patients decline to become involved in selecting their own treatment
    2. In this case the patient is essentially saying, “It’s up to you, doctor. You’re the expert.”
  - B. Early 1970s: shared model of care is taking hold, particularly in cancer setting (Feldmann, 1973)
    1. Paternalistic model of care is becoming unpopular.
  - C. Major factors for the emergence of SDM as the dominant model of care in today’s health care
    1. Rising cost of health care (Ford, 1977)
    2. Increasing health care consumerism in the United States, Europe, Australia, and Canada (McDevitt, 1986; Price, 1981)
    3. Increased desire for consumer involvement, autonomy, and control over their care (Tariman et al., 2012).
    4. Emphasis of patient-centered care as an indicator of high-quality care (Institute of Medicine, 2001)
    5. Explosion of cancer treatment choices (Tariman et al., 2012)
- II. Shared decision making: definition
  - A. A care delivery model that facilitates treatment decision making during the patient encounter (Charles, Gafni, & Whelan, 1997, 1999)
  - B. Steps in the SDM process (Agency for Healthcare Research and Quality, 2014)
    1. **Step 1: Involve your patient in the treatment decision process:** inform them of choices and invite them to be involved in the decisions.
    2. **Step 2: Assist your patient in comparing and evaluating treatment options:** discuss the risks and benefits of each option.
    3. **Step 3: Assess your patient’s goals, values, and priorities:** understand and incorporate what matters most to your patient.
    4. **Step 4: Make a decision with your patient:** decide the best course of treatment as a team.
    5. **Step 5: Evaluate the treatment decision:** plan to follow up and revisit the decision, monitor progress, and revise as needed. Communication is a critical aspect of SDM (Siminoff & Step, 2005).
  - C. Key elements (Charles et al., 1999)
    1. At least two participants: clinician and patient; often includes other treatment team members and patient’s family
    2. Both parties share information
    3. Both parties take steps to build consensus about preferred treatment, weighing risks and benefits
    4. Mutual agreement is reached between patient and clinician on treatment approach (verbal and/or written)
  - D. SDM is the preferred model of care delivery by lawmakers and policymakers because it supports the patient’s autonomy and empowers the patient to take responsibility of one’s own health (Légaré et al., 2014)
  - E. SDM has demonstrated short- and long-term benefits (Kane et al., 2014):
    1. Short-term benefits
      - a. Increased confidence in treatment decisions
      - b. Higher satisfaction with treatment decisions
      - c. Enhanced trust with providers
      - d. Improved self-efficacy
      - e. Mental health—less stress and anxiety related to treatment decision making

2. Long-term benefits
  - a. Patient treatment adherence
  - b. Quality of life
  - c. Disease remission
- F. SDM care delivery model is advantageous for older adults (Ramsdale et al., 2017):
  1. Facilitates collaboration, communication, and patient-centeredness
  2. Minimizes the fragmentation that impairs the current provision of cancer care
  3. This is particularly important with older adults, given their potential for not proactively participating in their care based on a multitude of factors (generational, lessened communication abilities), as well as having multiple providers due to many comorbidities.
- III. Barriers to SDM (McCarter et al., 2016)
  - A. Barriers perceived by oncology nurses
    1. Practice barrier—nonnursing responsibilities (e.g., charting, administrative tasks) take away time from patients; lack of provider confidence in the ability to participate effectively.
    2. Patient barrier—lack of readiness for patient to participate in SDM; lack of knowledge to participate; age-related challenges (cognition, mindset) (Tariman et al., 2012)
    3. Institutional policy barrier—lack of institutional policy that allows specific block of nurse’s time for patient education on therapy or lack of support for the process.
    4. Scope-of-practice barrier—Federal, state, and board of nursing laws and regulations that prohibit nurse practitioner from autonomous practice.
    5. Administration as a barrier—nursing administrators do not provide adequate support for nurses to actively participate in SDM process.
  - B. Barriers perceived by oncologists (Charles, Gafni, & Whelan, 2004)
    1. Lack of time
    2. Patient anxiety
    3. Patient lack of information and/or misinformation
    4. Patient unwillingness or inability to participate
    5. Inability to talk in language patients can easily understand (Joseph-Williams, Elwyn, & Edwards, 2014)
    6. Lack of commonality in approaches to SDM, while maintaining flexibility for modifications (Légaré & Witteman, 2013)
- IV. Patient preferences for decision making in oncology care
  - A. Patients with cancer prefer to have a role in cancer care and treatment decision making (Singh et al., 2010; Tariman et al., 2010)
  - B. Degner and Beaton’s Pattern of Treatment Decision Making questionnaire (Fig. 6.1) (Degner & Beaton, 1987; Degner, Sloan, & Venkatesh, 1997) is the most widely used instrument to elicit patient’s preferences for participation in cancer treatment decision-making process (Tariman et al., 2010)
- V. Influential factors in treatment decision making in older adults; ages 60+ (Puts et al., 2015):
  - A. Convenience and success rate of treatment
  - B. Seeing necessity of treatment
  - C. Trust in the physician
  - D. Following the physician’s recommendation

### DEGNER and BEATON’s Pattern of Decision Making

#### Active: Patient Controlled

##### Card A

I prefer to make the final treatment decision.

##### Card B

I prefer to make the final treatment decision after seriously considering my doctor’s opinion.

#### Collaborative: Jointly Controlled

##### Card C

I prefer that my doctor and I share responsibility for deciding which treatment is best.

#### Passive: Provider Controlled

##### Card D

I prefer my doctor to make the final treatment decision, but only after my doctor has seriously considered my opinion.

##### Card E

I prefer to leave all treatment decisions to my doctor.

**Fig. 6.1** The most widely used instrument to elicit patient’s preferences for participation in health care decision making. (From Degner, L. F., & Beaton, J. I. [1987]. *Life death decisions in health care*. New York: Hemisphere Publishing.)

- VI. Patient information needs
  - A. Information priorities in patients diagnosed with cancer (Tariman et al., 2014):
    1. Diagnosis
    2. Prognosis
    3. Treatment options
  - B. Assertion of independence and how to maintain self-care are priority information needs in older adults diagnosed with cancer (Sattar et al., 2018; Tariman et al., 2015)
- VII. Quality of communication and clinician factors
  - A. Clinician characteristics that have a positive impact on quality of communication and/or patient outcomes (De Vries et al., 2014)
    1. Communication skills training
    2. An external locus of control (focus on outward aspects from their own being, such as institutional and administrative factors)
    3. Empathy
    4. Socioemotional approach
    5. Shared decision-making style
  - B. Clinician characteristics that have a negative impact on patient outcomes
    1. Increased level of fatigue
    2. Burnout
    3. Expression of worry
- VIII. Decision aids and SDM (Kojovic & Tariman, 2017)
  - A. Decision aids for health treatment and screening decisions (Stacey et al., 2014)
    1. Explicit values clarification exercises improve informed values-based choices
    2. Positive effect on patient–practitioner communication
    3. Variable effect on length of consultation
    4. Increase patient’s involvement and improve knowledge and realistic perception of outcomes
    5. Less is known about the degree of detail that decision aids need in order to have positive effects on attributes of the decision or decision-making process, but they are proven to have positive effects.
- IX. Nursing roles during SDM (Tariman et al., 2016; Tariman & Szubski, 2015)
  - A. Patient needs assessment
  - B. Information sharing with oncology team
  - C. Patient education
  - D. Advocacy
  - E. Psychological support
  - F. Outcome evaluation
  - G. Management of side effects
  - H. Complex role contingent on several variables within the context of uncertainty
- X. Opportunities to improve outcomes related to SDM
  - A. Develop institutional policy supporting SDM model in current practice
    - B. Delineate the roles of nurses during SDM, particularly advocacy and patient education on treatment options
    - C. Annual education and training of nurses on SDM (as well as all treatment team members)
    - D. Develop and test a conceptual model of the roles of oncology nurses during SDM
    - E. Develop a measurement tool to assess the role competence of oncology nurses in SDM; nurses need more support and training to feel competent as part of the process (Katz, Tariman, Hartle, & Szubski, 2017)

## REFERENCES

- Agency for Healthcare Research and Quality. (2014). *The SHARE Approach Essential Steps of Shared Decision Making*. Content last reviewed April 2014. In: *Agency for Healthcare Research and Quality*. Rockville: MD. <http://www.ahrq.gov/professionals/education/curriculumtools/shareddecisionmaking/tools/shareposter/index.html>.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681–692. <https://doi.org/S0277953696002213> [pii].
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651–661.
- Charles, C., Gafni, A., & Whelan, T. (2004). Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. *Health Expectations*, 7(4), 338–348. HEX299 [pii] <https://doi.org/10.1111/j.1369-7625.2004.00299.x>.
- De Vries, A. M., de Roten, Y., Meystre, C., Passchier, J., Despland, J. N., & Stiefel, F. (2014). Clinician characteristics, communication, and patient outcome in oncology: a systematic review. *Psychooncology*, 23(4), 375–381. <https://doi.org/10.1002/pon.3445>.
- Degner, L. F., & Beaton, J. I. (1987). *Life death decisions in health care*. New York: Hemisphere Publishing.
- Degner, L. F., Sloan, J. A., & Venkatesh, P. (1997). The Control Preferences Scale. *Canadian Journal of Nursing Research*, 29(3), 21–43.
- Feldmann, E. G. (1973). Editorial: paternalism is out. *Journal of Pharmaceutical Sciences*, 62(10), 1.
- Ford, H. (1977). The rising cost of health care: the health services “crisis”—reality or fantasy? *Journal of the Tennessee Medical Association*, 70(11), 822–827.
- Institute of Medicine. (2001). *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: The National Academies Press.
- Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, 94(3), 291–309. doi: S0738-3991(13)00472-2 [pii] <https://doi.org/10.1016/j.pec.2013.10.031>.
- Kane, H. L., Halpern, M. T., Squiers, L. B., Treiman, K. A., & McCormack, L. A. (2014). Implementing and evaluating shared decision making in oncology practice. *CA: A Cancer Journal for Clinicians*, 64(6), 377–388. <https://doi.org/10.3322/caac.21245>.

- Katz, P., Tariman, J. D., Hartle, L., & Szubski, K. (2017). Development and testing of cancer treatment shared decision making scale for nurses (SDMS-N). In: *STTI 28th International Nursing Research Congress*. <http://www.nursinglibrary.org/vhl/handle/10755/621570>.
- Kojovic, B., & Tariman, J. D. (2017). Decision aids: assisting patients with multiple myeloma and caregivers with treatment decision making. *Clinical Journal of Oncology Nursing*, 21(6), 660–664. <https://doi.org/10.1188/17.CJON.660-664>.
- Légaré, F., & Witteman, H. O. (2013). Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff (Millwood)*, 32(2), 276–284. <https://doi.org/10.1377/hlthaff.2012.1078>. Review. PubMed PMID: 23381520.
- Légaré, F., Stacey, D., Turcotte, S., Cossi, M. J., Kryworuchko, J., Graham, I. D., & Donner-Banzhoff, N. (2014). Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews*(9), CD006732. <https://doi.org/10.1002/14651858.CD006732.pub3>.
- McCarter, S. P., Tariman, J. D., Spawn, N., Mehmeti, E., Bishop-Royse, J., Garcia, I., & Szubski, K. (2016). Barriers and promoters to participation in the era of shared treatment decision-making. *Western Journal of Nursing Research*, 38(10), 1282–1297. <https://doi.org/10.1177/0193945916650648>.
- McDevitt, P. K. (1986). Health care consumerism: the new force. *Journal of Hospital Marketing*, 1(1-2), 43–57.
- McKinstry, B. (1992). Paternalism and the doctor-patient relationship in general practice. *British Journal of General Practice*, 42(361), 340–342.
- Price, R. (1981). Consumerism in health—are we accountable and if so, how? *Australian Nurses Journal*, 10(9), 50–52.
- Puts, M. T., Tapscott, B., Fitch, M., Howell, D., Monette, J., Wan-Chow-Wah, D., & Alibhai, S. M. (2015). A systematic review of factors influencing older adults' decision to accept or decline cancer treatment. *Cancer Treatment Reviews*, 41(2), 197–215. <https://doi.org/10.1016/j.ctrv.2014.12.010>.
- Ramsdale, E. E., Csik, V., Chapman, A. E., Naeim, A., & Canin, B. (2017). *Improving quality and value of cancer care for older adults*. 37 (pp. 383–393). American Society of Clinical Oncology Education Book. [https://doi.org/10.14694/EDBK\\_175442](https://doi.org/10.14694/EDBK_175442).
- Sattar, S., Alibhai, S. M. H., Fitch, M., Krzyzanowska, M., Leighl, N., & Puts, M. T. E. (2018). Chemotherapy and radiation treatment decision-making experiences of older adults with cancer: a qualitative study. *Journal of Geriatric Oncology*, 9(1), 47–52. <https://doi.org/10.1016/j.jgo.2017.07.013>.
- Siminoff, L. A., & Step, M. M. (2005). A communication model of shared decision making: accounting for cancer treatment decisions. *Health Psychology*, 24(4 Suppl), S99–S105. 2005-08085-015 [pii] <https://doi.org/10.1037/0278-6133.24.4.S99>.
- Singh, J. A., Sloan, J. A., Atherton, P. J., Smith, T., Hack, T. F., Huschka, M. M., & Degner, L. F. (2010). Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the Control Preferences Scale. *American Journal of Managed Care*, 16(9), 688–696. doi:12718 [pii].
- Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., & Wu, J. H. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*(1), CD001431. <https://doi.org/10.1002/14651858.CD001431.pub4>.
- Tariman, J. D., Berry, D. L., Cochrane, B., Doorenbos, A., & Schepp, K. (2010). Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review. *Annals of Oncology*, 21(6), 1145–1151. mdp534 [pii] <https://doi.org/10.1093/annonc/mdp534>.
- Tariman, J. D., Berry, D. L., Cochrane, B., Doorenbos, A., & Schepp, K. G. (2012). Physician, patient, and contextual factors affecting treatment decisions in older adults with cancer and models of decision making: a literature review. *Oncology Nursing Forum*, 39(1), E70–E83. doi: X90151107806H032 [pii] <https://doi.org/10.1188/12.ONF.E70-E83>.
- Tariman, J. D., Doorenbos, A., Schepp, K. G., Singhal, S., & Berry, D. L. (2014). Information needs priorities in patients diagnosed with cancer: a systematic review. *Journal of the Advanced Practitioner in Oncology*, 2014(5), 115–122.
- Tariman, J. D., Doorenbos, A., Schepp, K. G., Singhal, S., & Berry, D. L. (2015). Top information need priorities of older adults newly diagnosed with active myeloma. *Journal of the Advanced Practitioner in Oncology*, 6(1), 14–21.
- Tariman, J. D., Mehmeti, E., Spawn, N., McCarter, S. P., Bishop-Royse, J., Garcia, I., & Szubski, K. (2016). Oncology nursing and shared decision making for cancer treatment. *Clinical Journal of Oncology Nursing*, 20(5), 560–563. <https://doi.org/10.1188/16.CJON.560-563>.
- Tariman, J. D., & Szubski, K. L. (2015). The evolving role of the nurse during the cancer treatment decision-making process: a literature review. *Clinical Journal of Oncology Nursing*, 19(5), 548–556. <https://doi.org/10.1188/15.CJON.548-556>.