



CANCER*care*®

Cancer Caregivers:

National Research Report on Shared Treatment Decision-Making



2022



About CancerCare

CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer. Since its founding in 1944, CancerCare has provided resources for millions of people living with cancer, post-treatment survivors, caregivers, and loved ones, including over \$284 million in financial assistance. CancerCare's network of support is anchored by world-leading cancer experts and master's-prepared oncology social workers. The organization's programs have expanded to provide case management, individual counseling, support groups, financial assistance, educational workshops, publications and online tools to find practical and financial resources.

In fiscal year 2021, CancerCare delivered 186,614 services to people affected by cancer, spanning all 50 states, and provided \$76.4 million in financial assistance to 30,944 people for costs including transportation and practical needs.

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A Message from CancerCare

Caregivers are the unsung heroes in cancer care.

They may be spouses, family members, or close friends. They are not paid and are usually not trained to provide cancer care, yet they often become the lifeline for a person with cancer.

There are nearly two million new cases of cancer diagnosed each year,¹ and it is estimated that two-thirds of these people will have the support of caregivers.² Cancer caregivers spend an average of 32.9 hours a week caring for their loved one, the equivalent of a full-time job,³ and nearly 50% more hours per week than caregivers of patients who have medical conditions other than cancer.⁴

The impact of performing these responsibilities is profound and life-defining for everyone involved. “Cancer has a ripple effect on families and patient support systems. . . . We need to do a better job of supporting these individuals as their wellbeing [sic] is essential to the patient’s quality of life and outcomes,” comments researcher Erin Kent, PhD, MS, regarding the findings of a survey among 1,200 caregivers completed in 2015.⁵

Indeed, much has been written about the enormous emotional and physical stress that cancer caregivers often experience. While there are many programs devoted to helping caregivers relieve this distress, the ever-changing healthcare landscape adds new challenges. Healthcare’s shift toward patient-centricity and shared decision-making—combined with breakthrough advances in treating cancer—requires that caregivers understand complex therapeutic options in order to offer effective support for patients as they decide on a treatment plan. Health insurance trends that shift cost from payers to patients create financial hardship for individuals and families, adding more strain to

the process of choosing among treatment options. Although shared decision-making tools are slowly being developed and tested to help patients and caregivers make choices among various treatment regimens, they don’t typically address the impact these treatments could have on caregivers: their careers, finances, relationships, and other logistics of life.

Existing programs don’t seem to be sufficient. Caregivers are faced with information needs as soon as their loved one is diagnosed, when they immediately become immersed in helping to make medical choices for which they are ill prepared. This report, based on the survey responses from a nationally representative sample of 2,700 unique caregivers, indicates that many of them are dissatisfied with the educational materials provided by the care team. Most noted that they need more information in order to more effectively share in making these very important decisions. The detailed data and analyses that follow identify the scenarios that caregivers find particularly perplexing and why. We learn what exacerbates their distress and their opinions regarding resources and programs that could help them as they strive to provide the very best care.

At CancerCare, we will use these study findings to inform the development and refinement of our programs and materials. We hope that our healthcare colleagues will appreciate the caregiver challenges noted in this report and consider how policies and programs can better support them.

Sincerely,

Ellen Miller-Sonet, JD, MBA
Chief Strategy and Policy Officer



References for A Message from CancerCare

- 1 American Cancer Society. *Cancer Facts & Figures 2022*. American Cancer Society, 2022. <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2022.html>. Accessed June 16, 2022.
- 2 CancerCare. *CancerCare Patient Access and Engagement Report*. 2016, <https://media.cancercare.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.
- 3 National Alliance for Caregiving in partnership with the National Cancer Institute and the Cancer Support Community. *Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience*. June 2016, https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf. Accessed March 5, 2022.
- 4 National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2015*. https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf. Accessed June 16, 2022.
- 5 American Society of Clinical Oncology. "Cancer Caregivers Experience Unique Burdens Compared with Other Conditions." September 2016. *ScienceDaily*, <https://www.sciencedaily.com/releases/2016/09/160907095539.htm>. Accessed March 5, 2022.

Executive Summary



An estimated 2.8 million to 6.1 million adults in the U.S. provide unpaid support to someone close to them who has cancer.¹ These caregivers offer “practical and emotional support across the continuum of care,”² which includes aiding patients as they confront the many decisions to be made about their cancer treatment. Studies in multiple countries find that most cancer patients—anywhere from 49% to nearly 95%—prefer to involve caregivers in medical decision-making.³ While further research is needed, new understanding suggests that caregiver involvement in treatment decision-making can impact patient outcomes and well-being, with indications for better treatment adherence, improved understanding of cancer topics, greater satisfaction and self-efficacy, and lower levels of stress and depression.⁴

Yet the ways caregivers participate in decision-making are variable, often unclear, and certainly under-supported by clinicians and educational materials.⁵ A caregiver’s daily life and long-term plans can be greatly impacted by the patient’s decisions about treatment, as such decisions place significant demands on caregivers’ time, resources, and mental and physical health.⁶ In a survey by Rx4Good, 70% of cancer caregivers reported that care decisions cause them much stress, even when they and their patient agree on treatment priorities.⁷ Caregivers’ unmet needs regarding treatment decision-making compound the well-documented burdens of providing care and can negatively impact the quality of care they provide.⁸

CancerCare’s Caregiver Decision-Making Survey set out to gather information from a robust sample of cancer caregivers representative of the U.S. population by ethnicity, race, gender, age, and geography. In total, 2,703 respondents completed the 30-minute online survey between February 16, 2021 and July 6, 2021. The survey seeks to provide a fuller understanding of caregivers’ needs and experiences in shared decision-making—including their roles, considerations, and challenges. By elucidating this information, we hope to inform and encourage organizations, medical associations, and healthcare systems to develop programs and materials that support patients and their caregivers as active, informed participants in shared decision-making and make progress toward achieving the goals of high-quality, patient-centered care.

The primary areas of inquiry for this survey included:

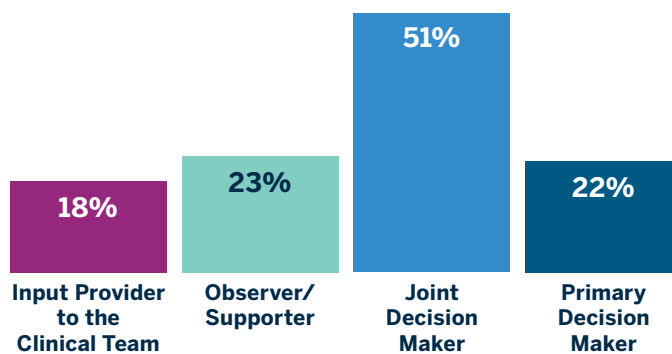
- Decision-making roles of caregivers
- Shared decision-making situations
- Caregivers’ information sources for decision-making
- Specific challenges/“pain points” in shared decision-making
- Caregivers’ attitudes and feelings, including depression and anxiety
- Correlations with patient cancer stage, treatment status, and age; caregiver demographics, attitudes, and perceptions



Key survey findings

Caregiver roles in decision-making

n=2703



Results total more than 100%; some respondents selected more than one role

We defined four decision-making roles for this survey:

Input Provider to the Clinical Team (18%): “The clinical team made the decision. The patient and I provided our input but left the final decision up to the doctors and nurses.”

Observer/Supporter (23%): “The patient made the decision. I was an observer and played a supportive role.”

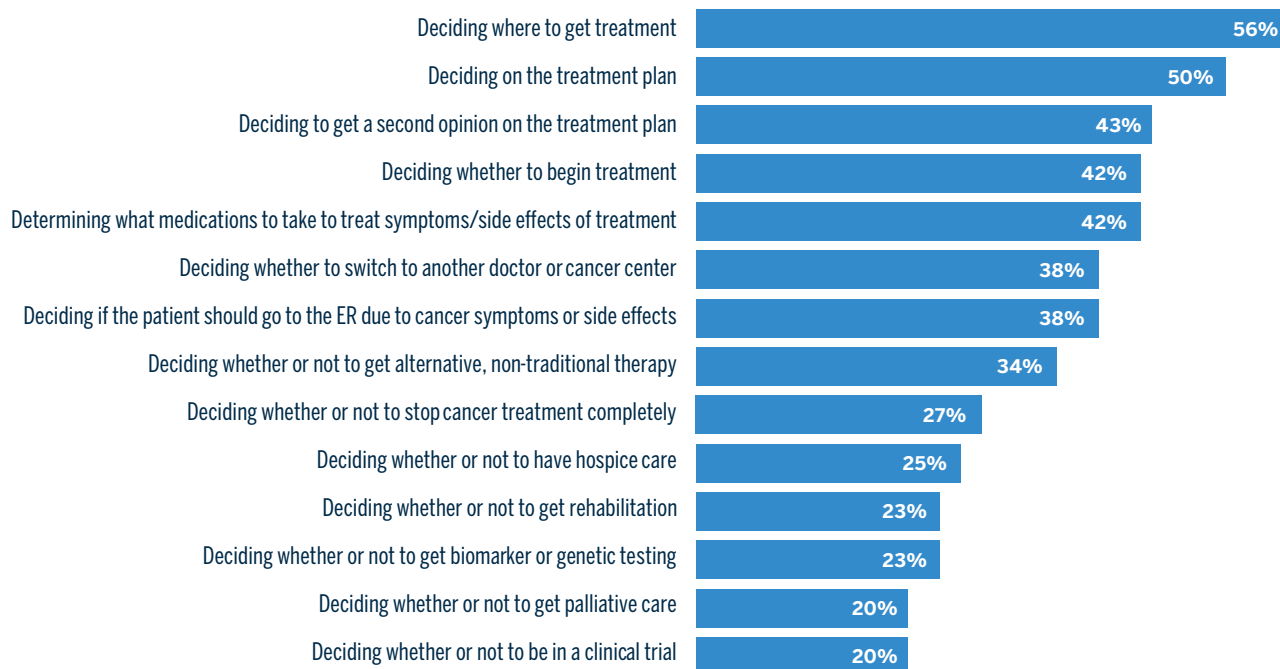
Joint Decision Maker (51%): “The patient and I made the decision together. We both agreed on the best choice.”

Primary Decision Maker (22%): “I made the decision. The patient and other family and/or friends provided their input.”

Other research shows a caregiver’s role may vary depending on the decision or along the cancer care continuum⁹; patient factors (such as gender or medical knowledge), relationship factors (e.g. spouses, child-parent, etc.), and cultural factors linked to racial and ethnic identity can also play a part in the role a caregiver fills.¹⁰

Caregiver involvement in treatment decisions

n=2703



Caregivers' involvement in decision-making situations

Caregivers were involved in decision-making regarding many different treatment-related situations. On average, caregivers had participated in 4.8 different decision-making scenarios.

- **Caregivers in different decision-making situations were significantly more or less likely to have certain roles.** For example, caregivers were significantly more likely to be Joint Decision Makers when deciding on the treatment plan and significantly less likely when deciding whether or not to stop cancer treatment completely—in that situation, they were significantly more likely to be Observers/Supporters while the patient made the decision.
- **Decision-making often involved a broader social network**, including family and/or close friends (37%), other medical professionals outside the clinical cancer team (14%), and faith or spiritual counselors (9%). This reinforces the need for decision-making models that consider dynamics beyond the patient-doctor dyad.¹¹

Caregivers' information sources for decision-making

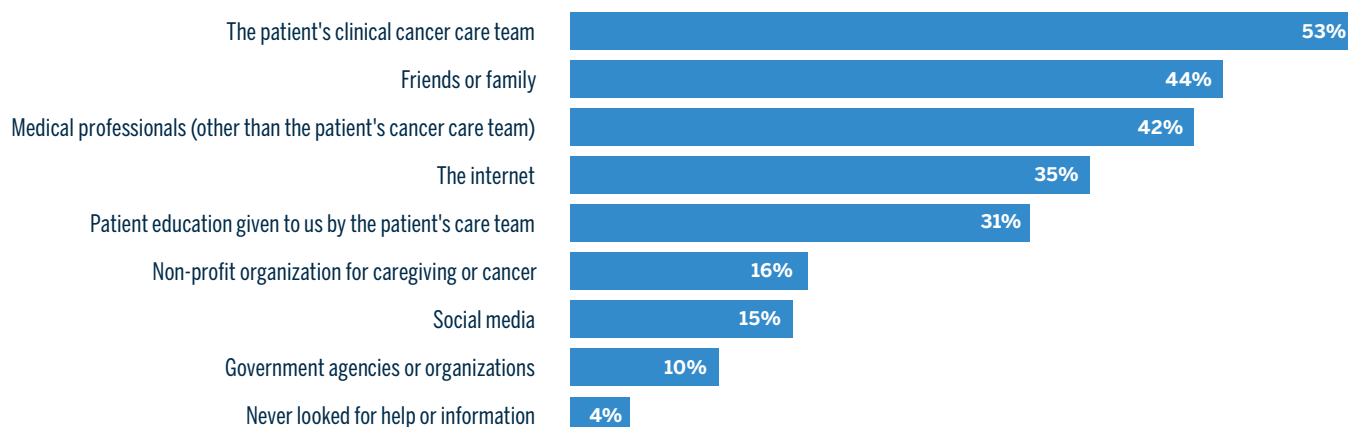
Most caregivers relied on the patient's clinical cancer care team for information and help regarding treatment decision-making (53%), as well as patient education provided by the team (31%).

- **Nearly a quarter (24%) felt the information they gathered or were given was not helpful** in their decision-making situation.



Sources of information for treatment decision-making

n=2703



Considerations and challenges that impact decision-making

Factors related to how a decision might affect the patient's overall well-being and quality of life were of primary importance to caregivers. Yet caregivers often felt ill-informed about these factors during past decision-making experiences, suggesting a significant disconnect between the information caregivers have and what they typically would like to have.

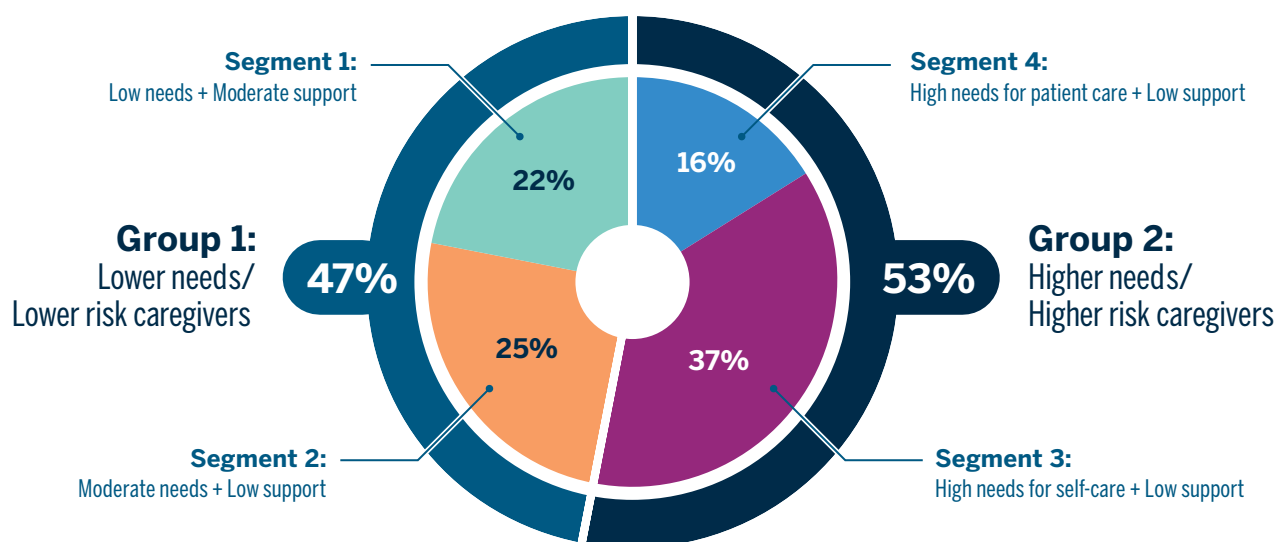
- Limited information, lack of understanding, and/or disagreement about important treatment factors made it more challenging to reach fully informed decisions. **Overall, 20% of caregivers reported they “didn’t have enough information” to make a past treatment-related decision.**
- A third of caregivers reported they had not been asked by a doctor, nurse, or social worker about what they needed to help share in making decisions.
- Responses point to a need for more open communication among clinicians, patients, and caregivers regarding cancer symptoms and treatment side effects, clinical trials, uses for and limitations of alternative therapies, and benefits and risks of biomarker testing.

- Just over a quarter (27%) of caregivers in this survey had not discussed any particular wishes the patient has about the care they would want to receive if they were dying. Studies indicate that patients benefit from earlier conversations about supportive/palliative care and their preferences for end-of-life care.¹²
- **Nearly half of all caregivers surveyed (47%) perceived bias from the healthcare team**, which they felt negatively impacted the support they and the patient received in treatment decision-making.



Caregivers by psychosocial groups and segments

n=2703



Caregivers' needs and attitudes

Using respondents' attitudes about caregiving, perceptions of support, responses to screeners that indicate the need for further depression and general anxiety evaluation, and correlations with demographic and social factors, we identified two groups of caregivers in our sample: *Lower needs/Lower risk of burden* and *Higher needs/Higher risk of burden*. These were further divided into four segments.

- **53% of caregivers surveyed were designated *Higher needs/Higher risk***, with high needs for either self-care or patient care, limited support, and a higher risk for significant burden.
- **The 37% of caregivers who made up Segment 3 (*High needs for self-care + Low support*) had distinctive needs and attitudes** compared to other caregivers surveyed. These caregivers were younger and felt the most overwhelmed, trapped, out of control, and unsupported; they also had the highest scores on screeners that indicate

a need for depression and general anxiety evaluations. While most were not the sole caregiver, the majority juggled a full-time work schedule with care for an immediate family member with advanced cancer.

- Segment 3 respondents were significantly more challenged by information gaps and care team disagreements when making decisions, as compared to other caregivers.
- Caregivers in Segment 3 and Segment 1, which also skewed younger, placed significantly more importance on how decisions might impact the patient's ability to continue to work and care for others, compared to the older caregivers in Segment 2 and Segment 4.
- Segment 3 respondents were most likely to feel that caregiver-focused resources (vs. patient-focused services) would be more helpful to future decision-making. **These caregivers would likely benefit from counseling with an oncology social worker.**

Hispanic caregivers' needs and attitudes

Survey data from Hispanic caregivers significantly differed from non-Hispanic caregivers and point to a clear need for support. The Hispanic caregivers in this survey tended to be younger than the non-Hispanic caregivers, so weighting was applied to enable more accurate comparisons between the two samples.

- **Responses from Hispanic caregivers indicated significantly more stress and less family support** compared to their non-Hispanic counterparts. This distress may relate to the greater care responsibilities they reported (including significantly more hours of care and more daily care for patients with advanced cancer), as well as cultural values that influence family dynamics (i.e. *familismo*)¹³ and societal/systemic factors.¹⁴
- **Hispanic caregivers were involved in more treatment decision-making situations** compared to non-Hispanic caregivers. Hispanic caregivers in this survey were significantly more likely to be involved in eight of the 14 decision-making situations presented and had a higher average rate of involvement (5.4 vs. 4.7 situations) compared to their non-Hispanic counterparts.

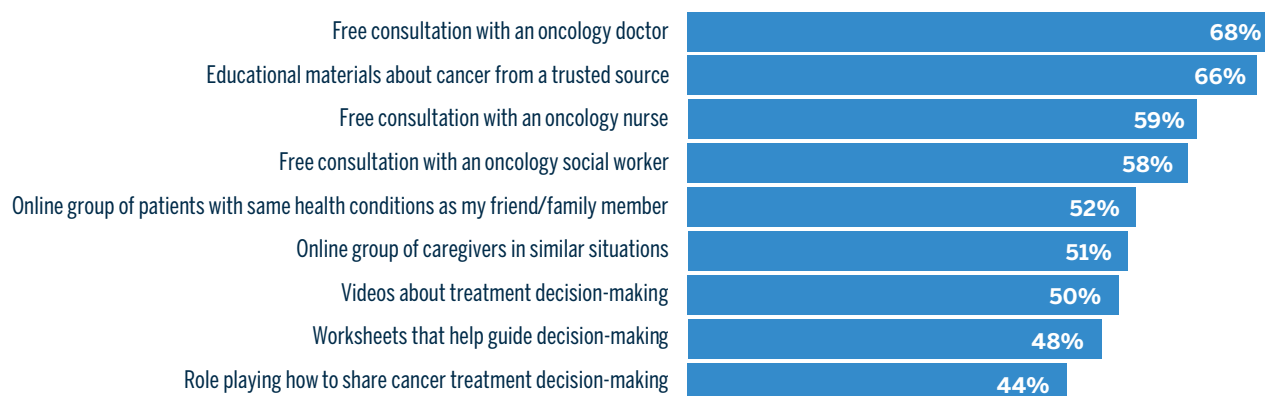
- **Hispanic caregivers faced greater barriers in making treatment decisions.** Nearly a third reported they “did not have enough information to make the decision,” compared to 18% of non-Hispanic caregivers, and they were significantly more likely to say that the information they found or received was not helpful. Hispanic caregivers were also more likely to experience decision-making disagreements among the care team.
- Compared to non-Hispanic caregivers, **they were significantly more likely to perceive bias from the patient’s doctor or healthcare team** that they felt negatively impacted the decision-making support they and the patient received.

Ways to improve support for caregivers in decision-making

The majority of caregivers rated seven of the nine support services included on the survey as “Very helpful” to decision-making; all nine services received positive scores.

“Very helpful” services for decision-making

n=2703



Recommendations

1. **Connect caregivers with non-profit organizations and government agencies, which were accessed by only a small portion of those surveyed.** CancerCare currently provides free consultations with oncology social workers, health-literate education materials, and counseling and support groups for patients and caregivers. Based on this survey data, CancerCare seeks to expand and add services, such as decision-making worksheets and decision-making role play videos.
2. **Clinical organizations should update patient forms, appointment scheduling procedures, and policies that define “family” to include caregivers and support their involvement.**¹⁵ Legislation such as the CARE Act¹⁶ and the RAISE Family Caregivers Act¹⁷ can make it easier to designate caregivers, share healthcare information, and address the care needs of patients and caregivers in tandem.
3. **Communication with the clinical cancer care team should be supported by patient portals** and similar information-exchange platforms that encourage active participation by clinicians, patients, and caregivers. Examples like CHESS (Comprehensive Health Enhancement Support System) include coaching services and other resources specifically for caregivers.¹⁸
4. **Clinicians should be more proactive in discussing the impact of treatment and patients’ quality-of-life priorities.** Open communication about prognosis, illness progression, risks and benefits of treatments, and potential for control or cure is crucial to making informed decisions, including whether to stop treatment.¹⁹ Resources such as *The Conversation Project*²⁰ and the Family Conference model/“VALUE” framework²¹ can help patients, caregivers, and physicians address these difficult but essential topics.
5. **Caregivers, patients, and clinicians should consider using decision-making tools.** Evidence-based decision aids can improve knowledge of treatment options, decrease decisional conflict, and help users identify personal priorities; aids may also foster more realistic perceptions of risks and benefits and encourage more active discussion with clinicians.²² The use of inclusive decision aids can help to counter implicit bias from healthcare professionals²³ that might otherwise lead to disparities in how treatment options and other health-related information are presented and perceived.
6. **Caregivers who have high needs for self-care should be connected with oncology social workers,** who can assist them in developing healthy techniques for coping, relating, and communicating. Healthcare systems can address barriers that make it difficult for cancer clinicians to refer caregivers to support services, such as a lack of “standards for handling family-level-data...in commonly used electronic record systems” and insurance reimbursement issues.²⁴
7. **Healthcare organizations and their staff should cultivate culturally responsive practices to support more successful interactions with caregivers.**²⁵ This includes improving access to professional translation services for appointments, translating healthcare materials for both language and cultural meaning, creating health-literate preferred-language resources, and developing in-language caregiver support groups.²⁶

Examining correlations among all the factors probed in the Caregiver Decision-Making Survey is beyond the scope of this report; however, the survey data are available to others for further analysis. Custom data runs can be performed and additional data for specific cancers can be provided, along with open-ended responses about treatment decisions. We invite those interested in working with the Caregiver Decision-Making Survey data to contact CancerCare at caregiverresearch@cancercare.org.

References for Executive Summary

- 1 See: National Alliance for Caregiving in partnership with the National Cancer Institute and the Cancer Support Community. *Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience*. June 2016, https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf. Accessed March 5, 2022.; National Cancer Institute. *Health Information National Trends Survey 5, Cycle 1*. 2017, <https://hints.cancer.gov/data/download-data.aspx>.
- 2 Acquati, Chiara, et al. "Patient Activation and Treatment Decision-making in the Context of Cancer: Examining the Contribution of Informal Caregivers' Involvement." *Journal of Cancer Survivorship*, September 12, 2021. *SpringerLink*, DOI: 10.1007/s11764-021-01085-9.
- 3 See: Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI: 10.1016/j.pec.2017.05.014.; Shin, Dong Wook, et al. "Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists." *Psycho-Oncology*, vol. 26, no. 6, 2016, pp. 770-778. *PubMed.gov*, DOI: 10.1002/pon.4226.
- 4 See: DiMatteo, M. Robin. "Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis." *Health Psychology*, vol. 23, no. 2, 2004, pp. 207-18. *APA PsychNet*, DOI: 10.1037/0278-6133.23.2.207.; Wolff, Jennifer L., and Debra L. Roter. "Hidden in Plain Sight: Medical Visit Companions as a Resource for Vulnerable Older Adults." *Archives of Internal Medicine*, vol. 168, no. 13, 2008, pp. 1409-15. *JAMA Network*, DOI: 10.1001/archinte.168.13.1409.; Irani, Eliane, et al. "Systematic Review of Technology-Based Interventions Targeting Chronically Ill Adults and Their Caregivers." *Western Journal of Nursing Research*, vol. 42, no. 11, 2020, pp. 974-992. *PubMed.gov*, DOI: 10.1177/0193945919897011.; Northouse, Laurel L., et al. "Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials." *CA: A Cancer Journal for Clinicians*, vol. 60, no. 5, 2010, pp. 317-339. *ACS Journals*, DOI: 10.3322/caac.20081.; Høeg, Beverley Lim, et al. "Is the Health Literacy of Informal Caregivers Associated with the Psychological Outcomes of Breast Cancer Survivors?" *Journal of Cancer Survivorship*, vol. 15, no. 5, 2021, pp. 729-737. *SpringerLink*, DOI: 10.1007/s11764-020-00964-x.
- 5 See: Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.; Garvelink, Mirjam M., et al. "A Synthesis Of Knowledge About Caregiver Decision Making Finds Gaps In Support For Those Who Care For Aging Loved Ones." *Health Affairs*, vol. 35, no. 4, 2016, pp. 619-626. *Health Affairs*, DOI: 10.1377/hlthaff.2015.1375.; Hashemi, Maryam, et al. "Caregivers Needing Care: The Unmet Needs of the Family Caregivers of End-of-Life Cancer Patients." *Supportive Care in Cancer*, vol. 26, no. 3, 2018, pp. 759-766. *SpringerLink*, DOI: 10.1007/s00520-017-3886-2.
- 6 See: CancerCare. *CancerCare Patient Access and Engagement Report*. 2016, <https://media.cancercare.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.; CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercare.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.
- 7 Rx4Good. "Supplemental Report: Findings for Caregivers Whose Recipient Is Diagnosed with Cancer." *The Caregiver Factor: Understanding the Medical Journey of the Caregiver and Their Information and Support Needs*, 2018.
- 8 See: Bastawrous, Marina. "Caregiver Burden—A Critical Discussion." *International Journal of Nursing Studies*, vol. 50, no. 3, March 2013, pp. 431-443. *ResearchGate*, DOI: 10.1016/j.ijnurstu.2012.10.005.; Liu, Zhu, et al. "Caregiver Burden: A Concept Analysis." *International Journal of Nursing Science*, vol. 7, no. 4, 2020, pp. 438-445. *ScienceDirect*, DOI: 10.1016/j.ijnss.2020.07.012.; Northouse, Laurel, et al. "Psychosocial Care for Family Caregivers of Patients With Cancer." *Journal of Clinical Oncology*, vol. 30, no. 11, 2012, pp. 1227-1234. *Journal of Clinical Oncology*, DOI: 10.1200/JCO.2011.39.5798.
- 9 See: Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.; CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercare.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.

References for Executive Summary

- 10** See: Hobbs, Gabriela S., et al. "The Role of Families in Decisions Regarding Cancer Treatments." *Cancer*, vol. 121, no. 7, 2015, pp. 1079-1087. *ACS Journals*, DOI: 10.1002/cncr.29064.; Lamore, Kristopher and Lucile Montalescot, et al. "Treatment Decision-making in Chronic Diseases: What Are the Family Members' Roles, Needs and Attitudes? A Systematic Review." *Patient Education and Counseling*, vol. 100, no. 12, 2017, pp. 2172-2181. *HAL Open Science*, DOI: 10.1016/j.pec.2017.08.003.
- 11** Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.
- 12** See: Wright, Alexi A., et al. "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment." *JAMA*, vol. 300, no. 14, 2008, pp.1665-1673. *PubMed.gov*, DOI: 10.1001/jama.300.14.1665.; Detering, Karen M., et al. "The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomized Controlled Trial." *BMJ*, vol. 340, c. 1345, 2010. DOI:10.1136/bmj.c1345.; Mack, Jennifer W., et al. "Associations Between End-of-life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study." *Journal of Clinical Oncology*, vol. 30, no. 35, 2012, pp. 4387-4395. DOI:10.1200/JCO.2012.43.6055.; Hoverman, J. Russell, et al. "If We Don't Ask, Our Patients Might Never Tell: The Impact of the Routine Use of a Patient Values Assessment." *Journal of Oncology Practice*, vol. 13, no. 10, 2017. *ASCOpubs.org*, DOI: 10.1200/JOP.2017.022020.
- 13** See: Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.; Florindez, Lucía I., et al. "Differing Interpretations of Health Care Encounters: A Qualitative Study of Non-Latinx Health Care Providers' Perceptions of Latinx Patient Behaviors." *PLoS ONE*, vol. 15, no. 8, 2020. *PLoS ONE*. DOI: 10.1371/journal.pone.0236706.; Miyawaki, Christina E. "Caregiving Practice Patterns of Asian, Hispanic, and Non-Hispanic White American Family Caregivers of Older Adults Across Generations." *Journal of Cross-Cultural Gerontology*, vol. 31, 2016, pp. 35-55. *SpringerLink*. DOI: 10.1007/s10823-016-9281-5.; Wells, Jo Nell, et al. "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger." *Journal of Transcultural Nursing*, vol. 19, no. 3, 2008, pp. 223-233. *SAGE Journals*, DOI: 10.1177/1043659608317096.; Losada, Andres, et al. "Cross-cultural Study Comparing the Association of Familism with Burden and Depressive Symptoms in Two Samples of Hispanic Dementia Caregivers." *Aging and Mental Health*, vol. 10, no. 1, 2006, pp. 69-76. *Taylor & Francis Online*. DOI:10.1080/13607860500307647.; Cox, Carole and Abraham Monk. "Hispanic Culture and Family Care of Alzheimer's Patients." *Health & Social Work*, vol. 18, no. 2, May 1993, pp. 92-100. *Oxford Academic*. DOI: 10.1093/hsw/18.2.92.
- 14** See: McGinty, Emma E., et al. "Psychological Distress and Loneliness Reported by US Adults in 2018 and April 2020." *JAMA*, vol. 324, no. 1, July 2020, pp. 93-94. *JAMA Network*. DOI:10.1001/jama.2020.9740.; Zamora, Eduardo R., et al. "The Impact of Language Barriers and Immigration Status on the Care Experience for Spanish-speaking Caregivers of Patients with Pediatric Cancer." *Pediatric Blood & Cancer*, vol. 63, no. 12, 2016, pp. 2173-2180. *Wiley Online Library*. DOI: 10.1002/pbc.26150.; Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.
- 15** See: Diverse Elders Coalition. "Resources for Providers: Meeting the Needs of Diverse Family Caregivers" from the *Caring for Those Who Care Curriculum*, March 2021. <https://diverseelders.org/caregiving/>. Accessed April 24, 2022.; Laidsaar-Powell, Rebekah, et al. "Facilitating Collaborative and Effective Family Involvement in the Cancer Setting: Guidelines for Clinicians (TRIO Guidelines-1)." *Patient Education and Counseling*, vol. 101, no. 6, 2018, pp. 970-982. *ResearchGate.net*, DOI: 10.1016/j.pec.2018.01.019. Accessed April 24, 2022.
- 16** AARP. "State Law to Help Family Caregivers." *AARP.org*, 2014, <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>. Accessed April 24, 2022.
- 17** See: 115th Congress of the United States of America. *Public Law 115-119: Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017*. January 22, 2018. <https://acl.gov/sites/default/files/about-acl/2018-10/PLAW-115publ119%20-%20RAISE.pdf>. Accessed April 24, 2022.; RAISE Family Caregiving Advisory Council with assistance from Administration for Community Living. "RAISE Family Caregivers Act Initial Report to Congress." September 22, 2021, *Administration for Community Living, U.S. Department of Health and Human Services*, https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf. Accessed April 24, 2022.
- 18** See: DuBenske, Lori L., et al. "Web-Based Cancer Communication and Decision Making Systems: Connecting Patients, Caregivers, and Clinicians for Improved Health Outcomes." *Medical Decision Making*, vol. 30, no. 6, 2010, pp. 732-744. *PubMed.gov*, DOI: 10.1177/0272989X10386382.; DuBenske, Lori L., et al. "CHESS Improves Cancer Caregivers' Burden and Mood: Results of an eHealth RCT." *Health Psychology*, vol. 33, no. 10, 2014, pp. 1261-1272. *PubMed.gov*, DOI: 10.1037/a0034216.



References for Executive Summary

- 19** See: CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancer.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.; Verini, Christine, et al. *Improving Support in Treatment Decision Making for Patients with Metastatic Breast Cancer*. CancerCare, February 2020. https://media.cancer.org/publications/original/396-396-2020_mbcroundtable.pdf. Accessed March 5, 2022.; Hoverman, J. Russell, et al. "If We Don't Ask, Our Patients Might Never Tell: The Impact of the Routine Use of a Patient Values Assessment." *Journal of Oncology Practice*, vol. 13, no. 10, 2017. ASCOpubs.org, DOI: 10.1200/JOP.2017.022020.; Lamont, Elizabeth B. and Nicholas A. Christakis. "Prognostic Disclosure to Patients with Cancer Near the End of Life." *Annals of Internal Medicine*, vol. 134, no. 12, 2001, pp. 1096-1105. ResearchGate.net, DOI: 10.7326/0003-4819-134-12-200106190-00009. Accessed May 5, 2022.; Keating, Nancy L., et al. "Physician Factors Associated with Discussions about End-of-Life Care." *Cancer*, vol. 116, no. 4, 2010, pp. 998-1006. DOI: 10.1002/cncr.24761.; Wright, Alexi A. et al. "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment." *JAMA*, vol. 300, no. 14, 2008, pp.1665-1673. PubMed.gov, DOI: 10.1001/jama.300.14.1665.; Detering, Karen M., et al. "The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomized Controlled Trial." *BMJ*, vol. 340, c. 1345, 2010. DOI:10.1136/bmj.c1345.; Mack, Jennifer W., et al. "Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study." *Journal of Clinical Oncology*, vol. 30, no. 35, 2012, pp. 4387-4395. DOI:10.1200/JCO.2012.43.6055.
- 20** Institute for Healthcare Improvement. *The Conversation Project*. <https://theconversationproject.org/>. Accessed April 24, 2022.
- 21** See: Hillman, Ken and Jack Chen. *Conflict Resolution in End of Life Treatment Decisions: An Evidence Check Rapid Review Brokered by the Sax Institute for the NSW Department of Health*. The Sax Institute, November 2008. https://www.saxinstitute.org.au/wp-content/uploads/REPORT_ConflictResEndOfLife.pdf. Access April 24, 2022.; University of Washington End-of-Life Care Research Program at Harborview Medical Center. "V.A.L.U.E." Reference Card. <http://depts.washington.edu/eolcare/products/communication-tools/>. Accessed April 24, 2022.
- 22** Stacey, Dawn, et al. "Decision Aids for People Facing Health Treatment or Screening Decisions." *Cochrane Database of Systematic Reviews*, version published April 12, 2017, DOI: 10.1002/14651858.CD001431.pub5.
- 23** Eggly, Susan, et al. "Development of a Question Prompt List as a Communication Intervention to Reduce Racial Disparities in Cancer Treatment." *Journal of Cancer Education*, vol. 28, no. 2, 2013, pp. 282-289. PubMed.gov, DOI: 10.1007/s13187-013-0456-2.
- 24** See: National Alliance for Caregiving. *Caring for the Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team*. National Alliance for Caregiving, November 2021, https://www.caregiving.org/wp-content/uploads/2021/11/NAC_CaringForCaregiver_Paper_111921.pdf. Accessed April 24, 2022.; Skufca, Laura. *Primary Care Providers' Experiences with Family Caregivers*. AARP Research, 2018, https://www.aarp.org/content/dam/aarp/research/surveys_statistics/lrc/2019/primary-care-provider-on-family-caregiver-role.doi.10.26419-2Fres.00273.001.pdf. DOI: 10.26419/res.00273.001.
- 25** See: Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.; Miyawaki, Christina E. "Caregiving Practice Patterns of Asian, Hispanic, and Non-Hispanic White American Family Caregivers of Older Adults Across Generations." *Journal of Cross-Cultural Gerontology*, vol. 31, 2016, pp. 35-55. SpringerLink. DOI: 10.1007/s10823-016-9281-5.; Diverse Elders Coalition. "Resources for Providers: Meeting the Needs of Diverse Family Caregivers" from the *Caring for Those Who Care Curriculum*, March 2021. <https://diverseelders.org/caregiving/>. Accessed April 24, 2022.
- 26** Diverse Elders Coalition. "Resources for Providers: Meeting the Needs of Diverse Family Caregivers" from the *Caring for Those Who Care Curriculum*, March 2021. <https://diverseelders.org/caregiving/>. Accessed April 24, 2022.

Background

From the “I have what...?” of diagnosis, cancer patients and their families must rapidly confront “what next?”—the cascade of decisions about where, when, how, and if they’ll seek treatment. In most cases, patients rely on family members and close friends to support them as caregivers. Caregivers join patients for most cancer-related healthcare consultations and appointments (64-85%),¹ where they gather information, ask questions, and probe for guidance. Studies in multiple countries find that most cancer patients—anywhere from 49% to nearly 95%—prefer to involve caregivers in medical decision-making as well.² In a large study of newly diagnosed patients with colorectal or lung cancer, more than 70% reported that family members were at least somewhat involved in treatment decisions; nearly 50% reported that they shared equally in decision-making.³ For people with cancer, the weight of treatment decision-making is undeniable; for caregivers, these decisions also carry significant logistical, physical, emotional, financial, and professional consequences.⁴ Yet the ways caregivers participate in decision-making are variable, often unclear, and certainly under-supported by clinicians and educational materials.⁵



Patient involvement in treatment decision-making is considered a best practice, as codified by a landmark 2001 publication from the Institute of Medicine (now the National Academies of Medicine). *Crossing the Quality Chasm* lays out six essential characteristics for quality healthcare delivery; one of these is being **patient-centered**, defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” The report calls for a shift from clinician-controlled processes to a patient-led shared decision-making model, in which patients and healthcare professionals collaborate as partners. It recognizes that patients’ personal circumstances, cultural contexts, and individual perspectives uniquely inform their goals and preferences for care. The report also cites numerous studies that indicate patients who are informed and actively involved in treatment decision-making have better outcomes and lower healthcare costs.⁶



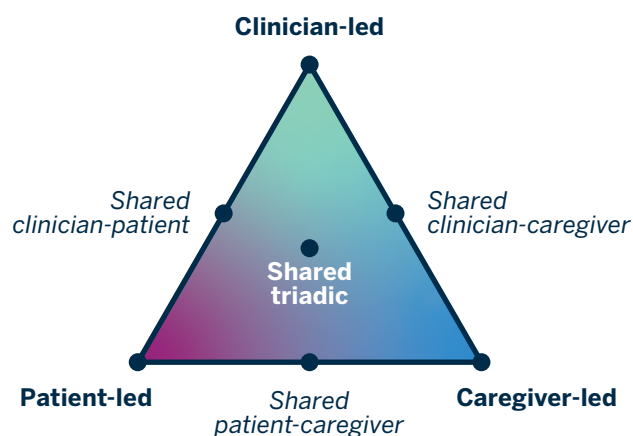
What roles do caregivers play in patient-centered care? A growing body of scholarship seeks to understand caregiver dynamics in shared decision-making and generate new models that reflect their involvement. For example, in place of the patient-clinician dyadic model, the TRIO framework visualizes the patient, caregiver, and clinician as three points of a triangle. Shared decision-making lies at the center of the triangle. The midpoint of each side reflects decision-making shared by a pair: caregiver-patient, patient-clinician, and clinician-caregiver. The influence a participant or pair has on a final decision pulls it toward them and away from the triangle's center. The TRIO framework makes a distinction between caregivers' involvement in the decision-making process (e.g. gathering info, joining appointments, asking questions, helping deliberate) and their influence on the actual decision made. Involvement and influence vary within the trio over time and with different decisions (see Appendix for examples); these dynamics also vary among different groups of patients, caregivers, and clinicians. Ultimately, caregivers' involvement and influence in decision-making is linked to the ongoing care and support

they provide.⁷ Other studies have found that patient factors (such as gender or medical knowledge), relationship factors (e.g. spouses, child-parent, etc.), and cultural factors linked to racial and ethnic identity (e.g. shared values and norms related to caregiving, family roles, spirituality, etc.) can all play a part in how passive, active, or dominant a caregiver is in different decision-making situations.⁸



TRIO Framework shared decision-making model

Laidsaar-Powell, et al. 2017



While further research is needed, new understanding suggests that caregiver involvement in treatment decision-making may impact patient outcomes and well-being. Studies have found links between caregiver involvement and better treatment adherence, improved understanding of cancer topics, greater satisfaction and self-efficacy, and lower levels of stress and depression.⁹ Conversely, failing to involve caregivers may “lead to the receipt of care and treatments inconsistent with the patient’s values and preferences.”¹⁰ Studies have found that lack of caregiver involvement in decision-making may reduce treatment adherence in otherwise engaged cancer patients¹¹ and result in suboptimal care for older cancer patients.¹²



Even as recognition of caregivers' significance in treatment decision-making grows, however, caregivers often feel excluded, unsupported, and stressed by how decisions are made.¹³ In a survey by Rx4Good, 70% of cancer caregivers reported that care decisions cause them much stress, even when they and their patient agree on treatment priorities. Among caregivers and patients who sometimes agree on treatment priorities, the number jumps up to 83%.¹⁴ It's unclear what resources, if any, are provided by healthcare teams to aid resolution; in general, treatment decision-making support is not widely or uniformly available. Research suggests some clinicians may feel uncertain or uneasy about how to address caregiver involvement in decision-making, expressing concerns about patient autonomy and negative or undue influence from caregivers.¹⁵ A 2020 national survey found that very few caregivers have had conversations with healthcare professionals "about what they need to care for their recipient (29%) or to support their own well-being (13%)."¹⁶

Communication gaps are common, and many caregivers struggle to access and process information that is important to care decisions,¹⁷ which then impairs their ability to actively participate in and add value to shared decision-making.

Caregivers' unmet needs regarding treatment decision-making compound the well-documented burdens of providing care and can negatively impact the quality of care they provide.¹⁸ **Through better understanding caregivers' experiences in shared decision-making—including their roles, considerations, and challenges—projects such as CancerCare's Caregiver Decision-Making Survey can inform the design of programs and materials to support patients and caregivers in treatment decision-making and help make progress toward achieving the goals of high-quality patient-centered care.**

Who is a caregiver?

Caregivers or care partners* provide unpaid support to someone close to them who has an illness, disability, or other health concern. While “family caregiver” is often used synonymously, caregivers are not necessarily related to their care recipients and may not live with them.

Caregivers provide “practical and emotional support across the continuum of care,”¹⁹ which includes making social visits; helping with household chores and errands; coordinating finances, services, and meals; attending clinical appointments; communicating with healthcare professionals and advocating for the patient; monitoring symptoms and side effects; managing medications; and providing physical care, including support for activities of daily life and some medical/nursing tasks.

While many find meaningful connections in providing care, caregiving takes a toll. Juggling care responsibilities changes personal relationships and daily routines; caregivers often feel isolated, exhausted, and stretched too far. Anxiety and depression are common,²⁰ as are physical health issues. Some cancer caregivers become hidden “second patients,” quietly drowning in the wake of their patient’s diagnosis.²¹

- In 2020, more than 1 in 5 Americans (21.3%) had served as caregivers in the past 12 months—a percentage that has grown since 2015²²
- The estimated number of cancer caregivers in the U.S. ranges from 2.8 million to 6.1 million adults²³
- Cancer caregivers average 32.9 hours of care a week; nearly one-third (32%) provide 41+ hours of care, the equivalent of a full-time job²⁴
- Cancer caregivers devote nearly 50% more hours per week to care than caregivers of non-cancer patients²⁵



*Caregiver vs. care partner:

CancerCare’s Caregiver Decision-Making Survey employed the term “caregiver” for its familiarity and common usage, so we have continued its use in this report. The term, however, is being reconsidered in healthcare circles, and “care partner” has emerged as a preferred term, among some.



References for Section 1: Background

- 1 Acquati, Chiara, et al. "Patient Activation and Treatment Decision-making in the Context of Cancer: Examining the Contribution of Informal Caregivers' Involvement." *Journal of Cancer Survivorship*, September 12, 2021. *SpringerLink*, DOI: 10.1007/s11764-021-01085-9.
- 2 See: Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.; Shin, Dong Wook, et al. "Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists." *Psycho-Oncology*, vol. 26, no. 6, 2016, pp. 770-778. *PubMed.gov*, DOI: 10.1002/pon.4226.
- 3 Hobbs, Gabriela S., et al. "The Role of Families in Decisions Regarding Cancer Treatments." *Cancer*, vol. 121, no. 7, 2015, pp. 1079-1087. *ACS Journals*, DOI: 10.1002/cncr.29064.
- 4 See: CancerCare. *CancerCare Patient Access and Engagement Report*. 2016, <https://media.cancercare.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.; CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercare.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.
- 5 See: Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.; Garvelink, Mirjam M., et al. "A Synthesis of Knowledge About Caregiver Decision Making Finds Gaps in Support for Those Who Care for Aging Loved Ones." *Health Affairs*, vol. 35, no. 4, 2016, pp. 619-626. *Health Affairs*, DOI: 10.1377/hlthaff.2015.1375.; Hashemi, Maryam, et al. "Caregivers Needing Care: The Unmet Needs of the Family Caregivers of End-of-Life Cancer Patients." *Supportive Care in Cancer*, vol. 26, no. 3, 2018, pp. 759-766. *Springer Link*, DOI: 10.1007/s00520-017-3886-2.
- 6 Institute of Medicine, Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academies Press, 2001. *The National Academies Press*, DOI: 10.17226/10027.
- 7 Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.
- 8 See: Hobbs, Gabriela S., et al. "The Role of Families in Decisions Regarding Cancer Treatments." *Cancer*, vol. 121, no. 7, 2015, pp. 1079-1087. *ACS Journals*, DOI: 10.1002/cncr.29064.; Lamore, Kristopher and Lucile Montalescot, et al. "Treatment Decision-making in Chronic Diseases: What Are the Family Members' Roles, Needs and Attitudes? A Systematic Review." *Patient Education and Counseling*, vol. 100, no. 12, 2017, pp. 2172-2181. *HAL Open Science*, DOI: 10.1016/j.pec.2017.08.003.
- 9 See: DiMatteo, M. Robin. "Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis." *Health Psychology*, vol. 23, no. 2, 2004, pp. 207-18. *APA PsychNet*, DOI: 10.1037/0278-6133.23.2.207.; Wolff, Jennifer L., and Debra L. Roter. "Hidden in Plain Sight: Medical Visit Companions as a Resource for Vulnerable Older Adults." *Archives of Internal Medicine*, vol. 168, no. 13, 2008, pp. 1409-15. *JAMA Network*, DOI: 10.1001/archinte.168.13.1409.; Irani, Elliane, et al. "Systematic Review of Technology-Based Interventions Targeting Chronically Ill Adults and Their Caregivers." *Western Journal of Nursing Research*, vol. 42, no. 11, 2020, pp. 974-992. *PubMed.gov*, DOI: 10.1177/0193945919897011.; Northouse, Laurel L., et al. "Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials." *CA: A Cancer Journal for Clinicians*, vol. 60, no. 5, 2010, pp. 317-339. *ACS Journals*, DOI: 10.3322/caac.20081.; Høeg, Beverley Lim, et al. "Is the Health Literacy of Informal Caregivers Associated with the Psychological Outcomes of Breast Cancer Survivors?" *Journal of Cancer Survivorship*, vol. 15, no. 5, 2021, pp. 729-737. *SpringerLink*, DOI: 10.1007/s11764-020-00964-x.
- 10 Dionne-Odom, J. Nicholas, et al. "How Family Caregivers of Persons with Advanced Cancer Assist with Upstream Healthcare Decision-Making: A Qualitative Study." *PLoS ONE*, vol. 14, no. 3, 2019. *PLoS ONE*, DOI: 10.1371/journal.pone.0212967.
- 11 Acquati, Chiara, et al. "Patient Activation and Treatment Decision-making in the Context of Cancer: Examining the Contribution of Informal Caregivers' Involvement." *Journal of Cancer Survivorship*, September 12, 2021. *SpringerLink*, DOI: 10.1007/s11764-021-01085-9.
- 12 Wan-Chow-Wah, Doreen, et al. "Difficulties in Decision Making Regarding Chemotherapy for Older Cancer Patients: A Census of Cancer Physicians." *Critical Reviews in Oncology/Hematology*, vol. 78, no. 1, 2011, pp. 45-58. *ScienceDirect*, DOI: 10.1016/j.critrevonc.2010.02.010.
- 13 See: Garvelink, Mirjam M., et al. "A Synthesis of Knowledge About Caregiver Decision Making Finds Gaps in Support for Those Who Care for Aging Loved Ones." *Health Affairs*, vol. 35, no. 4, 2016, pp. 619-626. *Health Affairs*, DOI: 10.1377/hlthaff.2015.1375.; Hashemi, Maryam, et al. "Caregivers Needing Care: The Unmet Needs of the Family Caregivers of End-of-Life Cancer Patients." *Supportive Care in Cancer*, vol. 26, no. 3, 2018, pp. 759-766. *Springer Link*, DOI: 10.1007/s00520-017-3886-2.

References for Section 1: Background

- 14 Rx4Good. "Supplemental Report: Findings for Caregivers Whose Recipient is Diagnosed with Cancer." *The Caregiver Factor: Understanding the Medical Journey of the Caregiver and Their Information and Support Needs*, 2018.
- 15 See: Shin, Dong Wook, et al. "Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists." *Psycho-Oncology*, vol. 26, no. 6, 2016, pp. 770-778. *PubMed.gov*, DOI: 10.1002/pon.4226.; Lamore, Kristopher and Lucile Montalescot, et al. "Treatment Decision-making in Chronic Diseases: What Are the Family Members' Roles, Needs and Attitudes? A Systematic Review." *Patient Education and Counseling*, vol. 100, no. 12, 2017, pp. 2172-2181. *HAL Open Science*, DOI: 10.1016/j.pec.2017.08.003.
- 16 National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>. Accessed March 5, 2022.
- 17 See: DuBenske, Lori L., et al. "Web-Based Cancer Communication and Decision Making Systems: Connecting Patients, Caregivers, and Clinicians for Improved Health Outcomes." *Medical Decision Making*, vol. 30, no. 6, 2010, pp. 732-744. *PubMed.gov*, DOI: 10.1177/0272989X10386382.; Hashemi, Maryam, et al. "Caregivers Needing Care: The Unmet Needs of the Family Caregivers of End-of-Life Cancer Patients." *Supportive Care in Cancer*, vol. 26, no. 3, 2018, pp. 759-766. *Springer Link*, DOI: 10.1007/s00520-017-3886-2.; CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercare.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.; Rx4Good. *The Caregiver Factor: Understanding the Medical Journey of the Caregiver and Their Information and Support Needs*. 2018, http://rx4good.com/admin/wp-content/uploads/2018/06/RX4G_Caregiver_Report.pdf. Accessed March 5, 2022.
- 18 See: Bastawrous, Marina. "Caregiver Burden—A Critical Discussion." *International Journal of Nursing Studies*, vol. 50, no. 3, March 2013, pp. 431-443. *ResearchGate*. DOI: 10.1016/j.ijnurstu.2012.10.005.; Liu, Zhu, et al. "Caregiver Burden: A Concept Analysis." *International Journal of Nursing Science*, vol. 7, no. 4, 2020, pp. 438-445. *ScienceDirect*. DOI: 10.1016/j.ijnss.2020.07.012.; Northouse, Laurel, et al. "Psychosocial Care for Family Caregivers of Patients With Cancer." *Journal of Clinical Oncology*, vol. 30, no. 11, 2012, pp. 1227-1234. *Journal of Clinical Oncology*, DOI: 10.1200/JCO.2011.39.5798.
- 19 Acquati, Chiara, et al. "Patient Activation and Treatment Decision-making in the Context of Cancer: Examining the Contribution of Informal Caregivers' Involvement." *Journal of Cancer Survivorship*, September 12, 2021. *SpringerLink*, DOI: 10.1007/s11764-021-01085-9.
- 20 Geng, Hai-Mei, et al. "Prevalence and Determinants of Depression in Caregivers of Cancer Patients: A Systematic Review and Meta-analysis." *Medicine*, vol. 97, no. 39, September 2018. DOI: 10.1097/MD.00000000000011863.
- 21 Williams, Anna-Leila. "Family Caregivers to Adults with Cancer: The Consequences of Caring." *Psycho-Oncology*, vol. 210, 2018, pp. 87-103. *Springer Link*, DOI: 10.1007/978-3-319-64310-6_6.
- 22 National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>. Accessed March 5, 2022.
- 23 See: National Alliance for Caregiving, in partnership with the National Cancer Institute and the Cancer Support Community. *Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience*. June 2016, https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf. Accessed March 5, 2022.; National Cancer Institute. *Health Information National Trends Survey 5, Cycle 1*. 2017, <https://hints.cancer.gov/data/download-data.aspx>.
- 24 National Alliance for Caregiving, in partnership with the National Cancer Institute and the Cancer Support Community. *Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience*. June 2016, https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf. Accessed March 5, 2022.
- 25 American Society of Clinical Oncology. "Cancer Caregivers Experience Unique Burdens Compared with Other Conditions." September 2016. *ScienceDaily*, <https://www.sciencedaily.com/releases/2016/09/160907095539.htm>. Accessed March 5, 2022.

Survey Development & Methodology

The Caregiver Decision-Making Survey builds on CancerCare's multi-stage investigation of caregiver engagement in patient-centered care. Under the umbrella of the Patient Values Initiative, CancerCare has gathered insights from patients, caregivers, clinicians, and other key stakeholders to ensure that patients' values and priorities are incorporated into treatment decision-making and national healthcare policy.¹ In 2020, CancerCare conducted focus groups with caregivers and social workers about the ways they support patients in treatment decision-making; the white paper *Cancer Caregivers and Treatment Decision Making*² shares what we learned, including:

- Engagement levels vary greatly among caregivers—they play a variety of decision-making roles in relation to patients' needs and group dynamics.
- Personal context creates unique decision-making challenges—experiences and needs vary between caregivers and patients, from caregiver to caregiver, and by situation; yet there are also some commonalities.
- Gaps in information make decision-making harder—caregivers often seek out information beyond what clinicians provide in order to aid decision-making.

These key themes and others informed the topics selected for the Caregiver Decision-Making Survey.

Ultimately, research calls us to approach the patient and caregiver as a joint “unit of care.”

If we can help caregivers better navigate the stress of treatment decision-making and feel more supported, they may better support patients' well-being.

The survey also draws on clinical research that indicates a significant link between caregiver state of mind and patient outcomes. For instance, worse mental health in caregivers predicted greater mortality rates among dementia patients, even when accounting for other high-risk factors.³ Other studies found a significant relationship between greater caregiver strain/distress and higher risk of clinical events for heart failure patients.⁴ Mental health can impact the quality of care provided, such as a caregiver's ability to manage a patient's medications.⁵ A caregiver's emotional state can also influence a patient's mental health and vice versa; studies suggest these responses are interdependent and bi-directional.⁶ Unraveling the relationship between a patient's worsening outcomes and a caregiver's worsening well-being poses a chicken-and-egg problem. Ultimately, research calls us to approach the patient and caregiver as a joint “unit of care.”⁷ When programs are designed to support caregivers, studies have found that participating patients had fewer symptoms, better physical health, better mental health, and lower mortality rates.⁸

Through this survey, we hope to provide a fuller understanding of caregivers' decision-making needs. If we can help caregivers better navigate the stress of treatment decision-making and feel more supported, they may better support patients' well-being.



Overview of survey topics

The key areas of inquiry for this survey included the following:

- Shared decision-making situations
- Decision-making roles of caregivers
- Caregivers' information sources for decision-making
- Specific challenges/pain points in shared decision-making
- Caregivers' attitudes and feelings, including depression and anxiety
- Correlations with patient cancer stage, treatment status, and age; caregiver demographics, attitudes, and perceptions

The breadth and depth of data collected also lends itself to custom data cuts for future analysis.

Shared decision-making situations

The survey presented respondents with 14 decision-making areas from across the continuum of cancer care—for example, deciding where to get treatment, determining what medications to take, and deciding whether or not to have hospice care. We asked them to select all the situations where they had been involved in decision-making regarding their care recipient. From among the decision-making areas they selected, respondents were asked to pick one they remember most clearly and answer more in-depth questions about that situation.

Caregivers' decision-making roles

For the decision-making situation they selected, we asked each caregiver to characterize the role they played using one of four options or supplying their own. The four pre-set options—coded as “Observer/Supporter,” “Input Provider to Clinical Team,” “Joint Decision Maker,” and “Primary



Decision Maker”—were based on common decision-making roles observed by CancerCare social workers and identified in past cancer caregiver studies.⁹

Caregivers’ information sources and needs for decision-making

Respondents were given a list of information sources (e.g. “the patient’s clinical care team,” “social media”) and asked to indicate all that they had used to help make the selected decision. We presented a set of statements related to information helpfulness and decision outcomes (e.g. “The information I found or was given was not helpful,” “The right decision was made”) and asked them to rate how much they agreed or disagreed with each on a four-point scale. They were also asked to select any personal factors (e.g. their or the patients’ age, race, language, income level) that they felt negatively affected the decision-making support provided by the clinical care team.

Finally, we provided a list of nine possible decision-making services or resources (e.g. “free consultation with an oncology nurse,” “worksheets that help guide decision-making”) and had caregivers rate how helpful they thought each would be on a three-point scale.

Specific challenges/“pain points” in shared decision-making

Related to the specific decision-making situation they selected, respondents were shown 10 statements about possible decision-making challenges (e.g. “Not everyone on the care team agreed,” “I didn’t have enough information to make this decision”). We asked caregivers to rate how much they agreed or disagreed with each statement using a five-point Likert scale. In an open-response section, we invited respondents to share additional details about what was challenging in their specific situation.

Caregivers were also shown 14 decision-making factors (e.g. “The patient’s quality of life,” “The consequences of this decision on my own day-to-day life”) and asked to rate how important each had been in their decision-making process.

Caregivers’ attitudes and feelings of depression and anxiety

Respondents were asked to rate how much various statements described their feelings about caregiving—for example, “I feel useful and needed” and “I feel trapped by this person’s illness.” In addition, respondents were shown a series of statements about feeling supported or burdened as a caregiver and asked how often they felt that way. Statements touched on family support (e.g. “Communication in your family has improved,” “Bothered that other family members have not shown interest in taking care of this person”), information needs (“Adequately informed about the person’s illness”), and personal needs/feelings of distress (“You have lost control of your life,” “You have a loss of privacy and/or personal time”).

To gauge caregivers’ feelings of depression and anxiety, the survey included two widely used and validated screening tools: the Patient Health Questionnaire-2 (PHQ-2), for major depression, and the Generalized Anxiety Disorder-2 (GAD-2). Scores on each screen range from zero to six, with scores of three or higher representing a positive screen for possible major depressive disorder or possible generalized anxiety disorder. The survey did not directly ask caregivers if decision-making was a source of anxiety/depression.

Correlations with patient stage/status/age and caregiver demographics/attitudes/perceptions

Along with demographic data, the survey asked respondents to provide information about the individual they care for (including cancer diagnosis, type, and stage, treatments received, and current treatment status) and certain aspects of their relationship (such as whether they live together, length of time providing care, and how they’re connected—e.g. married, relatives, friends, etc.).

Custom data cuts and future analysis

Examining all the factors listed here is beyond the scope of this report; however, the data is available to others for further analysis. Custom data runs can be performed and additional data for specific cancers can be provided (see list), along with open-ended responses about treatment decisions. We invite those interested in working with the Caregiver Decision-Making Survey data to contact CancerCare at caregiverresearch@cancer.org.

Survey sample size by cancer type:

- Breast: 568
- Prostate: 351
- Lung: 378
- Leukemia: 270
- Colo-Rectal: 189



Survey methodology

CancerCare set out to gather information from a robust sample of caregivers representative of the U.S. population by ethnicity, race, gender, age, and geography. Because the survey was administered online, we were able to recruit participants through consumer panels vetted by PureSpectrum, Inc., a market research and insights platform.

To be eligible, respondents needed to be at least 18 years old and meet the following screening criteria: 1) they provided unpaid support in the past 12 months to someone close to them who has cancer (not including non-melanoma skin cancer), 2) they currently provided this support, and 3) they have provided support for six months or longer. The survey specified that the cancer patient they support could be a family member or friend and did not have to live with them.

In addition, PureSpectrum used an advanced respondent scoring system (PureScore) to authenticate participants across online market research panels and block any duplicate or fraudulent activity. To ensure a nationally representative sample, CancerCare worked with PureSpectrum to set recruitment quotas by region, ethnicity, race, gender, and age.

CancerCare decided not to use survey responses from caregivers in its own client database. Our intent was to gather data on the experiences of a broad and diverse group, and not bias the results by enlisting individuals who have used our services and are therefore at least somewhat engaged in thinking about the process of caregiving. For that same reason, we did not solicit participation through online communities or chat rooms.





Data analysis and reporting

In total, 2,703 respondents completed the 30-minute survey between February 16, 2021 and July 6, 2021. This report focuses on overall findings and areas of significant differences among various segments. Additional facets of this rich database will likely be explored in future reports.

PureSpectrum collected, sorted, and validated all survey responses. CancerCare then closely collaborated with Praxis Research Partners to analyze the data. Responses to multiple decision-making situations were aggregated to identify similarities and differences in caregivers' decision-making roles, involvement in various treatment decisions, and experiences and attitudes related to specific treatment decisions (with small base values noted).

Using respondents' GAD-2 scores, PHQ-2 scores, and attitudes about caregiving, Praxis identified four segments of caregivers based on their needs and the support they receive from others. This informed the development of a caregiver profile for each segment. In addition, an initial review of survey results revealed numerous differences between responses from Hispanic caregivers and non-Hispanic caregivers. Praxis ran further comparisons of these two groups, with differences tested statistically at a confidence level of 95% (i.e. a 95% probability that the differences between the sample groups are meaningful, rather than random); this report includes findings on significant differences.

CancerCare prepared the final report with review and comments by the project's advisory board, including J. Nicholas Dionne-Odom, PhD, RN, ACHPN, FPCN, FAAN at the School of Nursing at the University of Alabama at Birmingham.

Study limitations

While the survey's online format supported our goal to reach a large, nationally representative sample of caregivers, it does not provide a random sample and excludes caregivers who are less tech-literate, have limited online access and/or are not part of the panels that PureSpectrum accesses. This may have contributed to the higher education levels we saw among respondents, compared to U.S. averages. The survey was delivered exclusively in English, thus excluding caregivers with limited English proficiency.

Cultural context—including cultural norms/attitudes toward caregiving and characteristics of national healthcare services—is crucial to interpreting results.

We also sought a diverse but balanced sample across ethnicity, race, gender, age, and geography; the survey's Hispanic sample, however, skewed notably younger. In our comparative analysis, weights were applied to control for age differences between the Hispanic and non-Hispanic samples. This weighting ensured that the samples were equally balanced on three age breaks: 18-to-34 years, 35-to-54 years, and 55+.

Research teams from numerous countries have contributed to the growing scholarship on caregivers and shared decision-making. Some studies note that cultural context—including cultural norms/attitudes toward caregiving and characteristics of national healthcare services—is crucial to interpreting results.¹⁰ Accordingly, these survey findings are specific to the U.S. population.

Our analysis of survey results examines significant differences between responses from Hispanic and non-Hispanic caregivers. Hispanic caregivers are not a monolithic group and studies have demonstrated differences in attitudes and norms among Hispanic caregivers of different backgrounds (e.g. Mexican, Dominican, Cuban); such an analysis is not possible, however, with this survey data. The survey's sample of Hispanic caregivers also skews more male, in contrast to numerous studies that find Hispanic caregivers are more typically female and that caregiving may be associated with gender-specific norms.¹¹ It's unclear how this greater portion of male Hispanic caregivers impacted the survey's results.

Finally, we collected all data during the COVID-19 pandemic, which has had a profound impact on every aspect of the U.S. healthcare system, including cancer treatment. How this influenced caregivers' decision-making, as well as their emotional, physical, and financial well-being, was not directly addressed in the survey. Caregivers were, however, asked if they or the patient had been diagnosed with COVID-19; 15% percent answered in the affirmative.





References for Section 2: Survey development & methodology

- 1 CancerCare. "CancerCare Patient Values Initiative." CancerCare.org. <https://www.cancercares.org/patientvaluesinitiative>. Accessed March 5, 2022.
- 2 CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercares.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.
- 3 Lwi, Sandy J., et al. "Poor Caregiver Mental Health Predicts Mortality of Patients with Neurodegenerative Disease." *Proceedings of the National Academy of Sciences*, vol. 114, no. 28, 2017, pp. 7319–7324. PNAS, DOI: 10.1073/pnas.1701597114.
- 4 Bidwell, Julie T., et al. "Caregiver Well-being and Patient Outcomes in Heart Failure: A Meta-analysis." *The Journal of Cardiovascular Nursing*, vol. 32, no. 4, 2017, pp. 372–382. PubMed.gov, DOI: 10.1097/JCN.0000000000000350.
- 5 Lau, Denys T., et al. "Exploring Factors That Influence Informal Caregiving in Medication Management for Home Hospice Patients." *Journal of Palliative Medicine*, vol. 13, no. 9, 2010, pp. 1085–1090. PubMed.gov, DOI:10.1089/jpm.2010.0082.
- 6 See: Bidwell, Julie T., et al. "Caregiver Well-being and Patient Outcomes in Heart Failure: A Meta-analysis." *The Journal of Cardiovascular Nursing*, vol. 32, no. 4, 2017, pp. 372–382. PubMed.gov, DOI: 10.1097/JCN.0000000000000350.; Litzelman, Kristin, et al. "How Does Caregiver Well-Being Relate to Perceived Quality of Care in Patients With Cancer? Exploring Associations and Pathways." *Journal of Clinical Oncology*, vol. 34, no. 29, 2016, pp. 3554–3561. *Journal of Clinical Oncology*, DOI: 10.1200/JCO.2016.67.3434.; Northouse, Laurel, et al. "Psychosocial Care for Family Caregivers of Patients With Cancer." *Journal of Clinical Oncology*, vol. 30, no. 11, 2012, pp. 1227–1234. *Journal of Clinical Oncology*, DOI: 10.1200/JCO.2011.39.5798.
- 7 See: Northouse, Laurel, et al. "Psychosocial Care for Family Caregivers of Patients With Cancer." *Journal of Clinical Oncology*, vol. 30, no. 11, 2012, pp. 1227–1234. *Journal of Clinical Oncology*, DOI: 10.1200/JCO.2011.39.5798.; Ozdemir, Semra, et al. "Patient–Caregiver Treatment Preference Discordance and Its Association With Caregiving Burden and Esteem." *Innovation in Aging*, vol. 5, no. 3, 2021. Oxford Academic, DOI:10.1093/geroni/igab020.
- 8 Northouse, Laurel, et al. "Psychosocial Care for Family Caregivers of Patients With Cancer." *Journal of Clinical Oncology*, vol. 30, no. 11, 2012, pp. 1227–1234. *Journal of Clinical Oncology*, DOI: 10.1200/JCO.2011.39.5798.
- 9 See: CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercares.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.; Dionne-Odom, J. Nicholas, et al. "How Family Caregivers of Persons with Advanced Cancer Assist with Upstream Healthcare Decision-making: A Qualitative Study." *PLoS ONE*, vol. 14, no. 3., 2019. DOI: 10.1371/journal.pone.0212967.
- 10 See: Shin, Dong Wook et al. "Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family, Caregivers, and Their Oncologists." *Psycho-Oncology*, vol.26, no.6, 2016, pp.770–778. PubMed.gov, DOI: 10.1002/pon.4226.; Ozdemir, Semra, et al. "Patient–Caregiver Treatment Preference Discordance and Its Association With Caregiving Burden and Esteem." *Innovation in Aging*, vol. 5, no. 3, 2021. Oxford Academic, DOI:10.1093/geroni/igab020.
- 11 See: Llanque, Sarah M., et al. "Interventions for Hispanic Caregivers of Patients with Dementia: A Review of the Literature." *American Journal of Alzheimer's Disease & Other Dementias*, vol. 27, no. 1, 2012, pp. 23–32. SAGE Journals, DOI: 10.1177/1533317512439794.; Wells, Jo Nell, et al. "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger." *Journal of Transcultural Nursing*, vol. 19, no. 3, 2008, pp. 223–233. SAGE Journals, DOI: 10.1177/1043659608317096.; Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.

Demographics

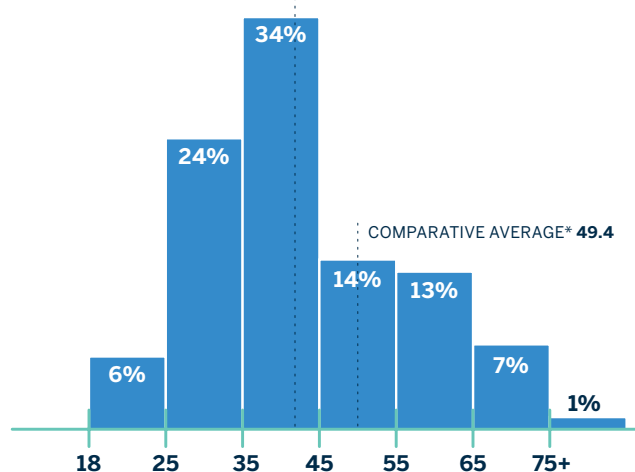
Caregiver Profile

The majority of caregivers—one-third of those surveyed—were between the ages of 35-44 years old, with an average age of 42.6. The group skewed female at 53%, slightly higher than the national composition of 51%.¹ Demographics by race and ethnicity closely followed the U.S. population, with the majority of respondents being white (78%) and Black/African American (13%); 16% of respondents reported being of Hispanic, Latino, or Spanish origin, slightly lower than the U.S. population at 18.5%. Survey demographic data also largely aligned with findings from the National Alliance for Caregiving/AARP's *Caregiving in the U.S. 2020* report. Their respondents were slightly older, with an average age of 49.4, and included a larger percentage of female caregivers, at 61%.² Most caregivers in the CancerCare survey were married (71%) and working full time (67%).

Caregiver age

n=2703

AVERAGE AGE: 42.6

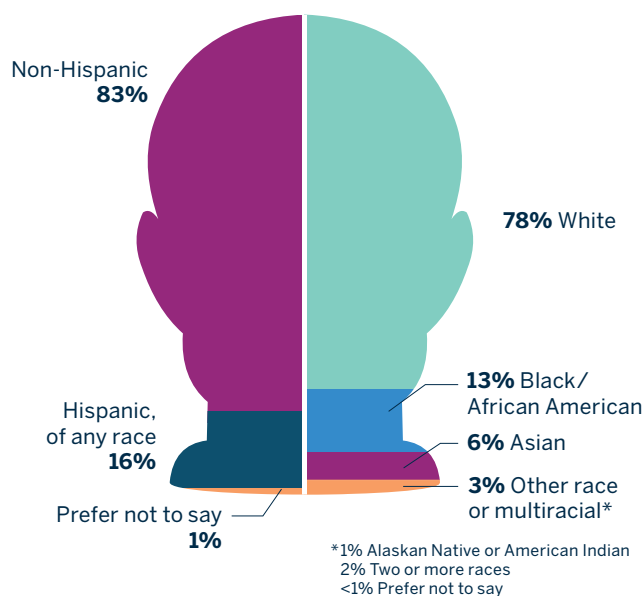


Results do not total 100% due to rounding

* National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*

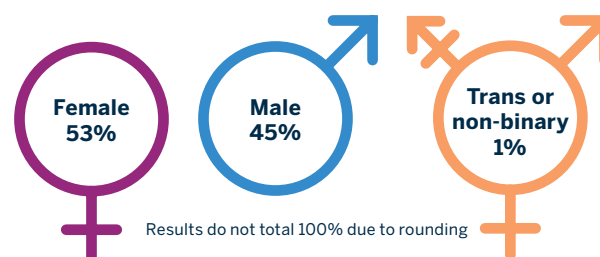
Caregiver ethnicity and race

n=2703



Caregiver gender

n=2703

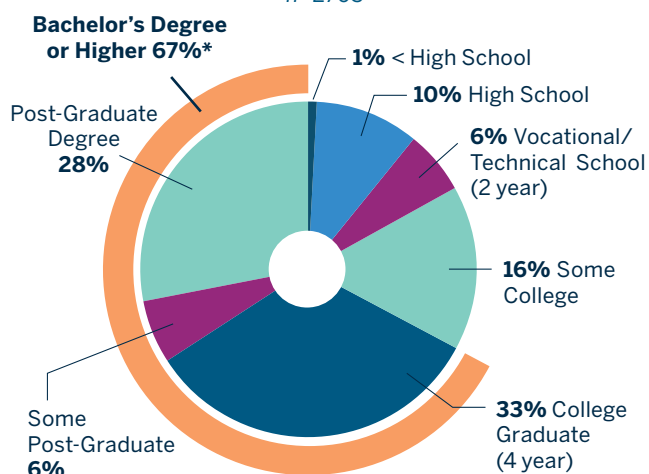


Results do not total 100% due to rounding

Comparative demographics: 61% women, 39% men
National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*

Caregiver education

n=2703



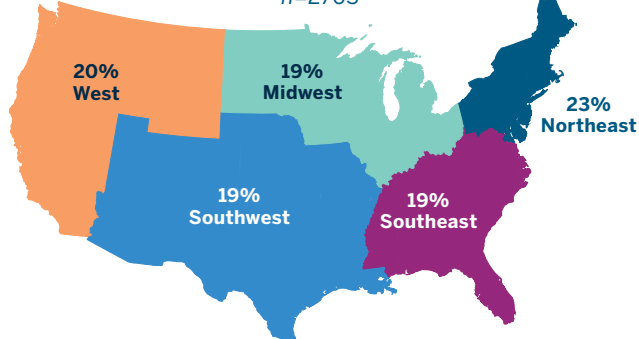
* U.S. population age 25+ with Bachelor's degree or higher: 37.9%
U.S. Census Bureau, 2021, Census.gov

Mean household income was \$94,700, with over a quarter (28%) earning \$100,000 to \$149,999 annually. This is slightly below the average U.S. household income of \$96,955 for 2021.³ Educational levels were high compared to national trends, with the majority having completed a four-year college degree or beyond (67% vs. 37.9% nationally in 2021).⁴

Roughly 20% of our respondents resided in each of the five geographic regions identified for this national survey; the Northeast had the largest sample with 23%.

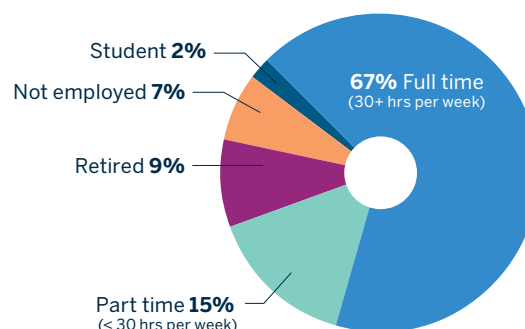
Caregiver geographic regions

n=2703



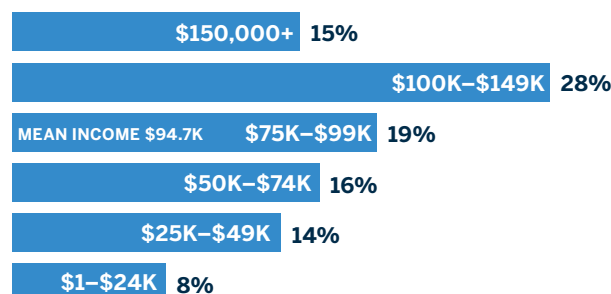
Caregiver employment

n=2703



Caregiver household income

n=2703

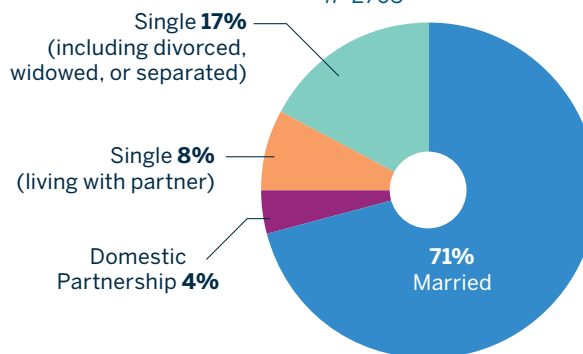


Average U.S. household income in 2021: \$96,955

PK. "Household Income by Year: Average, Median, One Percent (and a Percentile Calculator)." DQYDJ.

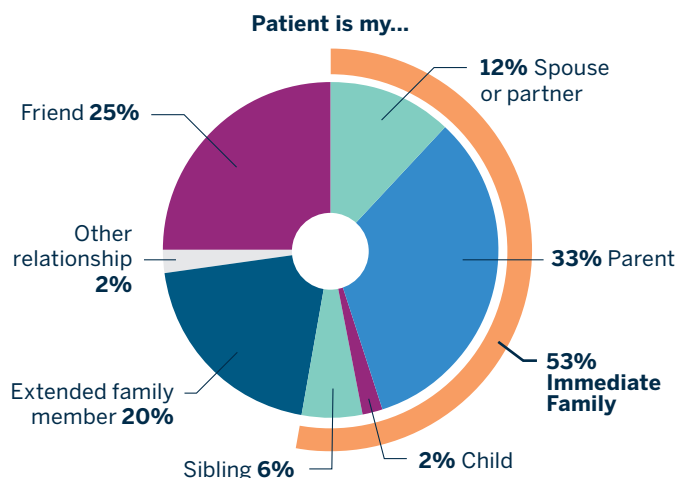
Caregiver marital status

n=2703



Caregiver relationship to patient

n=2703



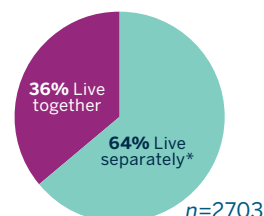
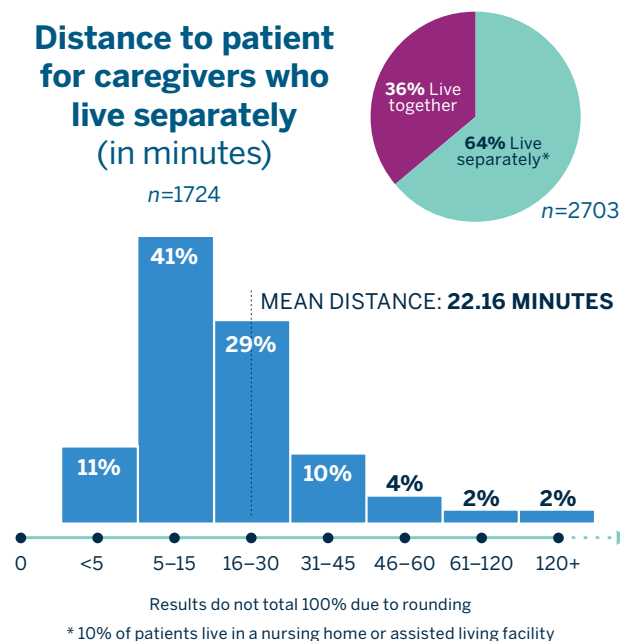
The survey sample speaks to the range of relationships between caregivers and their care recipients: a third (33%) reported caring for their mother or father, 25% for a friend, and 20% for someone in their extended family. In total, half of the caregivers (53%) provided care for an immediate family member (e.g. their mother/father, spouse/partner, brother/sister, or child).

Just over one-third of the caregivers lived in a home or apartment with their care recipient (36%). A slight majority of patients (52%) lived in a home or apartment separate from the caregiver, with a small portion in nursing homes (6%) and assisted living (4%). Caregivers who lived separately were still in close proximity, with a mean travel time of 22 minutes to the patient's residence and the largest portion living 5-15 minutes away (41% of those living separately).

Most caregivers surveyed have been supporting their care recipient for less than three years, with the largest portion providing care from one year to less than 3 years (43%).

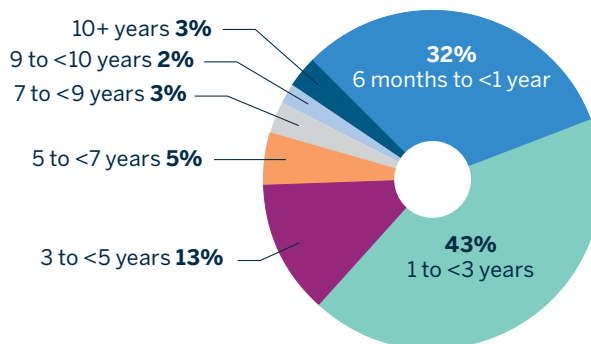
Distance to patient for caregivers who live separately (in minutes)

n=1724



Years providing care

n=2703



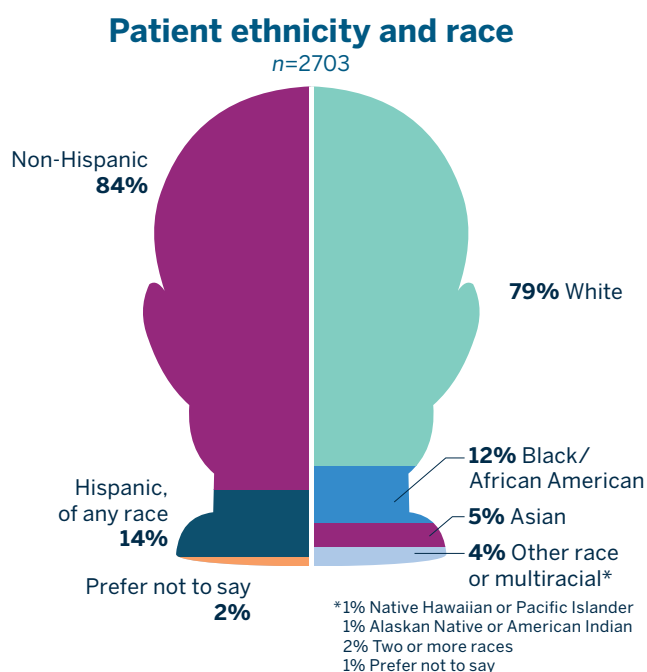
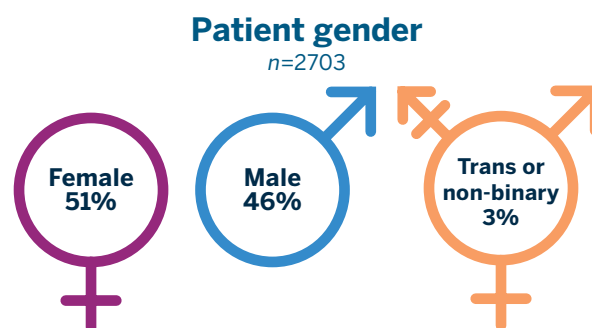
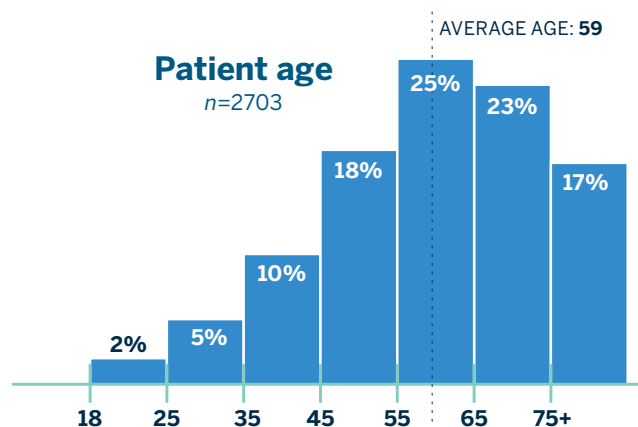
Results do not total 100% due to rounding

Patient Profile

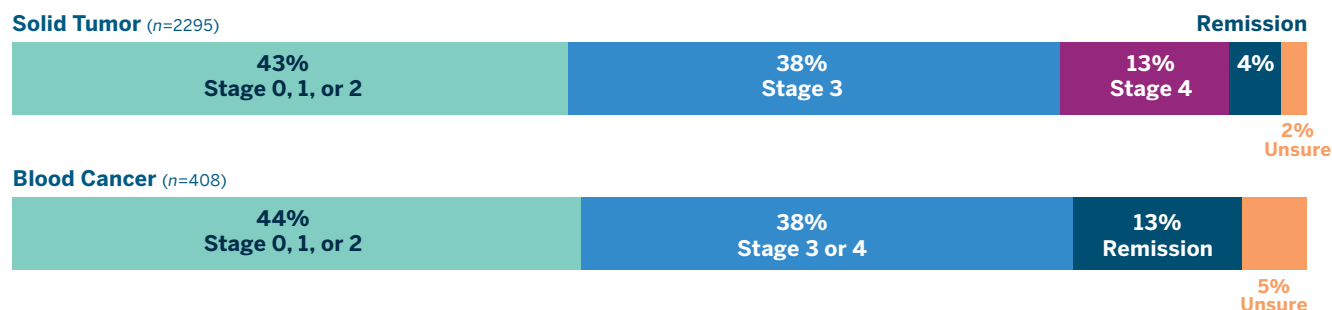
Patients tended to be older than caregivers, with nearly half (48%) between 55 and 74 years old and an average age of 59. It should be noted that this report focuses on the experiences of caregivers for adult patients with cancer. Only 2% of caregivers indicated their patient was between the ages of 18-24; the survey did not provide an option for under age 18. A small portion of caregivers surveyed reported the patient was their child (2%).

Just over half (51%) of patients were identified as female. As with the caregivers, the majority were white (79%) and Black/African American (12%); 14% were identified as Hispanic, Latino, or Spanish.

Over half the patients were married (53%) and retired (53%), with a mean household income of \$80,700. The majority received health insurance through Medicare (45%). While education levels were lower than the caregivers', they still exceeded national averages, with 50% of patients having graduated from college or higher.



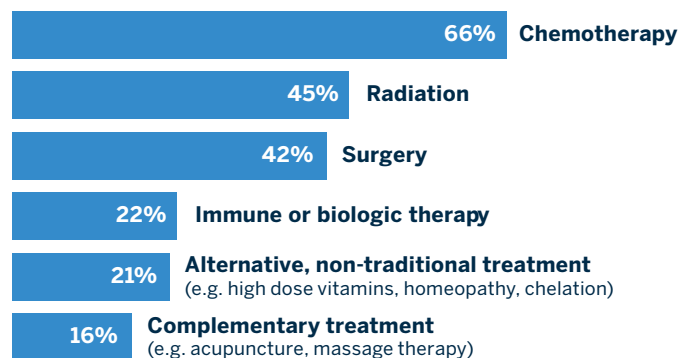
Stages of patients' cancer



The majority of patients had been diagnosed with solid tumor cancers (85%) and 43% were early stage (0, 1 or 2). Among the 15% of patients with blood cancers, 44% were in stages 0, 1, or 2. Two-thirds of patients had chemotherapy (66%); 45% received radiation therapy, 42% had surgery, and 22% received immune or biologic therapy. A fifth of patients (21%) opted for alternative, non-traditional treatments, such as high-dose vitamins, homeopathy, and chelation, and 16% incorporated complementary therapies, such as acupuncture or massage therapy.

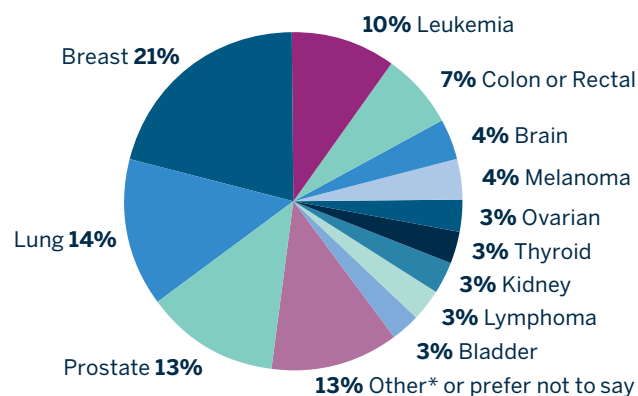
Patient treatment types

n=2703



Patient cancer types

n=2703



*2% Cervical, 2% Head and Neck, 2% Multiple Myeloma, 2% Pancreatic, 1% Endometrial/Uterine, 3% Other, 1% Prefer not to say

Results do not total 100% due to rounding



References for Section 3: Demographics

1 United States Census Bureau. "QuickFacts: United States." *Census.gov*. <https://www.census.gov/quickfacts/fact/table/US/LFE046219>. Accessed March 5, 2022.

2 National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>. Accessed March 5, 2022.

3 PK. "Household Income by Year: Average, Median, One Percent (and a Percentile Calculator)." *DQYDJ*. <https://dqydj.com/household-income-by-year/>. Accessed March 25, 2022.

4 United States Census Bureau. "Figure 2: Percentage Population Age 25 and Over by Educational Attainment, 1940 to 2021." *Census.gov*. https://www.census.gov/content/dam/Census/library/visualizations/time-series/demo/fig_2.png. Accessed March 25, 2022.

Caregiver Involvement & Roles in Decision-Making



To understand caregivers' involvement in decision-making across the cancer care continuum, survey respondents were presented with 14 decision-making situations and asked to indicate all those in which they had been involved. Caregivers were then prompted to select one decision-making situation and share more in-depth details about their involvement; this included the role they played in that specific situation, who else was involved, and any resources they used to help make the decision. Section 5 will further explore the factors that were important to caregivers and the challenges they faced in making these decisions.

Caregiver roles in decision-making

We defined four decision-making roles for this survey:

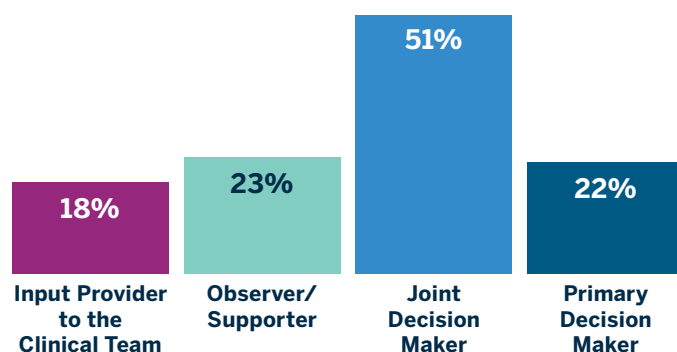
- **Input Provider to the Clinical Team:** “The clinical team made the decision. The patient and I provided our input but left the final decision up to the doctors and nurses.”
- **Observer/Supporter:** “The patient made the decision. I was an observer and played a supportive role.”
- **Joint Decision Maker:** “The patient and I made the decision together. We both agreed on the best choice.”
- **Primary Decision Maker:** “I made the decision. The patient and other family and/or friends provided their input.”

The delineation of these roles was informed by focus groups with caregivers and CancerCare social workers and aligns with caregiver decision-making roles identified in other studies.¹ While each role includes caregiver involvement, how much influence they had on the final decision ranges from support only to full responsibility.

Half of caregivers surveyed identified themselves as Joint Decision Makers (51%), with roughly 20% of respondents selecting each of the other three roles. (Some respondents selected more than one role, so percentages total more than 100.) In the survey, caregivers indicated their role for a specific decision-making situation; hence, the results reported here provide an aggregate snapshot across all decision-making situations. Based on other studies, it should be noted that a caregiver's role may vary depending on the decision or along the cancer care continuum; for example, a caregiver might need to step into the role of Primary Decision Maker for end-of-life care decisions.²

Caregiver roles in decision-making

n=2703



Results total more than 100%; some respondents selected more than one role



Joint Decision Maker (51%)

“The patient and I made the decision together. We both agreed on the best choice.”

Half the caregivers surveyed partnered with the patient as **Joint Decision Makers**. This is consistent with findings from the large-scale Cancer Care Outcomes Research and Surveillance Consortium survey, in which 49% of recently diagnosed cancer patients reported sharing treatment decisions equally with their families.³

A caregiver’s daily life and long-term plans can be greatly impacted by the patient’s decisions about treatment; such decisions place demands on caregivers’ time, resources, and mental and physical health. Dionne-Odom et al. describe how caregivers often become “Collateral Decisions Managers” who handle the ripple effect that cancer treatment decisions have on other aspects of family and work life; for example, adjusting work demands to accommodate appointments, as well as accounting for any changes in

income and health insurance that result.⁴ As Joint Decision Makers, caregivers have an opportunity to advocate for choices that reflect realistic and manageable accommodations they can make to best support the patient throughout their treatment.

Observer/Supporter (23%)

“The patient made the decision. I was an observer and played a supportive role.”

The patient had control over the decision in situations where the caregiver served as an **Observer/Supporter**. This doesn’t necessarily mean the caregiver played a passive role, however; as highlighted by the TRIO framework, caregivers can be very involved in the decision-making process without having direct influence on the final decision made.⁵ Involvement by Observers/Supporters (or other caregiver roles) might include any of a number of forms of support: seeking out information to share with the patient, helping the patient ask questions at appointments to better understand their



diagnosis, offering “what if” scenarios to help the patient compare options, acting as a sounding board as the patient deliberates and articulates their values, “cheering on” the patient to bolster their decision-making confidence, and/or facilitating communication to ensure clinicians and other family or friends understand the patient’s wishes.⁶

Primary Decision Maker (22%)

“I made the decision. The patient and other family and/or friends provided their input.”

Caregivers who acted as **Primary Decision Makers** were responsible for making final decisions. Studies on cancer treatment decision-making indicate caregivers take on the role of Primary Decision Maker for a variety of reasons: they may be delegated by the patient, step in when a patient is too ill to make decisions or when other barriers make their involvement difficult (such as a language difference with the clinical team), or when the patient’s social network is acting in accordance with cultural beliefs.⁷ Hispanic caregivers in this survey were significantly more likely than non-Hispanic caregivers to be Primary Decision Makers, discussed further in Section 7. In another national survey, Asian cancer patients reported a higher rate of family-controlled decisions, particularly among Chinese-speaking vs. English-speaking Asian patients.⁸

Primary Decision Makers were significantly more likely to feel “completely or quite a bit overwhelmed” (28%) about decision-making. While this is understandable given the pressure of increased responsibility, other decision-making challenges likely added to their stress. For instance, caregivers of end-of-life cancer patients have reported that a lack of adequate information about the patient’s cancer and their care options, along with family disagreements about care, made decision-making on behalf of their patients “one of the most difficult caregiving experiences.”⁹

Input Provider to Clinical Team (18%)

“The clinical team made the decision. The patient and I provided our input but left the final decision up to the doctors and nurses.”

Caregivers who were **Input Providers** relied on healthcare professionals to make the final decision. While they may be more detached from controlling the decision, this role can still be vital to identifying best-fit options and reaching positive treatment outcomes. For example, 54% of cancer caregivers in a national survey reported they “often need to remind healthcare professionals of the other health conditions affecting [their] care recipient.” The same survey found that, on average, cancer caregivers had seen seven different healthcare professionals with their patient over the course of two years.¹⁰ Clearly, Input Providers and other caregivers play a crucial role in coordinating care and integrating information among specialists.

Like Primary Decision Makers, Input Providers reported significantly more stress regarding decision-making, with 22% who felt “completely or quite a bit overwhelmed.” Cause and effect here is unclear. It may be that distressed caregivers were more likely to lean on the clinical team to make final decisions and opted to be Input Providers. It’s also possible, however, that caregivers experienced more stress when they felt the decision was out of their hands or that they couldn’t play a more active role. For example, caregivers involved in decisions about medications—a group that was more likely to be Input Providers—reported that a lack of understanding about medication options, how they worked, and their impact on the patient made decision-making more difficult. Having to trust the expertise of the clinical team regarding these knowledge gaps may have led caregivers to feel that the decision was out of their or the patient’s control.

Case studies: When caregivers and patients don't agree on their role in decision-making

Beth*, 61, has always had a close relationship with her son Russell, 35, so she found it difficult to understand why he wanted to limit her involvement following his diagnosis with anaplastic astrocytoma (grade 3). Russell prefers to make treatment plan decisions with his spouse and has placed strict boundaries on what information is shared with his mom. Beth has been an Observer/Supporter, but desires to be more involved in appointments and build a relationship with the medical team. Without information about her son's prognosis, Beth felt anxious, hurt, and fearful; she was confused about her role as a caregiver and found it challenging to cope with Russell's diagnosis.



John, 35, also struggles with uncertainty about their caregiving role and a lack of communication. John moved in with their partner Jane (both identify as genderqueer/gender non-conforming) only a short time before they were diagnosed with stage 3 ovarian cancer. Jane prefers to make treatment decisions on their own and has friends accompany them to chemotherapy appointments, while John's role is more limited as an Observer/Supporter. John would like to know more about how Jane is feeling and how treatment is progressing. They feel anxious not knowing when or how to help. Most recently, John joined for an appointment with the oncologist and was distressed to learn Jane had been experiencing pain—something they hadn't shared at home during John's frequent check-ins. John is at a loss for how to best support Jane without overwhelming or annoying them.

Both John and Beth are caregivers who see CancerCare social workers for counseling. While John just started the process as this report is being written, Beth has learned to practice acceptance around her son's healthcare decisions and has developed coping tools to help process difficult emotions. With time, communication between Beth and Russell is improving and he has started sharing more treatment information with her.

** All caregiver and patient names have been changed.*

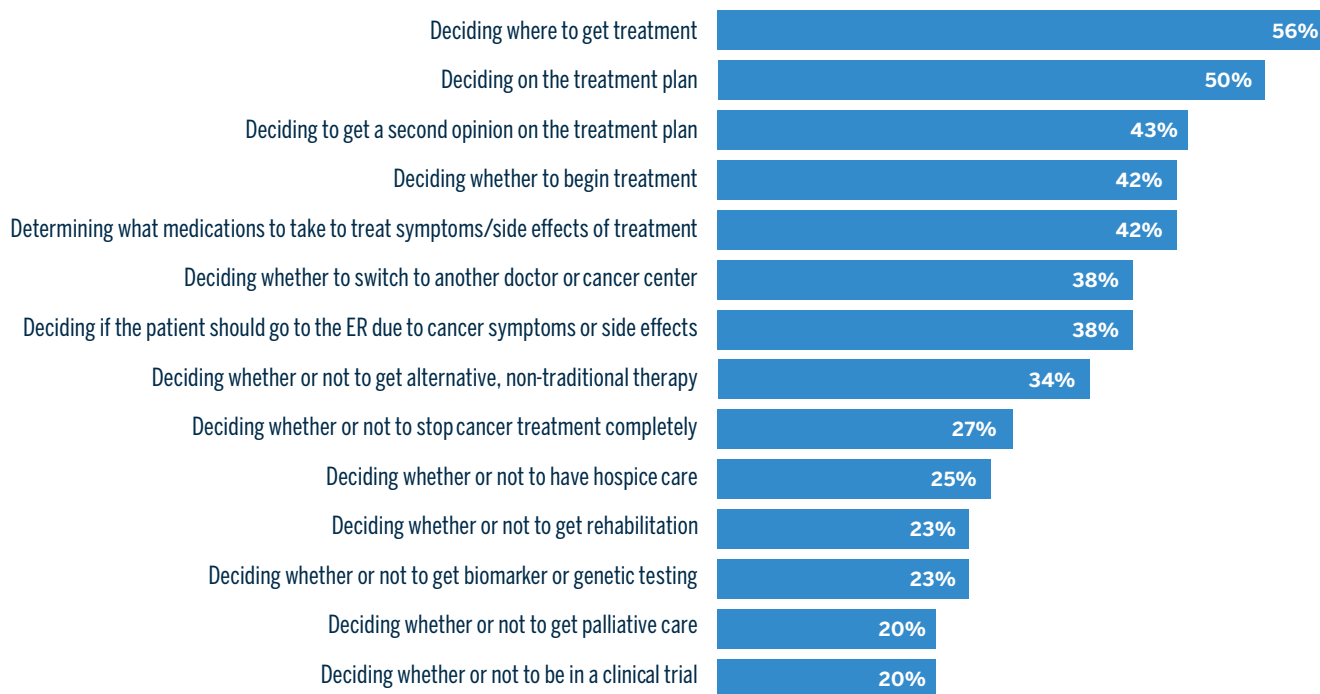
Caregiver involvement in decision-making situations

Report findings clearly indicate that caregivers are involved in decision-making across the cancer care continuum. For each of the 14 decision-making scenarios presented in the survey, at least 20% of the respondents noted their involvement. On average, caregivers had participated in 4.8 different decision-making scenarios.



Caregiver involvement in treatment decisions

n=2703



Roles associated with decision-making situations

Data analysis showed that some caregiver roles are significantly (95% confidence level) more or less likely to be associated with specific decision-making situations, when compared to the overall distribution of caregiver roles.

Joint Decision Maker:

- **More** likely when deciding on the treatment plan
- **Less** likely when deciding whether or not to stop cancer treatment completely

Observer/Supporter:

- **More** likely when deciding whether or not to stop cancer treatment completely
- **More** likely when deciding whether or not to get alternative, non-traditional therapy
- **Less** likely when deciding where to get treatment

Primary Decision Maker:

- **More** likely when deciding where to get treatment
- **More** likely when deciding whether or not to get biomarker or genetic testing
- **Less** likely when deciding on the treatment plan
- **Less** likely when deciding whether or not to get a second opinion on the treatment plan

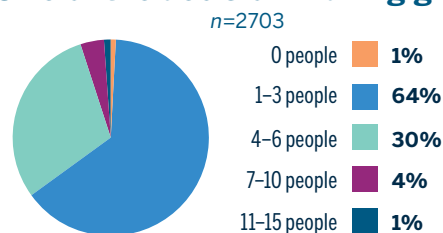
Input Provider:

- **More** likely when deciding whether or not to get biomarker or genetic testing
- **More** likely when determining what medications to take to treat the symptoms and side effects of treatment
- **Less** likely when deciding if the patient should go to the emergency room
- **Less** likely when deciding whether or not to have hospice care

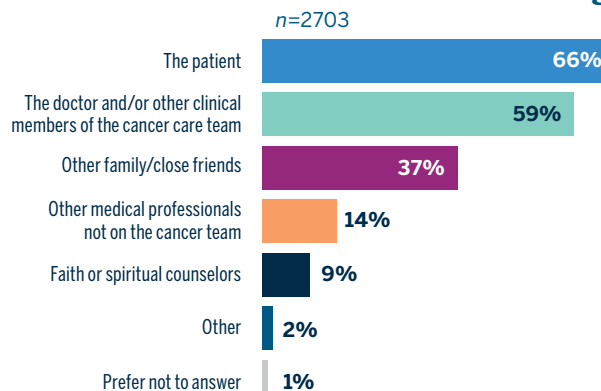
Who else was involved in decisions

Caregivers reported that most decision-making situations involved a small group of one to three participants (64%). Nearly a third involved a larger group of four to six participants (30%), and a small portion involved groups of seven or more (5%). As is expected in patient-centered care, patients and doctors and/or other clinical members of the cancer care team were the most frequent decision-making participants. Caregivers reported patient involvement in 66% of decision-making situations and doctor and/or clinical team member involvement in 59%. More than a third of decision-making situations included other family and/or close friends (37%). A smaller number of decision-making situations involved other medical professionals (14%) and faith or spiritual counselors (9%). This involvement by a broader social network reinforces the need for decision-making models that consider other dynamics beyond the patient-doctor dyad.

Size of the decision-making group



Who else was involved in decision-making?



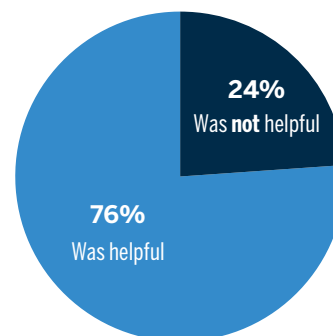
Sources of information and help in decision-making

Just over half of caregivers relied on the patient's clinical cancer care team for information and help regarding treatment decision-making (53%), as well as patient education (31%). Family and/or friends again played a role, providing this support for 44% of caregivers. Other medical professionals were a resource for 42% of caregivers. Caregivers also turned to the internet (35%) and social media (15%) for information and help; some looked to non-profit organizations (16%) and government agencies (10%). A small portion (4%) reported they never looked for information or help with their treatment decision-making.

While most caregivers surveyed found these decision-making resources to be useful, nearly a quarter (24%) felt the information they gathered or were given was not helpful in their decision-making situation.

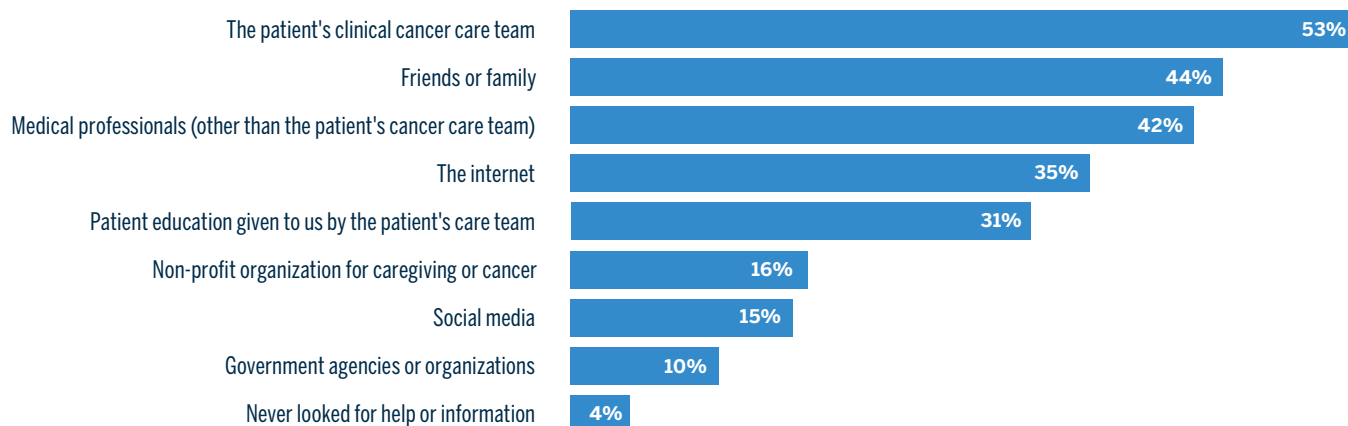
Caregivers' perception of the information they found or were given

n=2703



Sources of information for treatment decision-making

n=2703



Overview of decision-making situations with key highlights from in-depth responses

Decisions about treatment providers

More than half of caregivers (56%) were involved in decisions about **where to get treatment**. As seen in the previous section on caregiver roles, this decision was significantly more likely to be made by the caregiver (Primary Decision Maker) and less likely to be determined by the patient.

Deciding whether to get a second opinion on a treatment plan included 43% of caregivers; in contrast, caregivers were significantly less likely to be Primary Decision Makers in this situation. Over a third of the caregivers surveyed reported being involved in decisions about **whether to switch to another doctor or cancer center** (38%).

Decisions about the treatment plan

Half of caregivers noted being involved in **deciding on the treatment plan**. Choosing a treatment plan can sound deceptively straightforward, like ordering from a menu; in reality, patients and caregivers struggle with a frightening new diagnosis, complex medical jargon, an uncertain future, and the stress of making the “right” choices. Disagreements may arise. Some physicians take a cautious view of family involvement in treatment planning, leaning toward patient autonomy or physician-directed decisions. Yet multiple studies show many patients and caregivers believe families should be involved in treatment decision-making.¹¹ Newer research suggests this involvement may benefit patients’ outcomes. For example, when caregivers are less involved in treatment decision-making, cancer patients may be less likely to follow treatment plans. One study found that caregiver involvement had a bigger influence on treatment adherence than a patient’s otherwise positive engagement in managing their own health (i.e. “patient activation”).¹²



Looking closer: Deciding on a treatment plan

A total of 449 caregivers (17% of the sample) provided in-depth information about their involvement with deciding on the treatment plan. While shared decision-making was common across all situations, caregivers involved in treatment plan decisions were significantly more likely to characterize their role as Joint Decision Makers with the patient (57%) and significantly less likely to have made the decision themselves as Primary Decision Makers (16%). In addition to the caregiver, the vast majority of treatment plan decisions included the doctor and/or other members of the clinical care team (83%) and the patient (70%). Over a third (38%) indicated that family and/or close friends were also involved in the decision.

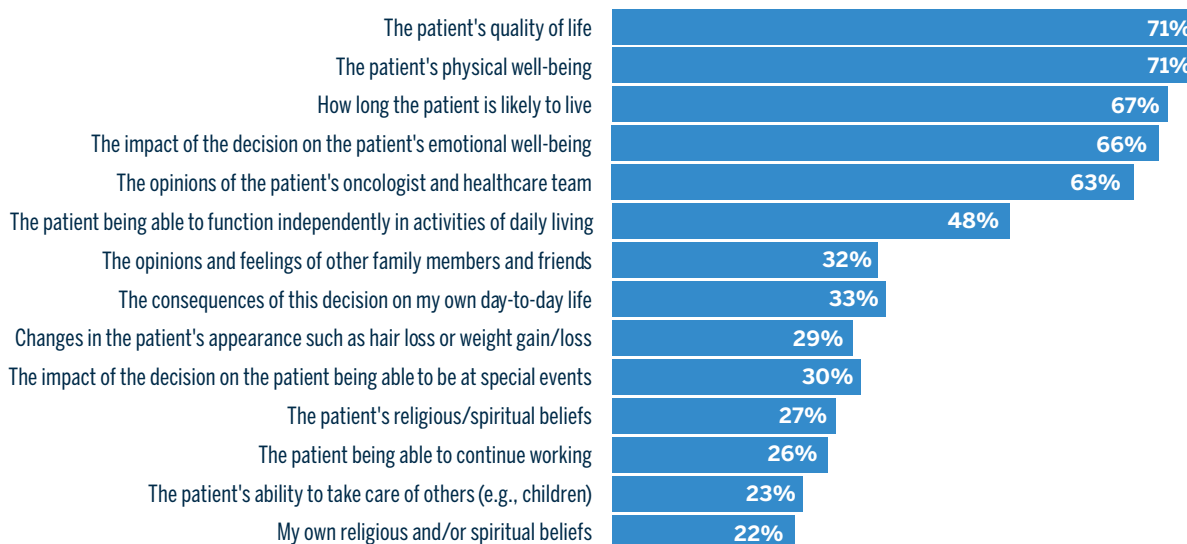
Sources of information and help regarding treatment plan decisions were similar to those used across all decision-making situations. Most caregivers relied on information from the patient’s clinical care team (68%) and patient education they provided (46%); other sources of information for treatment plan decisions included other medical professionals (41%), friends or family (39%), the internet (39%) and social media (10%), non-profit organizations (16%), and government agencies (10%). Most felt the information they found or were given regarding the decision was helpful (81%).

In making treatment plan decisions, caregivers were concerned with the impact on the patient's well-being, including the patient's quality of life (71% "Very important"), physical well-being (71%), how long the patient is likely to live (67%), and the patient's emotional well-being (66%). Caregivers also considered the opinions of the patient's oncologist and healthcare team (63%).

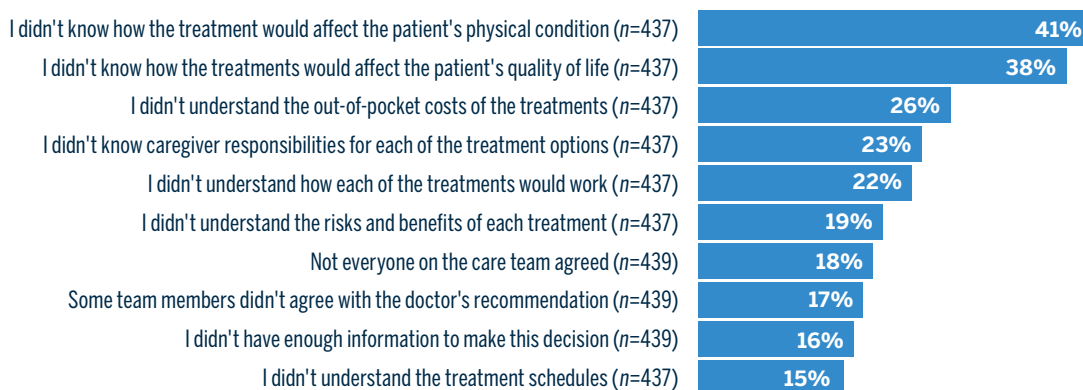
Caregivers reported that making decisions about the treatment plan was made more difficult by gaps in information, particularly not knowing how the treatment would affect the patient's physical condition (41%) or quality of life (38%), not knowing the caregiver responsibilities for each treatment option (23%) or the risks and benefits of each treatment (19%), and not understanding the out-of-pocket costs of the treatments (26%).

"Very important" factors when deciding on the treatment plan

n=449



Decision-making challenges for caregivers involved in deciding on the treatment plan



Decisions about symptom/side-effect management

Less than half (42%) of surveyed caregivers helped make decisions about **what medications the patient could/should take to treat symptoms and side effects of treatment**. Furthermore, 38% were involved in deciding **whether the patient should go to the ER due to cancer symptoms or side effects**.

In CancerCare's Patient Access and Engagement study, a concerning number of patients did not report symptoms or side effects "because they did not want to 'bother' their doctor," yet nearly half of respondents said they changed treatment "sometimes," "often," or "always" because of symptoms and side effects.¹³ Among patients in active treatment, only 62% indicated they were very or somewhat satisfied with the way their clinical care team prepared them for the symptoms and side effects they experienced.¹⁴ These data and CancerCare's other work with patients and caregivers indicate a widespread need for better communication between patients, families, and clinicians about their symptom experiences. It may be that clinicians don't provide information about cancer symptoms and treatment side effects if patients don't ask, or they may be concerned that discussing symptoms and side effects will scare patients and family members. Regardless of the

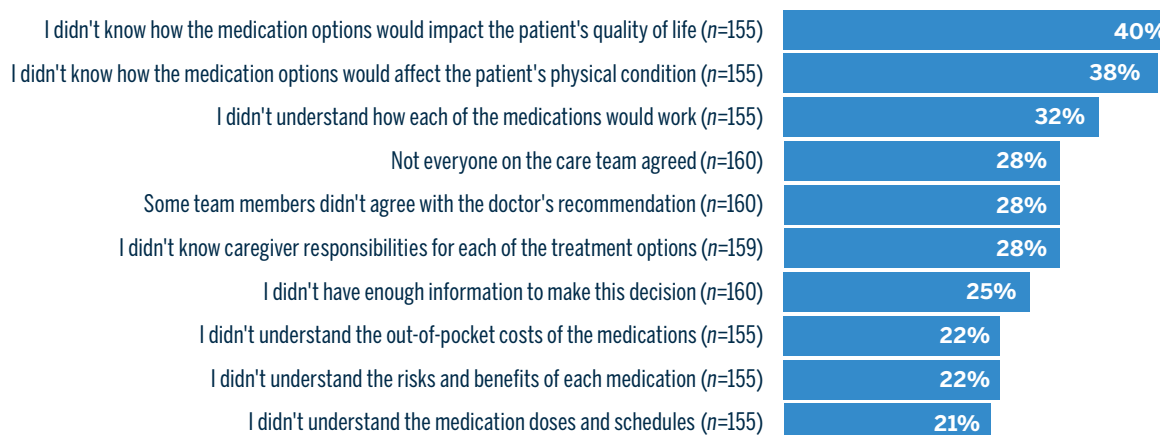
rationale, neglecting to provide this important information prevents caregivers and patients from making well-informed decisions regarding care and treatment. Encouraging open communication empowers patients to discuss their symptoms and the impact on their life.

Looking closer: Determining what medications to take for symptoms and treatment side effects

A total of 163 caregivers shared details on their involvement in decisions about medications to treat symptoms and side effects. While half served as Joint Decision Makers, 29% reported being Input Providers with the clinical team making the final decisions.

Nearly a third of caregivers (32%) in this subsample felt decision-making was harder because they "didn't understand how each medication would work." Many were uncertain how the patient would be affected: 40% "didn't understand how medication options would impact the patient's quality of life" and 38% "didn't understand how the medications would affect the patient's physical condition." In addition, caregivers weren't clear on how medications would be administered once the decision was made, including their responsibilities for each medication option (28%) and the medication doses and schedules (21%).

Decision-making challenges for caregivers determining what medications to take for symptoms and treatment side effects



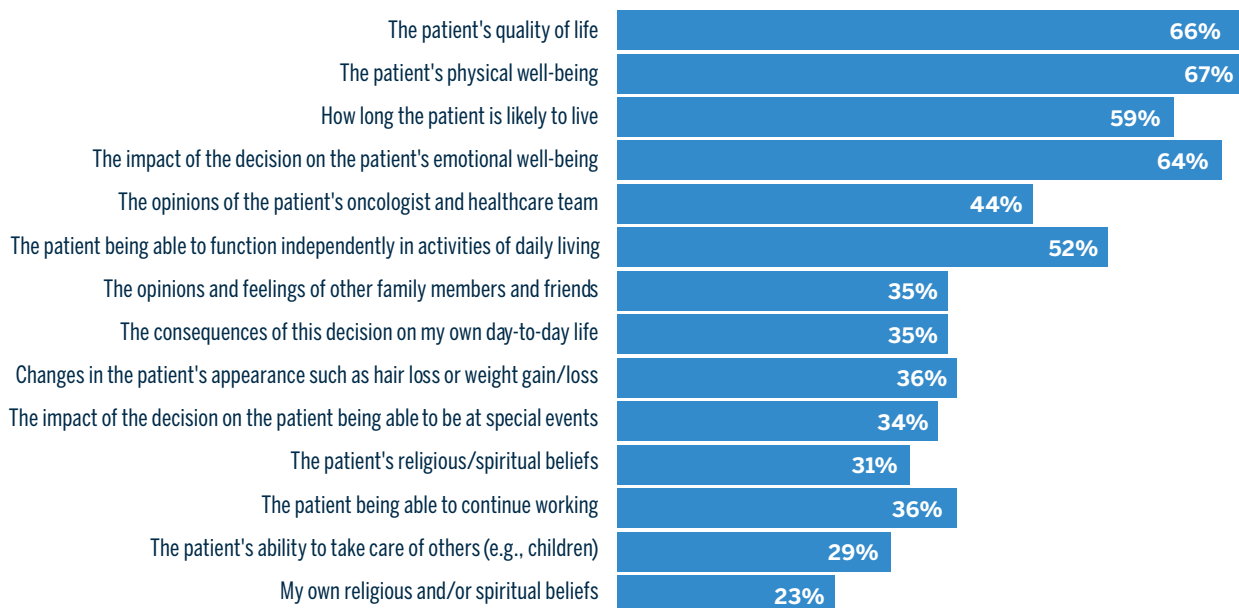
Survey data show that caregivers who are Input Providers involved in decisions regarding medications were significantly more likely to report feeling “completely overwhelmed,” which may be related to the many questions and limited understanding they had about medication options and what to expect. Access to clear information regarding symptom/side-effect management should start early in the treatment planning process and continue along the cancer care continuum. In previous qualitative CancerCare research, caregivers reported that limited information on the side effects associated with different treatment options made deciding on a plan more difficult.¹⁵ In roundtable discussions, patients with metastatic breast cancer and their caregivers stressed the importance of receiving reassurance from the healthcare team about side-effect management once treatment starts.¹⁶ A large study on end-of-life care found that 71% of caregivers reported a need for substantial help with symptom management; for 43% of them, the need was not met and negatively affected the quality of care they could provide.¹⁷

Decisions about alternative therapies

A third of caregivers were involved in decisions about **whether to get alternative, non-traditional therapy**, defined by such examples as high-dose vitamins and supplements, homeopathy, and chelation. And, in fact, 21% of caregivers reported that their patient had received this kind of therapy. While the frequency of making such decisions might surprise clinicians and drug manufacturers, a national survey commissioned by ASCO in 2018 found that 39% of Americans believe alternative therapies alone can cure cancer—a belief prevalent among cancer caregivers (38%) and patients (22%) as well.¹⁸ Common depictions of debilitating side effects from chemo and radiation therapies likely fuel this mistrust of conventional treatments, as do their debt-inducing costs. Sadly, mistrust can lead to deadly misinformation: patients who delay or reject traditional cancer treatments and choose to rely solely on alternative therapies have significantly worse survival rates, with one study finding two to five times greater risk of death.¹⁹

“Very important” factors when deciding whether to get alternative, non-traditional therapy

n=135



Looking closer: Deciding whether to get alternative, non-traditional therapy

A sample of 135 caregivers shared details regarding their involvement in decisions about alternative, non-traditional therapy. Compared to other decisions, patients led a significantly higher portion of alternative therapy decisions (35%) with caregivers serving as Observers/Supporters. Less than half (44%) of caregivers were Joint Decision Makers in this situation.

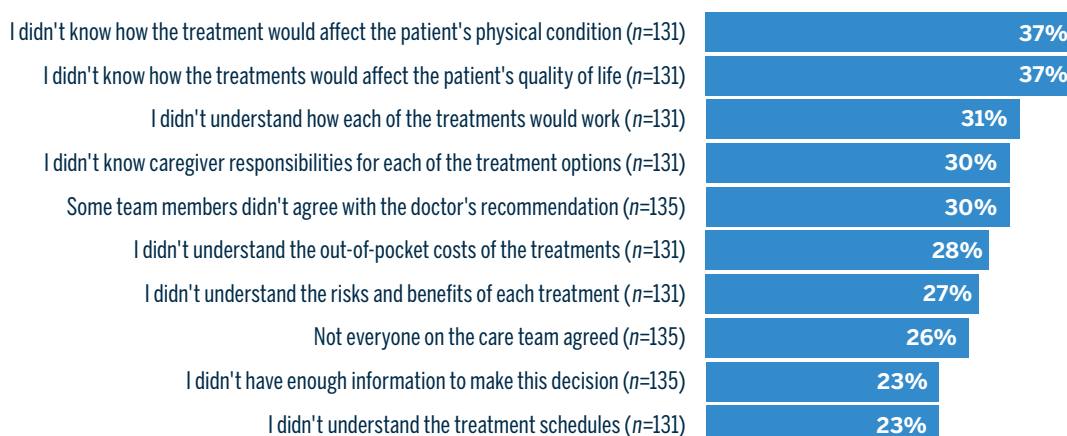
While these caregivers used similar sources of information and help as those in other decision-making situations, a third (32%) felt the information they found or were given was not helpful—compared to 24% of caregivers across all decisions. This may be because information on alternative therapies is more likely to lack support from clinical data, come from dubious sources and/or include more divergent views.

Factors related to patient well-being were most important to caregivers in deciding about alternative therapy. Less than half (44%) felt the opinions of the patient's oncologist and

healthcare team were “Very important” to the decision, compared to 56% of respondents across all decisions. Other research has found that 40-77% of patients who use complementary and/or alternative therapies do not disclose them to their physicians; some patients don't discuss these therapies because they anticipate a negative reaction or disinterest from their physician, don't think it will be beneficial or relevant to their medical treatment, prefer to keep such practices private, or have not been asked by clinicians.²⁰

The decision about alternative therapies was more difficult for caregivers due to uncertainty about how treatments would affect the patient's quality of life (37%) and physical condition (37%). Almost a third didn't understand how treatments would work (31%) or what their responsibilities would be in providing care with each option (30%). Caregivers also reported that “some team members didn't agree with the doctor's recommendation” (30%, compared to 24% of caregivers across all decisions); this may again relate to clinician skepticism toward the alternative therapies in question.

Decision-making challenges for caregivers involved in deciding whether or not to get alternative, non-traditional therapy



Decisions about clinical trials

One-fifth of caregivers (20%) were involved in deciding **whether or not to be in a clinical trial**. Only 55 caregivers chose this situation as the one they remembered best; the small base size limits what we can draw from the data. Given the recognition of clinical trials as “best management for any patient”²¹ and their importance in access to newer targeted cancer therapies, it is discouraging but not surprising to see such low involvement. A past CancerCare survey found that only 13% of cancer patients felt they had enough information about clinical trial opportunities when planning their treatment.²² In a roundtable discussion coordinated by the National Alliance for Caregiving, caregivers noted numerous obstacles to obtaining information about clinical trials; these included healthcare providers who were unaware of or did not offer information about trials, online search tools that are not comprehensive and can be stressful to use, and technical jargon that make trial descriptions difficult to understand.²³ The information they sought regarding clinical trials included trial logistics (cost, location, timing, number of required visits, selection criteria), the screening process, alternative therapy options, and understanding potential risks or harm to the patient and impacts on their quality of life.²⁴



Decisions about transitions in care

Many caregivers were involved in making decisions regarding transitions in care, such as **whether to begin treatment** (42%), **whether or not to stop cancer treatment completely** (27%), and **whether or not to have hospice care** (25%).

Of these situations, deciding whether to stop cancer treatment completely was significantly more likely to be patient-led, with caregivers serving as Observers/Supporters (38%); it also included the smallest portion of Joint Decisions Makers (41%). Enmeshed with end-of-life questions about bodily autonomy and suffering, this can be a particularly difficult decision to make. Several studies have found that caregivers and patients often have different preferences about whether to continue more aggressive treatment with the hope of extending life or to shift toward palliative care only.²⁵ For instance, one study found that patients with



Case study: Deciding whether or not to end treatment

Jerry*, 79, a healthcare professional with a private practice, cares for his wife Lynette. Given her current diagnosis with aggressive stage 4 metastatic bile duct cancer, the clinical care team has recommended that she discontinue treatment. Lynette, however, wants to continue with chemotherapy and immunotherapy. Jerry is torn: He knows that Lynette believes she can live longer with more intensive treatment, but is fearful of the side effects and worries his wife will be too unwell to tolerate treatment. Although he has been a Joint Decision Maker with Lynette on other aspects of her cancer care, Jerry ultimately stepped back to be an Observer/Supporter in this situation and honored her decision to pursue further treatment.

** Caregiver and patient names have been changed.*



advanced lung cancer were more willing to stop treatment if it was no longer effective, while their caregivers were more likely to advocate for stopping treatment if the treatment side effects had a negative impact on the patient's quality of life. Caregivers were more likely to support continued treatment out of "respect [for the] patient's personal choice" or if other family members wanted to keep trying. Notably, higher depression scores in both patients and caregivers were associated with family disagreements about treatment, particularly when a caregiver's preference was to stop a treatment.²⁶ Another study found that caregivers reported higher perceived burden when they disagreed with their patient regarding life-extending vs. symptom-managing treatment for advanced cancer.²⁷

Unfortunately, it appears many caregivers in our sample did not receive support from cancer care professionals in facing decisions about whether to end treatment. A concerning 42% reported they were not asked by a nurse, doctor, or social worker about what they needed to help them share in making the decision, compared to 30% of caregivers across all situations.



Decisions about supportive cancer care

A smaller percentage of caregivers were involved in decisions about supportive care—that is, care to address “the prevention and management of the adverse effects of cancer and its treatment” and improve patients’ health-related quality of life.²⁸ This included deciding **whether or not to get rehabilitation** (23%) and **whether or not to get palliative care** (20%).

Ideally, decisions about supportive care should occur across the cancer care continuum. Research indicates that, in addition to improving quality of life and decreasing pain, supportive care can improve treatment outcomes and decrease patients’ use of other healthcare resources.²⁹ However, the term “palliative care” is often misunderstood; in CancerCare’s Patient Access and Engagement Report, respondents from all age groups had widespread misconceptions about palliative care. These included worries about prohibitive costs and potential for pain medication addiction, conflicting fears about whether it would delay or hasten death, and a belief that palliative care signaled “giving up hope.”³⁰ In reality, findings suggest that initiating palliative care earlier not only improves quality of life and survival for advanced cancer patients, but can reduce depression rates and stress burden for caregivers.³¹

Decisions about biomarker testing

Decisions about **whether or not to get biomarker or genetic testing** were reported by 23% of caregivers in this survey. In its first two decades, biomarker testing has already transformed many aspects of oncology, as it may allow the use of precisely targeted therapies to more effectively control or even cure cancer. Genetic testing can also help clinicians better understand a patient’s cancer, as well as provide information on hereditary cancer risks for immediate family members. Based on the responses to this survey, however, it seems a lack of information and understanding about testing may be limiting its transformative potential.



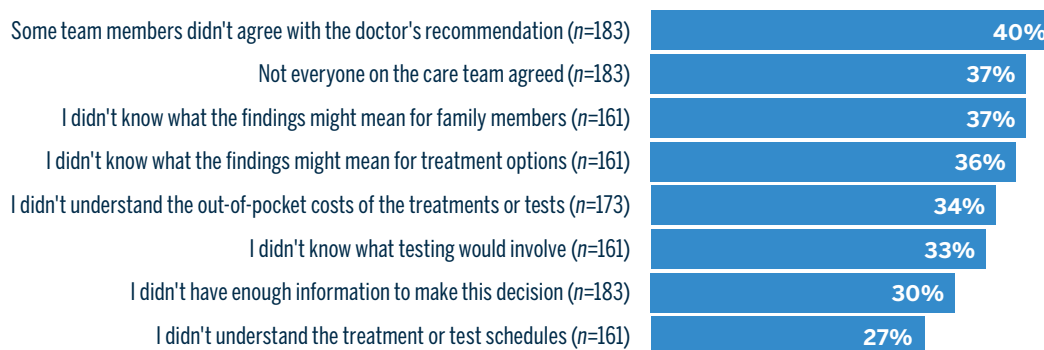
Looking closer: Deciding whether to get biomarker or genetic testing

Among the 183 caregivers who shared details from their experience making decisions about biomarker or genetic testing, a third indicated they “didn’t understand what testing would involve” and 30% “didn’t have enough information to make this decision” (compared to 20% of caregivers across all decision-making situations). Uncertainty about testing resulted in conflict, with 37% reporting that “not everyone on the care team agreed” and 40% noting “some team members didn’t agree with the doctor’s recommendation” (compared to 24% of caregivers across all decisions). Given that 37% of these caregivers “didn’t know what the findings might mean for family members,” disagreements may have involved immediate family members on the care team for whom genetic testing could carry personal and potentially

worrisome information; indeed, specialized counseling to help individuals and families psychologically prepare is a best-practice component of genetic testing.

In addition, 34% of caregivers in this subsample said they “didn’t understand the out-of-pocket costs of the treatment or tests.” While many private insurers, Medicare, and Medicaid do cover biomarker and genetic testing, the potential out-of-pocket costs are not straightforward; patients often need to demonstrate a test is “medically necessary” and receive pre-authorization from their insurer. This additional barrier of cost and time may dissuade patients and caregivers from testing if they and their insurers don’t also have a clear understanding of its importance and purpose to inform cancer treatment.

Decision-making challenges for caregivers involved in deciding whether or not to get biomarker or genetic testing





References for Section 4: Caregiver involvement & roles in decision-making

- 1 See: CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancer-care.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.; Dionne-Odom, J. Nicholas, et al. "How Family Caregivers of Persons with Advanced Cancer Assist with Upstream Healthcare Decision-Making: A Qualitative Study." *PLoS ONE*, vol. 14, no. 3, 2019. *PLoS ONE*, DOI: 10.1371/journal.pone.0212967.
- 2 See: Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.; CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancer-care.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.
- 3 Hobbs, Gabriela S., et al. "The Role of Families in Decisions Regarding Cancer Treatments." *Cancer*, vol. 121, no. 7, 2015, pp. 1079-1087. *ACS Journals*, DOI: 10.1002/cncr.29064.
- 4 Dionne-Odom, J. Nicholas, et al. "How Family Caregivers of Persons with Advanced Cancer Assist with Upstream Healthcare Decision-Making: A Qualitative Study." *PLoS ONE*, vol. 14, no. 3, 2019. *PLoS ONE*, DOI: 10.1371/journal.pone.0212967.
- 5 Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.
- 6 See: CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancer-care.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.; Dionne-Odom, J. Nicholas, et al. "How Family Caregivers of Persons with Advanced Cancer Assist with Upstream Healthcare Decision-Making: A Qualitative Study." *PLoS ONE*, vol. 14, no. 3, 2019. *PLoS ONE*, DOI: 10.1371/journal.pone.0212967.
- 7 See: Dionne-Odom, J. Nicholas, et al. "How Family Caregivers of Persons with Advanced Cancer Assist with Upstream Healthcare Decision-Making: A Qualitative Study." *PLoS ONE*, vol. 14, no. 3, 2019. *PLoS ONE*, DOI: 10.1371/journal.pone.0212967.; CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancer-care.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.; Hashemi, Maryam, et al. "Caregivers Needing Care: The Unmet Needs of the Family Caregivers of End-of-Life Cancer Patients." *Supportive Care in Cancer*, vol. 26, no. 3, 2018, pp. 759-766. *SpringerLink*, DOI: 10.1007/s00520-017-3886-2.; Hobbs, Gabriela S., et al. "The Role of Families in Decisions Regarding Cancer Treatments." *Cancer*, vol. 121, no. 7, 2015, pp. 1079-1087. *ACS Journals*, DOI: 10.1002/cncr.29064.; Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.
- 8 Hobbs, Gabriela S., et al. "The Role of Families in Decisions Regarding Cancer Treatments." *Cancer*, vol. 121, no. 7, 2015, pp. 1079-1087. *ACS Journals*, DOI: 10.1002/cncr.29064.
- 9 Hashemi, Maryam, et al. "Caregivers Needing Care: The Unmet Needs of the Family Caregivers of End-of-Life Cancer Patients." *Supportive Care in Cancer*, vol. 26, no. 3, 2018, pp. 759-766. *SpringerLink*, DOI: 10.1007/s00520-017-3886-2.
- 10 Rx4Good. "Supplemental Report: Findings for Caregivers Whose Recipient Is Diagnosed with Cancer." *The Caregiver Factor: Understanding the Medical Journey of the Caregiver and their Information and Support Needs*. 2018.
- 11 See: Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. *ScienceDirect*, DOI:10.1016/j.pec.2017.05.014.; Shin, Dong Wook, et al. "Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists." *Psycho-Oncology*, vol. 26, no. 6, 2016, pp. 770-778. *PubMed.gov*, DOI: 10.1002/pon.4226.
- 12 Acquati, Chiara, et al. "Patient Activation and Treatment Decision-making in the Context of Cancer: Examining the Contribution of Informal Caregivers' Involvement." *Journal of Cancer Survivorship*, September 12, 2021. *SpringerLink*, DOI: 10.1007/s11764-021-01085-9.
- 13 CancerCare. *CancerCare Patient Access and Engagement Report*. 2016, <https://media.cancer-care.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.
- 14 CancerCare. *CancerCare Patient Access and Engagement Report*. 2016. Note: Data available in print version of report.
- 15 CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancer-care.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.



References for Section 4: Caregiver involvement & roles in decision-making

- 16 Verini, Christine, et al. *Improving Support in Treatment Decision Making for Patients with Metastatic Breast Cancer*. CancerCare, February 2020. https://media.cancercare.org/publications/original/396-396-2020_mbcroundtable.pdf. Accessed March 5, 2022.
- 17 Park, Sang Min, et al. "Impact of Caregivers' Unmet Needs for Supportive Care on Quality of Terminal Care Delivered and Caregiver's Workforce Performance." *Supportive Care in Cancer*, vol. 18, 2010, pp. 699-706. *SpringerLink*, DOI: 10.1007/s00520-009-0668-5.
- 18 ASCO. "National Survey Reveals Surprising Number of Americans Believe Alternative Therapies Can Cure Cancer." October 30, 2018. *ASCO.org*. <https://www.asco.org/about-asco/press-center/news-releases/national-survey-reveals-surprising-number-americans-believe>. Accessed March 5, 2022.
- 19 Johnson, Skyler B., et al. "Use of Alternative Medicine for Cancer and Its Impact on Survival." *JNCI: Journal of the National Cancer Institute*, vol. 110, no. 1, 2018, pp. 121-124. *Oxford Academic*, DOI: 10.1093/jnci/djx145.
- 20 See: Verhoef, M.J., H.S. Boon, and S.A. Page. "Talking to Cancer Patients about Complementary Therapies: Is It the Physician's Responsibility?" *Current Oncology*, vol. 15, no. S-2, 2008. *PubMed.gov*, DOI: 10.3747/co.v15i0.279.; Robinson, A. and M.R. McGrail. "Disclosure of CAM Use to Medical Practitioners: A Review of Qualitative and Quantitative Studies." *Complementary Therapies in Medicine*, vol. 12, no. 2-3, 2004, pp. 90-98. *Academia.edu*, DOI: 10.1016/j.ctim.2004.09.006.; Adler, Shelley R. and Jennifer R. Fosket. "Disclosing Complementary and Alternative Medicine Use in the Medical Encounter: A Qualitative Study in Women with Breast Cancer." *Journal of Family Practice*, vol. 48, no. 6, 1999, pp. 453-458. https://cdn.mdedge.com/files/s3fs-public/jfp-archived-issues/1999-volume_48/JFP_1999-06_v48_i6_disclosing-complementary-and-alternative.pdf. Accessed May 6, 2022.
- 21 National Comprehensive Cancer Network. "Policy Priority: Ensure Patient Accessibility to Guideline-supported Care." *National Comprehensive Cancer Network*. <https://www.nccn.org/business-policy/policy-and-advocacy-program/policy-priority-ensure-patient-accessibility>. Accessed April 7, 2022.
- 22 CancerCare. *CancerCare Patient Access and Engagement Report*. 2016, <https://media.cancercare.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.
- 23 National Alliance for Caregiving. *Reimagining Clinical Trial Recruitment Through a Family-centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity*. March 2022. https://www.caregiving.org/wp-content/uploads/2022/03/NAC_ClinicalTrialProcessReport_v2.pdf. Accessed May 5, 2022.
- 24 National Alliance for Caregiving. *Reimagining Clinical Trial Recruitment Through a Family-centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity*. March 2022. https://www.caregiving.org/wp-content/uploads/2022/03/NAC_ClinicalTrialProcessReport_v2.pdf. Accessed May 5, 2022.
- 25 See: Zhang, Amy Y., et al. "Differential Patient-Caregiver Opinions of Treatment and Care for Advanced Lung Cancer Patients." *Social Science & Medicine*, vol. 70, no. 8, April 2010, pp. 1155-1158. *PubMed.gov*, DOI: 10.1016/j.socscimed.2009.12.023.; Ozdemir, Semra, et al. "Patient-Caregiver Treatment Preference Discordance and Its Association with Caregiving Burden and Esteem." *Innovation in Aging*, vol. 5, no. 3, 2021. *Oxford Academic*, DOI:10.1093/geroni/igab020.
- 26 Zhang, Amy Y., et al. "Differential Patient-Caregiver Opinions of Treatment and Care for Advanced Lung Cancer Patients." *Social Science & Medicine*, vol. 70, no. 8, April 2010, pp. 1155-1158. *PubMed.gov*, DOI: 10.1016/j.socscimed.2009.12.023.
- 27 Ozdemir, Semra, et al. "Patient-Caregiver Treatment Preference Discordance and Its Association with Caregiving Burden and Esteem." *Innovation in Aging*, vol. 5, no. 3, 2021. *Oxford Academic*, DOI:10.1093/geroni/igab020.
- 28 Multinational Association of Supportive Care in Cancer (MASCC). "What Is Supportive Care?" *MASCC.org*. <https://mascc.org/what-is-supportive-care/>. Accessed March 25, 2022.
- 29 Berman, R., et al. "Supportive Care: An Indispensable Component of Modern Oncology." *Clinical Oncology*, vol. 32, 2020, pp. 781-788. *Clinical Oncology*, DOI: 10.1016/j.clon.2020.07.020.
- 30 CancerCare. *CancerCare Patient Access and Engagement Report*. 2016, <https://media.cancercare.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.
- 31 See: Bakitas, Marie A., et al. "Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial." *Journal of Clinical Oncology*, vol. 33, no. 13, May 2015. *ASCOpubs.org*, DOI: 10.1200/JCO.2014.58.6362.; Temel, Jennifer S., et al. "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer." *New England Journal of Medicine*, vol. 363, no. 8, 2010, pp. 733-742. DOI: 10.1056/NEJMoa1000678.; Dionne-Odom, J. Nicholas, et al. "Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial." *Journal of Clinical Oncology*, vol. 33, no. 13, May 2015. *ASCOpubs.org*, DOI: 10.1200/JCO.2014.58.7824.

Considerations & Challenges in Decision-Making

An important objective of this study was to better understand the challenges caregivers faced as they participated in making decisions regarding the care and treatment of a loved one with cancer.

The survey asked caregivers to reflect on one specific decision-making experience and provide further details about it. As part of these responses, caregivers selected the factors they considered most important in making the decision (e.g. the patient's ability to continue working, the opinions of family and friends, etc.). They also reported on any challenges or confounders that created barriers to making a well-informed decision—for example, not understanding how a treatment would work—and indicated whether they had encountered bias from healthcare professionals that negatively impacted the decision-making support they received. Findings presented here reflect aggregated data for all respondents.



Factors important to decision-making

Caregivers have a lot on their minds when it comes to treatment decision-making. Of the 14 factors presented on the survey, the majority were considered “Very important” by a third or more of caregivers; five factors were “Very important” to more than 50% of caregivers. How do caregivers weigh these many factors? Several groupings have been identified from their responses. All percentages presented below are the portion of caregivers who selected “Very important” for that factor.

Patient's well-being

Factors related to the patient's overall well-being were of primary importance to caregivers. These factors included the **patient's quality of life** (68%), **physical well-being** (67%), **how long the patient is likely to live** (63%), **impact on the patient's emotional well-being** (62%), and the **patient's ability to function independently in activities of daily life** (49%).

Expert opinions

It's clear the guidance they receive from the clinical team carried a great deal of weight for caregivers, with 56% indicating that the **opinions of the patient's oncologist and healthcare team** were very important to making decisions.

Personal relationships

While expert opinions carried the most weight, caregivers were also attuned to what their social network had to say: 37% reported that the **opinions and feelings of other family members and friends** were very important to their decision-making.

Maintaining “normal life”

After their primary concern for the patient’s well-being, caregivers placed secondary importance on factors related to the patient’s ability to maintain (or return to) “normal life.” These factors include **changes in the patient’s appearance**, such as hair loss or weight gain/loss (33%); **impact on the patient’s ability to be at special events**, such as weddings, births, or travel plans (31%); **the patient’s ability to continue working** (30%); and **ability to take care of others**, such as children (28%).

Notably, caregivers put the patient’s well-being ahead of their own needs. The **consequences of the decision on their own day-to-day life** was very important to 36% of caregivers.

Religious/spiritual beliefs

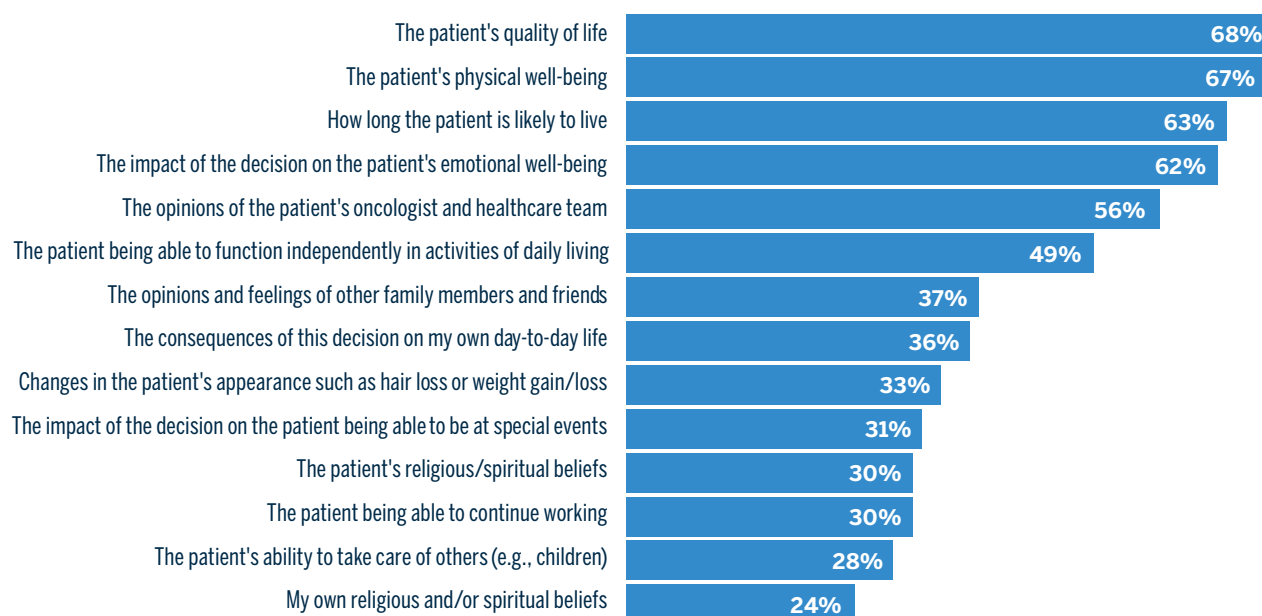
Again, putting an emphasis on the patient’s needs, 30% of caregivers considered the **patient’s religious and/or**

spiritual beliefs very important to making the decision. This was placed ahead of **their own religious and/or spiritual beliefs**, which 24% of caregivers considered very important.



Factors considered “very important” to decision-making

Aggregate data from all decision-making situations, n=2703





Case study: Factoring in a patient's ability to be at special events

Emily,* 27, has been a key player in her father Mark's support system throughout his treatment for brain cancer. Although she works full time and lives in another city, Emily regularly travels at least an hour to see him. Her family has collaborated with Mark and the medical team on treatment plan decisions, with Emily actively involved as an Observer/Supporter and an Input Provider. While communication among the care team has been clear overall, Emily and her family have been unable to get answers about Mark's prognosis. This is a particularly emotional question, as Emily is planning her wedding for the coming year and fears her dad may not be alive then. She and her fiancé have tried to move the date earlier without success, and rushing a smaller event now feels like it would painfully highlight Mark's uncertain future. Without this important piece of her dad's cancer diagnosis, Emily is uncertain how to proceed and her stress about treatment is heightened.

** Caregiver and patient names have been changed.*

Decision-making barriers, challenges, and confounders

Caregivers often encounter decision-making challenges that add confusion and uncertainty to what is already an emotionally draining process for many. The survey presented each caregiver with a list of statements regarding possible decision-making barriers and had them indicate how much they agreed with each. Several statements were tailored to specific decision-making situations and were presented only to caregivers who responded about those situations—for example, caregivers who answered questions about biomarker or genetic testing decisions responded to the statement “I didn't know what the findings might mean for family members,” but caregivers answering questions about palliative care decisions did not. As a result, base sizes vary (some are quite small) and are noted with the data for each statement.

Overall, 20% of caregivers reported they “didn't have enough information to make this decision” ($n=2661$). Limited knowledge, lack of understanding, and/or disagreement about important treatment factors, as discussed below, made it more challenging to reach fully informed decisions.

Impact on patient

Feeling ill-informed about how treatments might impact the patient made decision-making more challenging for many caregivers: 39% ($n=1422$) agreed with the statement, “I didn't know how the treatment would affect the patient's physical condition” and 37% ($n=1422$) agreed they “didn't know how the treatments would affect the patient's quality of life.” Among a smaller sample of caregivers ($n=155$), 40% reported uncertainty about “how the medication options would impact the patient's quality of life” and 38% “didn't know how medications would affect the patient's physical condition.” While base size was very small ($n=52$), 50% of caregivers involved in decisions about clinical trials also

struggled with questions about how treatment would affect the patient's quality of life. These findings all reflect the importance caregivers placed on the patient's well-being in making treatment decisions. Caregivers' responses suggest a significant disconnect between the factors of greatest importance to them and the information they actually had about what the patient might experience during treatment.

Overall, 20% of caregivers reported they "didn't have enough information to make this decision."

Treatment/testing options

Knowledge gaps regarding treatment options were also a common barrier to decision-making, with about a quarter of caregivers indicating they "didn't understand how each of the treatments would work" (27%, $n=1422$) or "didn't understand the risks and benefits of each treatment" (22%, $n=1422$). Among smaller samples, a third of caregivers "didn't know how cancer treatment differs by doctor or cancer center" (33%, $n=753$) and "didn't understand

how each of the medications would work" (32%, $n=155$). Caregivers who made decisions about biomarker or genetic testing ($n=161$) were particularly challenged in this area: roughly a third "didn't know what testing would involve" (33%), "didn't know what the findings might mean for treatment options" (36%), or "didn't know what findings might mean for family members" (37%).

Treatment/testing implementation

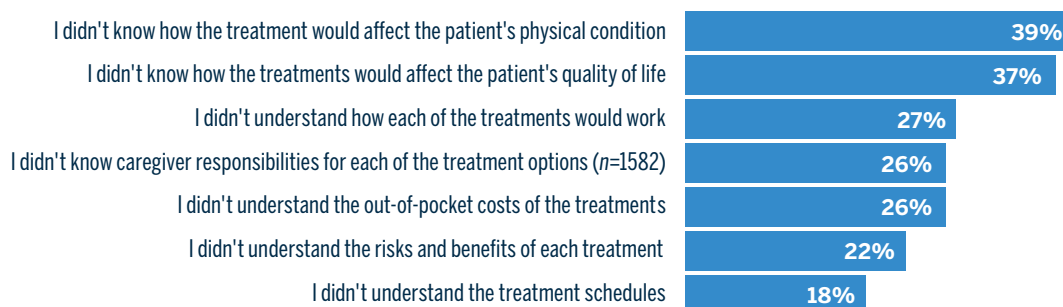
Similarly, caregivers were unclear regarding how treatment or testing would be implemented. A quarter indicated they "didn't know caregiver responsibilities for each of the treatment options" (26%, $n=1582$) and 18% ($n=1422$) "didn't understand the treatment schedules." Caregivers in smaller samples encountered the same barriers, with roughly a quarter who "didn't understand the treatment or test schedules" (27%, $n=161$) or "didn't know about the treatment schedules" (23%, $n=753$).

Out-of-pocket costs

Caregivers also reported a lack of understanding about out-of-pocket costs for treatments (26%, $n=1422$) or out-of-pocket costs for treatments and tests (27%, $n=928$).

Caregivers' decision-making challenges

Aggregate data from relevant decision-making situations*, $n=1422$ unless noted



* The survey asked caregivers to indicate how much they agreed or disagreed with statements regarding possible decision-making barriers; statements were tailored to specific decision-making situations and were presented only to caregivers who responded about those situations. As a result, this sample does not include all respondents.

Case study: When some team members don't agree with the doctor's recommendations

Paula* and Amir are a married couple in their early 30s, navigating Amir's stage 4 colorectal cancer. Paula serves as an Input Provider to the clinical team and supports her husband as a Joint Decision Maker. The treatment decision they currently face has become increasingly stressful due to disagreements between doctors and a discouraging lack of information. Amir's primary oncologist at a local medical center wants to adjust his course of treatment to prepare for HIPEC surgery, a procedure that would remove the tumor and deliver localized chemotherapy drugs. A second opinion from an oncologist at a cancer center, however, recommends maintaining the current treatment and dismisses the surgery, as they don't believe it will extend Amir's life. Paula knows her husband is looking to her for help with this decision, but worries that she will carry guilt and feel responsible if the outcome is poor—no matter which choice is made. "It's hard to know what the right decision is," Paula shares. She understands the risks of a serious surgery and the lengthy recovery time; if surgery is not successful, she fears it will be a "waste of time, energy, and resources." With the help of a CancerCare social worker and family members, Paula put together a list of questions for both oncologists to gather more information, including pros and cons for both treatment options. While she continues to push forward, Paula is frustrated by the limited information provided so far and disheartened by how hard she has had to advocate on Amir's behalf to make a fully informed treatment decision.

** Caregiver and patient names have been changed.*

Among a smaller sample, 22% ($n=155$) agreed they "didn't understand the out-of-pocket costs of the medications." Despite the longstanding evidence that out-of-pocket costs are considered important in treatment planning for most caregivers (including this survey's sample), information regarding cost was not sufficiently addressed during the decision-making process.

Disagreements among the decision-making group

A lack of consensus made treatment decision-making more challenging for some caregivers. A quarter reported that "Not everyone on the care team agreed" (24%, $n=2661$) or that "Some team members didn't agree with the doctor's recommendations" (24%, $n=2661$). Navigating disagreements was



particularly challenging for caregivers involved in decisions about whether to get biomarker or genetic testing (37% “not everyone agreed”/40% “didn’t agree with doctor’s recommendations,” $n=183$) and caregivers involved in decisions about whether to end cancer treatment entirely (31% “not everyone agreed”/35% “didn’t agree with doctor’s recommendations,” $n=107$).

Caregivers' experiences with decision-making disagreements

Aggregate data from relevant decision-making situations, $n=2661$



Disagreements amplify the stress of decision-making and can strain relationships that might usually provide support for patients and caregivers alike. As noted earlier, the Rx4Good survey found that cancer caregivers who only sometimes agree with their patients on treatment priorities were more likely to experience “much stress” making care decisions compared to caregivers who agree with their patients on treatment priorities (83% vs. 70%). They were also more likely to report that “care decisions put a great deal of stress on [their] relationship” with the patient (54% for caregivers who “sometimes agree” vs. 44% for caregivers who agree on priorities).¹ Other studies indicate that disagreements in treatment decision-making are associated with greater caregiver burden and increased rates of depression among patients and caregivers.² The impact of disagreements on patient-caregiver relationships could ultimately affect outcomes, as family conflict is associated with poorer treatment adherence.³

Encountering bias from the healthcare team

Survey respondents were asked if they felt the support they and the patient received from the healthcare team to make cancer-related decisions had been negatively affected by their age, race, or other personal characteristics—that is, whether bias from healthcare professionals impacted treatment decision-making. Caregivers reviewed 13 characteristics and reported whether they felt each has or has not had a negative effect on the support they received.

Nearly half of all caregivers surveyed (47%) perceived bias from the healthcare team during treatment decision-making. The most common were bias related to body weight (25%), age (22%), and income level (20%). Caregivers who were younger, male or transgender/gender non-conforming were more likely to experience one or more types of bias. Hispanic caregivers reported bias more than non-Hispanic caregivers, and Black/African American and Alaskan Native, American Indian, Native Hawaiian or Pacific Islander caregivers experienced more bias than white and Asian caregivers. Caregivers with higher education levels and those who had been providing care for a longer time were also more likely to perceive bias from healthcare professionals in decision-making.⁴

Nearly half of all caregivers surveyed (47%) perceived bias from the healthcare team during treatment decision-making.



References for Section 5: Considerations & challenges in decision-making

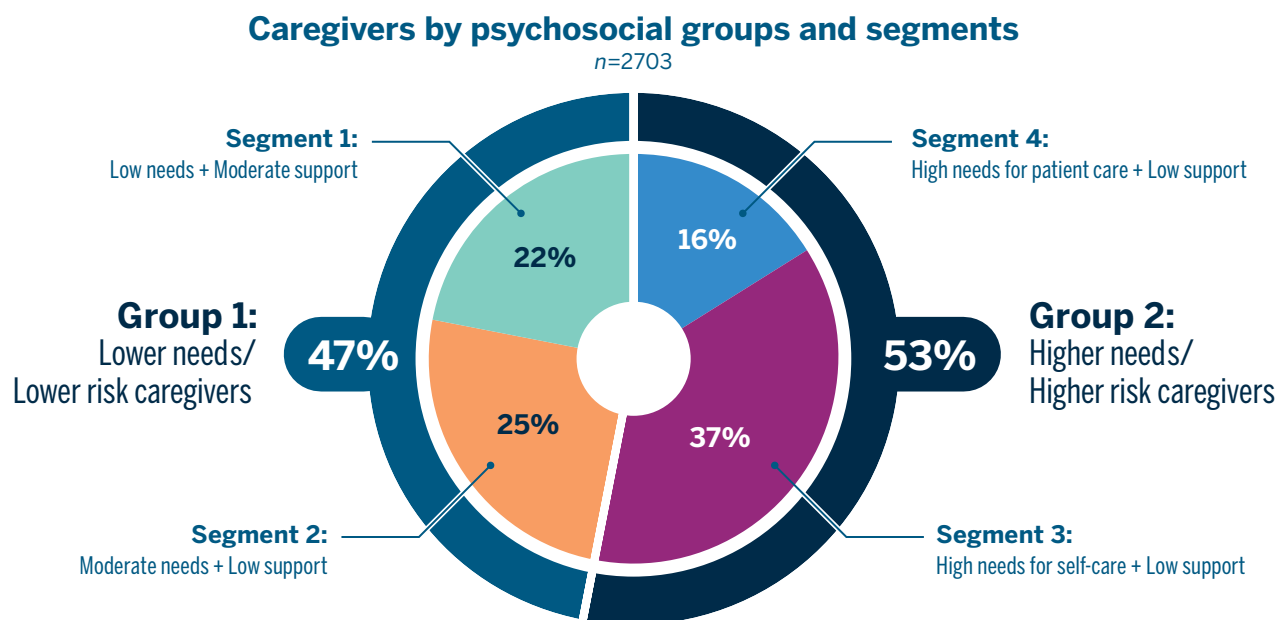
- 1 Rx4Good. "Supplemental Report: Findings for Caregivers Whose Recipient Is Diagnosed with Cancer." *The Caregiver Factor: Understanding the Medical Journey of the Caregiver and Their Information and Support Needs*, 2018.
- 2 See: Zhang, Amy Y., et al. "Differential Patient-Caregiver Opinions of Treatment and Care for Advanced Lung Cancer Patients." *Social Science & Medicine*, vol. 70, no. 8, April 2010, pp. 1155-1158. *PubMed.gov*. DOI: 10.1016/j.socscimed.2009.12.023.; Ozdemir, Semra, et al. "Patient-Caregiver Treatment Preference Discordance and Its Association with Caregiving Burden and Esteem." *Innovation in Aging*, vol. 5, no. 3, 2021. *Oxford Academic*, DOI:10.1093/geroni/igab020.
- 3 DiMatteo, M. Robin. "Social Support and Patient Adherence to Medical Treatment: A Meta-analysis." *Health Psychology*, vol. 23, no. 2, 2004, pp. 207-18. *APA PsychNet*, DOI: 10.1037/0278-6133.23.2.207.
- 4 Dionne-Odom, J. Nicholas, et al. "Bias Reported by Family Caregivers in Support Received When Assisting Patients with Cancer-related Decision-making." Submitted to *The Journal of Clinical Oncology*, March 26, 2022.

Caregiver Segments by Needs & Attitudes

A key area of inquiry for this survey was understanding caregivers' attitudes and feelings about providing care, including their perceptions of support and scores on screeners that indicate needing further evaluation for general anxiety and depression (indicated by a score of three points or more for frequency of symptoms on the GAD-2 and on the PHQ-2). When these responses were analyzed and correlations to other demographic and social factors were examined, two groups clearly emerged: caregivers who are managing relatively well (47% of survey sample), with low to moderate needs and low risk of burden; and caregivers who are struggling (53%), with high needs for self-care or patient care and high risk for significant burden. These groups were further dissected, yielding a total of four caregiver segments—two within the “Lower needs/Lower risk” group and two within

the “Higher needs/Higher risk” group. Significant differences among these groups and segments are discussed below (95% confidence level).

The term “burden” relates to the mental and physical toll that providing care takes on a caregiver's well-being. This, in turn, impacts the patient's well-being. As seen in the differences among segments, risk of burden corresponds to a caregiver's emotional state and personal perceptions (subjective stress) and to the care responsibilities they handle, particularly the patient's level of need (objective stress).¹ According to the Transactional Model of Stress and Coping, a sense of burden arises when demands on a caregiver outweigh their available resources, such as coping techniques or the support of others.²



While the survey did not ask directly about the burden caused by the challenges of decision-making, studies show that care decisions cause significant stress for many caregivers.³ For a caregiver already at high risk for burden, decision-making likely amplifies their distress and sense of strain. They may be unable to provide the involvement and support their patient needs to make informed treatment decisions.

Caregiver groups based on needs and risk of burden

Lower needs/Lower risk for burden (47% of respondents)

Caregivers in the “Lower needs/Lower risk” group feel more confident, competent, and useful in their role, with the majority having found personal growth and a sense of purpose in providing care. They are satisfied with the support they receive from family, even indicating that communication in their family has improved.

They expressed less distress and loss of control. They seem to successfully balance their caregiving with other responsibilities and personal care.

These caregivers feel adequately informed about the person’s illness and express greater satisfaction with the care provided by the doctors and clinical team, whom they also feel value their input about treatment.

This group includes:

- **Segment 1:** Caregivers with low needs who have moderate support (22% of respondents)
- **Segment 2:** Caregivers with moderate needs who have low support (25% of respondents)



Higher needs/Higher risk for burden (53% of respondents)

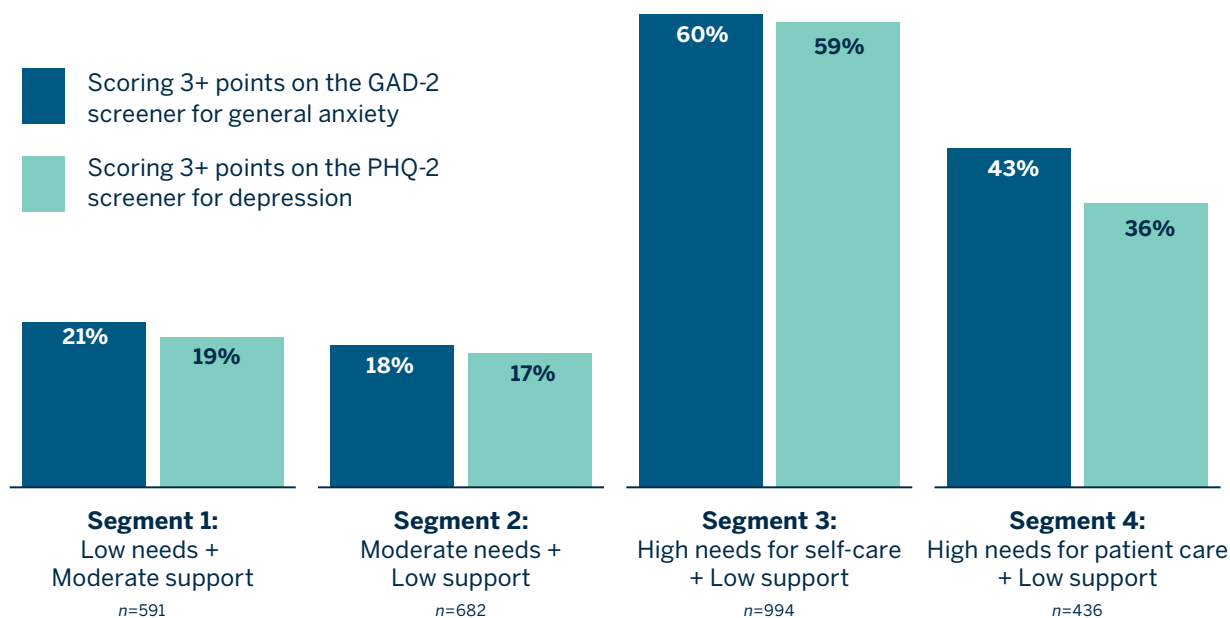
Caregivers in the “Higher needs/Higher risk” group feel more stressed and less satisfied with the support they get from family. They find it more difficult to balance caregiving with other responsibilities at work or for their family. They are more likely to feel they’ve lost control of their lives, expressing a loss of privacy and personal time.

The majority of this group met the criteria warranting further diagnostic evaluation for general anxiety and for depression. Compared to the “Lower needs/Lower risk” group, they feel less informed about the person’s illness and express less satisfaction with the care provided; they are also less likely to feel valued by the patient’s doctors and clinical team.

This group includes:

- **Segment 3:** Caregivers with high needs for self-care who have low support (37% of respondents)
- **Segment 4:** Caregivers with high needs for patient care who have low support (16% of respondents)

Depression and general anxiety by segment



Scores on the PHQ-2 and GAD-2 each range from zero to six, with scores of three or higher representing a positive screen for possible major depressive disorder or possible generalized anxiety disorder.

The COVID-19 pandemic and measures of mental health:

Prior to the COVID-19 pandemic, the average monthly percentage of U.S. adults reporting symptoms of depression ranged from 5.9%-7.5% and those reporting symptoms of anxiety ranged from 7.4-8.6%. Between April 2020 and August 2021, which included the early pandemic and several major waves, average sub-monthly percentages rose to 20.2-31.1% for depression and 29.2%-37.2% for anxiety.⁴ Data collection for the Caregiver Decision-Making Survey took place during the later third of that date range (February 16-July 6, 2021) and responses to GAD-2 and PHQ-2 screeners no doubt reflect these heightened rates of depression and anxiety. Against this elevated baseline, differences in the screening scores for depression and anxiety symptoms can still be seen among several caregiver segments.



Caregiver segments based on needs and support

Segment 1: Low needs + Moderate support

“Since becoming a caregiver I have become more aware of my inner strengths.”

Making up 22% of the caregivers surveyed, Segment 1 faces fewer direct caregiving burdens (“low needs”) and reported having support from family (“moderate support”). They are the least likely to be the sole caregiver (31%), the least likely to have the patient live with them (25%), and the least likely to be caring for an immediate family member (42%). While the patients they support may be less able to care for themselves (48% “all/most of the time” can do this), their cancer diagnosis skews more toward stage 1 or 2 (50%), with only 9% in stage 4. Segment 1 has also spent the shortest time in their caregiving roles, on average 2.1 years.

Segment 1 has the highest satisfaction score for family support and rated family involvement positively across all measures. They also expressed the greatest satisfaction with the clinical team. These caregivers reported the most positive views of their role, seeing it as a source of purpose and greater inner strength. The confidence they express about caregiving extends to their ability to balance care demands with other responsibilities—most notably their jobs, as the majority work full time (78%).

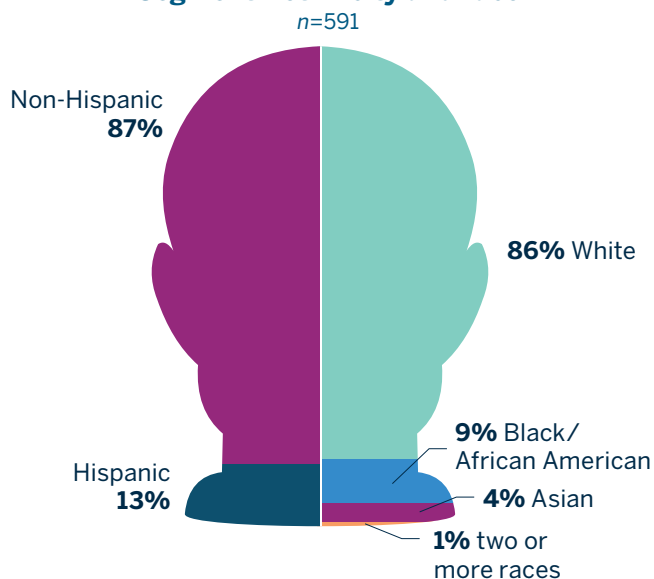
Among Segment 1 caregivers, 21% had a score of three or higher for symptoms that indicate needing further evaluation for general anxiety and 19% for depression.

Segment 1 key demographics

- Average age: 39
- Male: 56%
- Married: 80% [▲]
- Completed college or higher: 78% [▲]
- Average household income: \$106,700 [▲]
- Working full time: 78% [▲]
- Sole caregiver: 31% [▼]
- Patient lives in same home: 25% [▼]
- Patient stage 1 or 2: 50% [▲]

[▲] = significantly higher compared to all respondents (95% confidence level)
[▼] = significantly lower compared to all respondents (95% confidence level)

Segment 1 ethnicity and race



Segment 2: Moderate needs + Low support

“The Lord won’t give you more than you can handle.”

Caregivers in Segment 2, comprising 25% of all respondents, meet potential challenges with a positive outlook. Compared to Segment 1 they are more often the sole caregiver (38%), supporting an immediate family member (55%) who may live in their home (34%) and have more advanced cancer (44% stage 1 or 2; 15% stage 4). They and the person they care for tend to be older. Overall, Segment 2 shares Segment 1’s views on caregiving: they feel useful, competent, and purpose-driven.

Of the four segments, Segment 2 most identifies with statements that affirm both their abilities as caregivers and the struggles they face—for example, “I would not have chosen this situation I’m in, but I get satisfaction from providing care.” Segment 2 feels satisfied with the family support they receive, but not quite as strongly as Segment 1. They are generally satisfied with the patient’s healthcare team as well, feeling valued for their input and well informed about the illness.

Segment 2 caregivers were the least likely to report feeling overwhelmed, trapped, lacking in privacy/personal time, or out of control. They are also the least stressed about providing care while managing other responsibilities; this may be due in part to their lower employment levels (54% work full time). These caregivers had the lowest scores on the screeners for needing further evaluation for general anxiety (18%) and depression (17%).

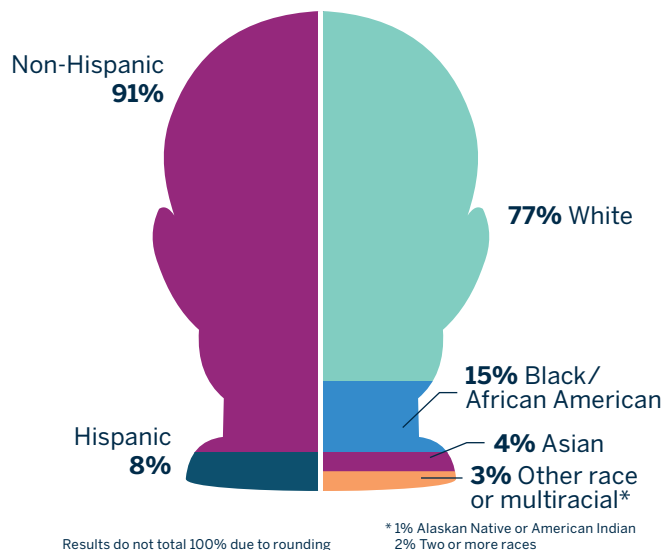
Segment 2 key demographics

- Average age: 47
- Female: 63% ▲
- Married: 69%
- Completed college or higher: 60%
- Average household income: \$87,700 ▼
- Working full time: 54% ▼
- Sole caregiver: 38% ▲
- Patient lives in same home: 34%
- Patient stage 1 or 2: 44%

▲ = significantly higher compared to all respondents (95% confidence level)
▼ = significantly lower compared to all respondents (95% confidence level)

Segment 2 ethnicity and race

n=682



Segment 3: High needs for self-care + Low support

"I feel I've lost control of my life."

The largest portion at 37%, Segment 3 caregivers struggle to address their own needs while providing support for their care recipient. More than any other segment, these caregivers feel they've lost control of their lives. They feel the most overwhelmed, the most trapped, the most acute loss of privacy/personal time, and the most frustration with family—they're clearly in need of personal support. These feelings may be linked to being the segment most likely to have patients live with them (43%). Few are sole caregivers (33%); most juggle a full-time work schedule (73%) with care for an immediate family member (51%) who has advanced cancer (60% in stage 3 or 4).

Segment 3 caregivers recognize their usefulness, but score relatively low on statements reflecting confidence and personal growth as a caregiver. Like Segment 2, they identify with statements that acknowledge both their efforts and their hardships (e.g. "I would not have chosen this situation I'm in, but I get satisfaction from providing care" and "The Lord won't give you more than you can handle"). Adding to their stress at managing multiple responsibilities is a perceived lack of interest from their family in providing care.

Although Segment 3 caregivers feel the clinical team values their input, they are the least satisfied with the care provided and feel the least informed about the patient's illness. This discontent and apparent disconnection is evident in their responses about specific decision-making experiences, discussed below.

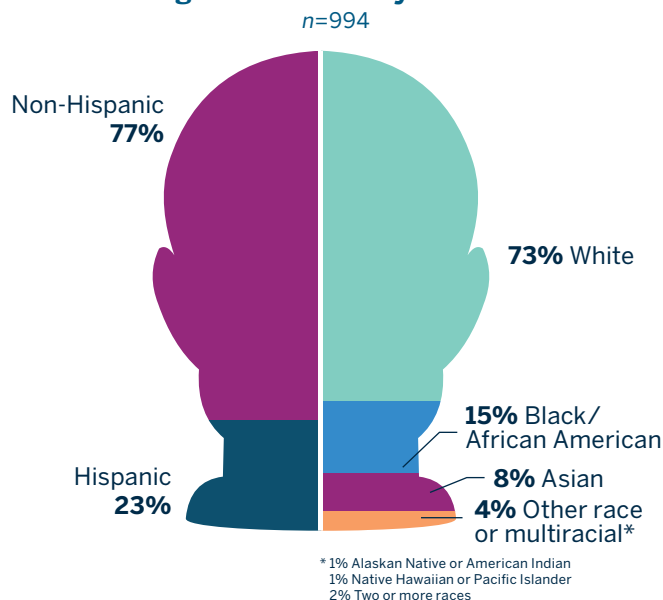
Caregivers in Segment 3 had the highest scores on the screeners indicating the need for further evaluation for general anxiety (60%) and depression (59%).

Segment 3 key demographics

- Average age: 40
- Male: 51%
- Married: 69%
- Completed college or higher: 69%
- Average household income: \$94,600
- Working full time: 73% ▲
- Sole caregiver: 33% ▼
- Patient lives in same home: 43% ▲
- Patient stage 1 or 2: 40%

▲ = significantly higher compared to all respondents (95% confidence level)
▼ = significantly lower compared to all respondents (95% confidence level)

Segment 3 ethnicity and race



Segment 4: High needs for patient care + Low support

"I feel stress between caring for this person and meeting other family or work responsibilities."

Caregivers in Segment 4, the smallest at 16%, struggle to shoulder the significant health challenges of the person for whom they provide care. Most likely to be sole caregivers (40%), they support older patients (average age 64) with the most advanced cancer (43% in stage 3, 20% in stage 4). Their patients are also least able to communicate effectively with doctors on their own (57% can "all/most of the time"). Segment 4 caregivers often live with the patient, who is most likely to be an immediate family member (66%). They are the least likely to view caregiving through a lens of personal growth; rather, it's a confidence-shaking balancing act.

Segment 4 caregivers are least likely to feel their input is valued by the clinical team, despite being well informed about the patient's illness and satisfied with the care received. They're least likely to express self-confidence or find inner strength, personal growth, or a sense of purpose in caregiving.

Instead, they most identify with the stress of providing care while meeting other family or work responsibilities. Given that 43% do not work full time, it may be family matters they find difficult to balance: they're the least satisfied with family support and least likely to say communication among family has improved.

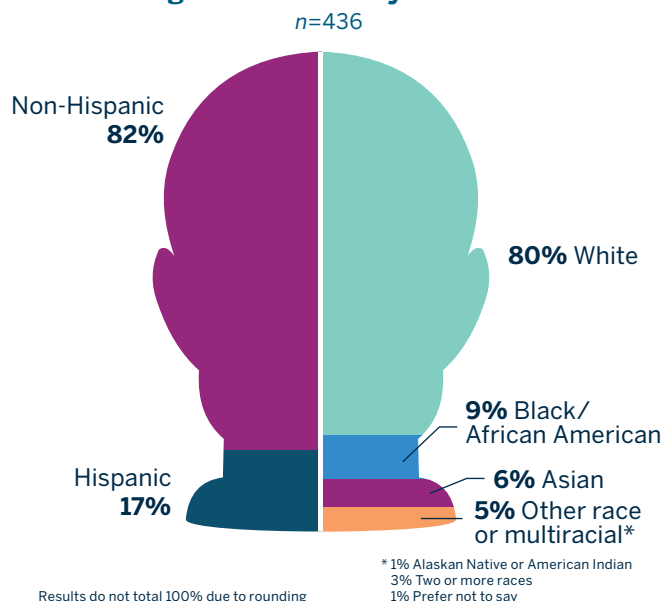
These caregivers feel overwhelmed, trapped, and out of control, though not as severely as Segment 3. Their scores for needing further evaluation for general anxiety (43%) and depression (36%) were lower than Segment 3, but elevated compared to Segments 1 and 2.

Segment 4 key demographics

- Average age: 47
- Female: 65% ▲
- Married: 64% ▼
- Completed college or higher: 64%
- Average household income: \$89,900 ▼
- Working full time: 57% ▼
- Sole caregiver: 40% ▲
- Patient lives in same home: 39% ▲
- Patient stage 1 or 2: 37% ▼
- Patient stage 4: 20% ▲

▲ = significantly higher compared to all respondents (95% confidence level)
▼ = significantly lower compared to all respondents (95% confidence level)

Segment 4 ethnicity and race





Factors important to decision-making by psychosocial segment

As reviewed in Section 5, the in-depth information that caregivers shared about one specific decision-making situation included rating which factors they considered most important to the decision. Analysis of the aggregate data revealed that each of the four identified segments had differing opinions about which factors were most important in decision-making. All differences are based on indexed mean scores by factor for individual segments compared to those for all caregivers in the survey sample (95% confidence level).

Patient's well-being

The factors considered most important by respondents were related to the patient's well-being, such as the decision's impact on **quality of life, physical well-being, emotional well-being, length of life, and independence in activities of daily living**. While Segments 1, 2, and 4 rated these factors higher than the total caregiver sample, the outliers were Segment 3 caregivers (High needs for self-care + Low support); they gave significantly lower ratings to all factors regarding patient well-being. This may be related to Segment 3 caregivers' overarching need for more personal support. When asked what services they'd find most helpful to aid future decision-making, this was the only segment that placed more importance on caregiver-focused resources than patient-focused resources (discussed further in Section 8).



Personal relationships

Compared to the overall sample, caregivers in Segment 4 (High needs for patient care + Low support) gave significantly less importance to the **opinions and feelings of other family members and friends** in making their decisions. As the segment most likely to be sole caregivers and who indicated limited involvement from family, Segment 4 caregivers may not have a sufficient support network to assist with decision-making. While they may be accustomed to handling care decisions on their own, increased decision-making support could alleviate some stress and perhaps address these caregivers' sense that their input is less valued by the healthcare team.

Segment 1 and Segment 3 both gave significantly higher scores to the opinions and feelings of others in their social network. Given that Segment 1 has moderate family support while Segment 3 reported very little, this suggests ways that others might inform care decisions even if they are not active in providing care. (It's also possible the caregivers in these segments were considering the needs of children or other care recipients, as they were also concerned about the patient's ability to care for others.)

Expert opinions

The **opinions of the oncologist/healthcare team** ranked among the top five most important factors across all four segments. Segments 1 and 2, which make up the "Lower needs/Lower risk" group, rated expert opinions significantly higher. Segment 3, again, gave this factor significantly less importance compared to caregivers overall. These ratings may relate to the differing opinions these segments have about the care and information provided by the clinical team. Segment 1 had the highest satisfaction with the clinical team, followed by Segment 2; caregivers in these two segments were also significantly more likely to feel well informed about the patient's illness. Segment 3 caregivers were the least satisfied with the care provided and felt the least informed.





Maintaining “normal life”

Caregivers in Segment 3 and Segment 1 (Low needs + Moderate support) placed significantly more importance on the patient’s **ability to continue working, to care for others, and to attend special events**. While Segment 1 and Segment 3 have little in common when it comes to level of need and risk of burden, both segments do include younger caregivers; their concerns about maintaining “normal life” may be related to age and stage of life. Segment 1 and Segment 3 also awarded significantly more importance to the **decision’s consequences on their own day-to-day life**, which may again relate to age and to the majority of caregivers in both segments (>70%) having full-time jobs. In contrast, the older caregivers in Segment 2 and Segment 4, who have lower rates of full-time employment (<60%), placed significantly less importance on all these factors.

Religious/spiritual beliefs

Compared to all caregivers in the sample, both Segment 2 (Moderate needs + Low support) and Segment 3 caregivers gave greater importance to **the patient’s religious or spiritual beliefs and their own religious or spiritual beliefs**—with the patient’s beliefs given more weight. As noted earlier, Segment 2 and Segment 3 were also most likely to identify with the statement, “The Lord won’t give you more than you can handle.” Caregivers in Segment 1 and Segment 4 rated the factors related to spirituality significantly lower.

A closer look at Segment 3: High needs for self-care + Low support

Along with indicating which factors they considered most important in making the decision, caregivers reported on challenges and barriers to decision-making. Analysis of these responses showed that decision-making was especially difficult for caregivers in Segment 3 (High needs for self-care + Low support). All findings look at aggregate data for Segment 3 caregivers compared to caregivers not in Segment 3, i.e. all other segments.

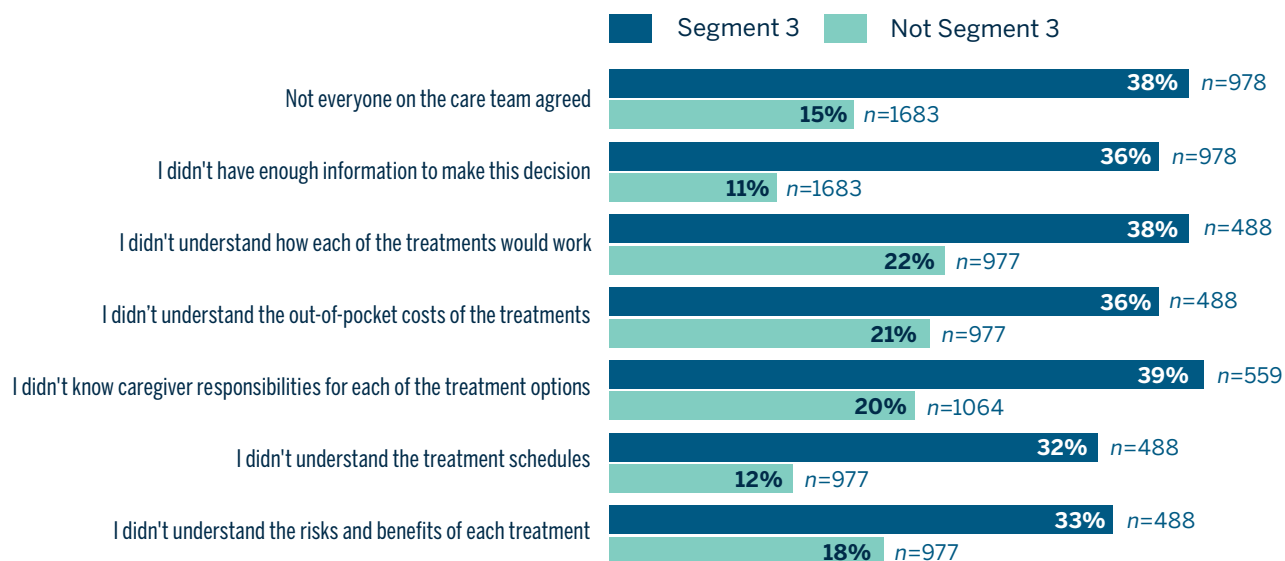
Overall, 36% of Segment 3 caregivers said they “didn’t have enough information to make the decision” and 45% felt “the information they found or was given was not helpful.” That’s nearly three- and four-times more, respectively, than the rates for caregivers not in Segment 3.

In particular, Segment 3 caregivers lacked an understanding of treatment or testing options. Compared to caregivers not in Segment 3, they were more likely to not know how each of the treatments would work (38% vs. 22%) and to not understand the risks and benefits of each treatment (33% vs. 18%). They also lacked information regarding how treatment or testing would be implemented once the decision was made. Segment 3 caregivers were more likely to report they “didn’t know the caregiver responsibilities for each treatment” (39% vs. 20%) and that they “didn’t understand the treatment schedules” (32% vs. 12%). Caregivers in Segment 3 also indicated that they “didn’t know the out-of-pocket costs associated with treatments” (36% vs. 21%).

Along with unmet needs for information, Segment 3 caregivers were twice as likely to report that “not everyone on the care team agreed” (38% vs. 15%). This experience with decision-making conflict may play into the doubt they expressed about the decisions that were ultimately made.

Decision-making challenges—Segment 3 vs. Not Segment 3 caregivers

Aggregate data from relevant decision-making situations; all differences statistically significant at 95%





Compared to caregivers not in Segment 3, Segment 3 caregivers were more than five times more likely to regret the choice made (39% vs. 7%) and to worry that the choice made was harmful to the patient (40% vs. 7%). As discussed in Sections 4 and 5, disagreements about treatment priorities greatly increase the stress of decision-making for caregivers and have been associated with higher rates of depression and perceived caregiver burden.⁵ While we don't know how decision-making stress relates to Segment 3's higher rates of depression and anxiety, it's evident there is a need here for resources that aid consensus building and address the affective impact of treatment decision-making.

References for Section 6: Caregiver segments by needs & attitudes

- 1 Liu, Zhu, et al. "Caregiver Burden: A Concept Analysis." *International Journal of Nursing Science*, vol. 7, no. 4, 2020, pp. 438-445. *ScienceDirect*. DOI: 10.1016/j.ijnss.2020.07.012.
- 2 PDQ® Supportive and Palliative Care Editorial Board. "Informal Caregivers in Cancer: Roles, Burden, and Support (PDQ®)-Health Professional Version." Updated on January 5, 2022. *National Cancer Institute*. <https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq>. Accessed February 26, 2022.
- 3 Rx4Good. *The Caregiver Factor: Understanding the Medical Journey of the Caregiver and Their Information and Support Needs*. 2018, http://rx4good.com/admin/wp-content/uploads/2018/06/RX4G_Caregiver_Report.pdf. Accessed March 5, 2022.
- 4 DeAngelis, Tori. "Depression and Anxiety Escalate During COVID." *Monitor on Psychology*, vol. 52, no. 8, November 2021. *American Psychological Association*. <https://www.apa.org/monitor/2021/11/numbers-depression-anxiety>. Accessed February 2, 2022.
- 5 See: Rx4Good. *The Caregiver Factor: Understanding the Medical Journey of the Caregiver and Their Information and Support Needs*. 2018, http://rx4good.com/admin/wp-content/uploads/2018/06/RX4G_Caregiver_Report.pdf. Accessed March 5, 2022.; Ozdemir, Semra, et al. "Patient-Caregiver Treatment Preference Discordance and Its Association With Caregiving Burden and Esteem." *Innovation in Aging*, vol. 5, no. 3, 2021. *Oxford Academic*. DOI:10.1093/geron/igab020.; Zhang, Amy Y., et al. "Differential Patient-Caregiver Opinions of Treatment and Care for Advanced Lung Cancer Patients." *Social Science & Medicine*, vol. 70, no. 8, April 2010, pp. 1155-1158. *PubMed.gov*. DOI: 10.1016/j.socscimed.2009.12.023.

Hispanic Caregivers & Treatment Decision-Making

Survey data from Hispanic caregivers significantly differed from non-Hispanic caregivers in a number of ways and point to a clear need for support. This is evident in Hispanic caregivers' feelings of being trapped and overwhelmed, their higher scores on screeners suggesting the need for further evaluation for depression and general anxiety disorder, and the numerous barriers to treatment decision-making they encountered.

The Hispanic caregivers in this survey tend to be younger than the non-Hispanic caregivers, so weighting was applied to enable comparisons between the two samples. The weights ensured that the samples were equally balanced on three age breaks: 18 to 34, 35 to 54, and 55+. All differences discussed are at a 95% confidence level. Comparisons of population percentages (i.e. X% vs. Y%) list the figure for the Hispanic sample first, followed by the non-Hispanic sample.



Key demographics: Hispanic (n=439) vs. non-Hispanic (n=2256) caregivers

- Younger: average age 41.9 vs. 42.7
- Slight male skew: 49%
 - Fewer female caregivers compared to non-Hispanic sample (47% vs. 54%)
- Married: 68%
 - More likely to be single and living with a partner compared to non-Hispanic sample (12% vs. 7%)
- Completed college or higher: 70%
 - More likely than non-Hispanic sample to have completed college (43% vs. 31%); less likely to have some post-graduate education/post-graduate degree (26% vs. 36%)
- Average household income: \$95,500
 - More likely to be in the \$75,000 to \$99,999 income bracket (24% vs. 18%) than non-Hispanic caregivers, who are more likely to be in the \$100,000 to \$149,999 bracket (24% vs. 29%)
- More likely to work full time (74% vs. 66%)
- Less likely to be retired (5% vs. 9%)

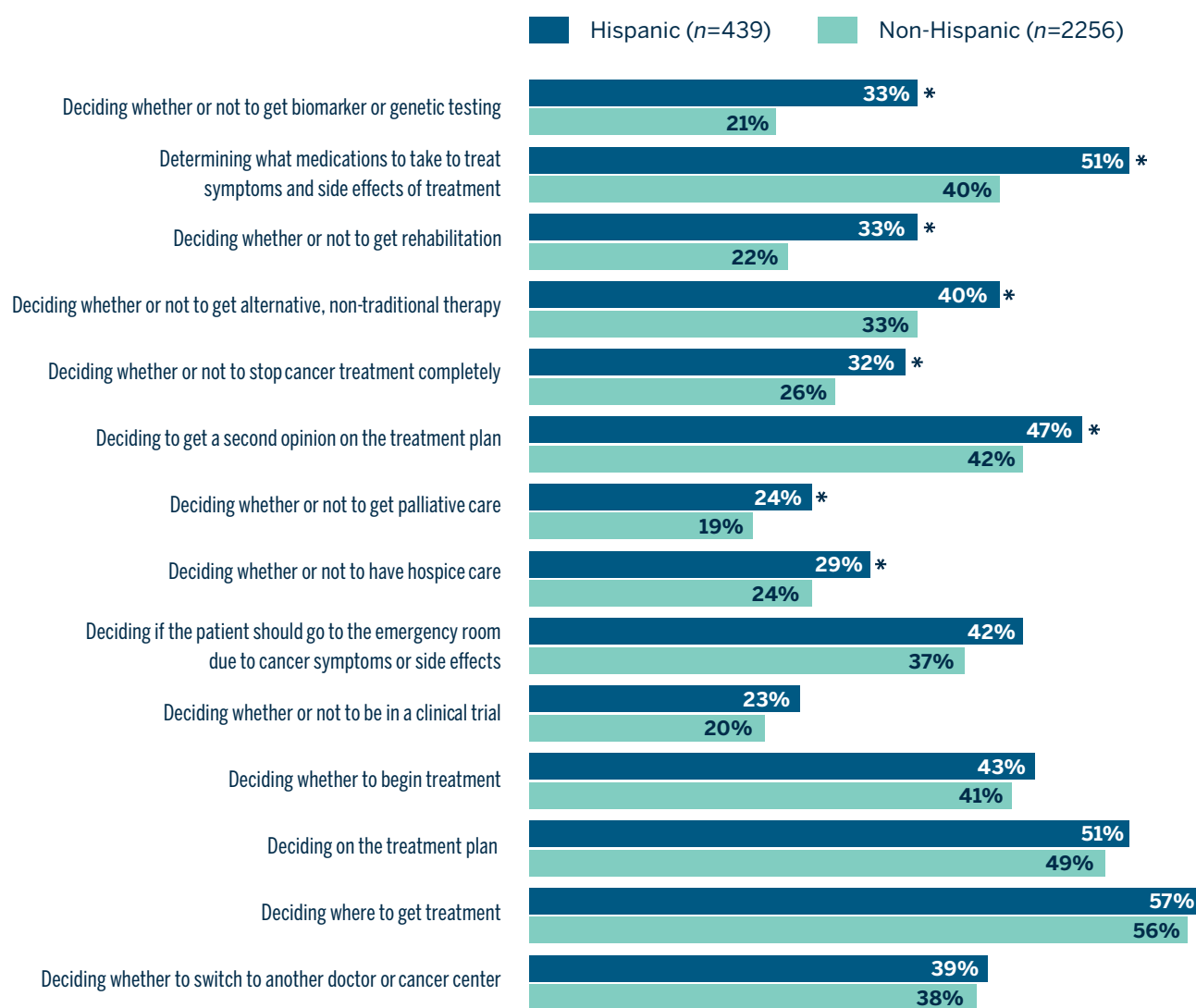
Involvement in treatment decision-making

Our survey data indicate Hispanic caregivers may play a larger role in treatment decision-making compared to non-Hispanic caregivers. Of the scenarios presented in the survey, Hispanic caregivers were significantly more likely to be involved in more than half of them (eight of 14). Hispanic caregivers averaged involvement in 5.4 decision-making

scenarios, compared to 4.7 for non-Hispanic caregivers. In particular, Hispanic caregivers in our sample were more involved in decisions that come later in the cancer care continuum: for example, they are more likely to help make decisions about palliative care, hospice care, and stopping treatment (i.e. later decisions) compared to non-Hispanic

caregivers. This may be related to their care recipients having more advanced cancer, as 42% of Hispanic caregivers' patients have stage 3 cancer compared to 37% for non-Hispanic caregivers. Hispanic caregivers were also significantly more likely to have served as Primary Decision-Makers (27% vs. 22%).

Involvement in treatment decisions—Hispanic vs. non-Hispanic caregivers



* Decision-making situations in which Hispanic respondents were significantly more likely to be involved



Other scholarship supports the idea that Hispanic caregivers tend to be closely involved in treatment decision-making. In one U.S. study, 52% of Hispanic caregivers of advanced cancer patients preferred shared decision-making.¹ A national survey of recently diagnosed cancer patients found that the majority of Spanish-speaking Hispanic patients equally shared decisions with their families (57%); English-speaking Hispanic patients reported equal sharing at the same rate as non-Hispanic white patients (both 48%). Researchers note that this involvement may reflect a reliance on family members to translate healthcare information and/or relate to cultural beliefs about family roles.² Indeed, much of the research on Hispanic caregivers examines cultural values and the concept of *familismo* or familism. *Familismo*

emphasizes devotion to and identification with one's family network, including a duty to provide reciprocal support and prioritize family needs over one's own.³ This means "a collective group orientation toward decision-making is adopted" and "all family may wish to be present during healthcare visits, especially given the unexpected nature and high stress of cancer prognoses and care." Non-Hispanic healthcare professionals, however, may misinterpret or fail to accommodate this level of involvement.⁴ Scholars point to the need for more culturally relevant healthcare resources to support Hispanic caregivers in the U.S. and amplify the call to "change current cancer care approaches from patient-focused to family-focused care."⁵



Needs and attitudes

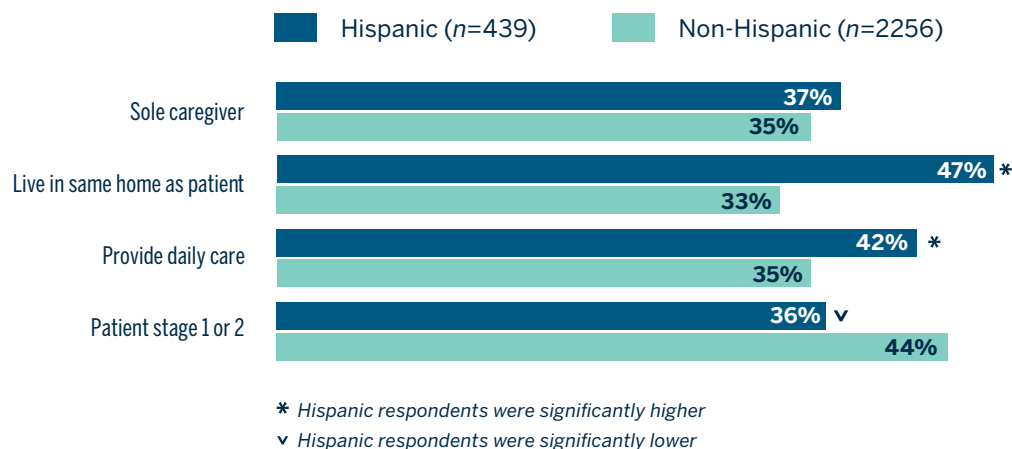
Hispanic caregivers in our study carry a heavy load. Although they are no more likely than their non-Hispanic counterparts to serve as sole caregivers (37% vs. 35%), they are more likely to have the patient live with them (47% vs. 33%), more likely to provide daily care (42% vs. 35%), and deliver more hours of care on average (38% vs. 25% providing 5-10+ hours of care). The patients they care for tend to have more advanced cancer, with significantly fewer in stage 1 or 2 (36% vs. 44%). All this while the Hispanic caregivers are also more likely to be working full time (74% vs. 66%).

Given the weight of these responsibilities, it's understandable that many Hispanic caregivers are significantly more stressed by the pressures of caring for a person with cancer and meeting other responsibilities (72% vs. 64%). Family dynamics apparently exacerbated the situation, as Hispanic caregivers indicated being significantly less satisfied with their family's support (82% vs. 87%), don't feel they get enough help from family (66% vs. 47%), and

are bothered that other family members have not shown an interest in providing care (65% vs. 51%). Compared to non-Hispanic caregivers, they're also significantly less likely to feel communication in the family has improved (81% vs. 86%). (Of note, a regression analysis of variables that might account for these differences, such as the higher rates of advanced cancer among patients cared for by Hispanic caregivers in this study, has not been done.)

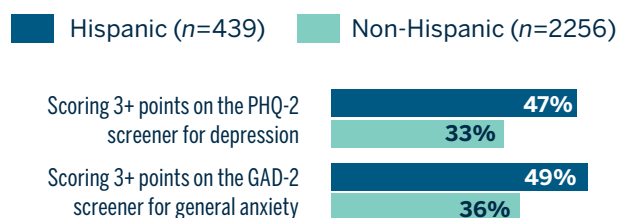
A positive perspective may help buoy the weight of care, but many Hispanic caregivers feel its life-defining burden. Hispanic caregivers are as likely as their non-Hispanic counterparts to agree that providing care imparts personal growth, newfound confidence, and a sense of purpose and usefulness. They are more likely, however, to also feel overwhelmed (77% vs. 67%) and trapped by the person's illness (60% vs. 47%), and that they've lost control of their life (49% vs. 36%) and their privacy and personal time (63% vs. 56%). They also have significantly higher scores that suggest the need for further evaluation for depression (47% vs. 33%) and general anxiety (49% vs. 36%).

Caregiver-patient factors—Hispanic vs. non-Hispanic caregivers

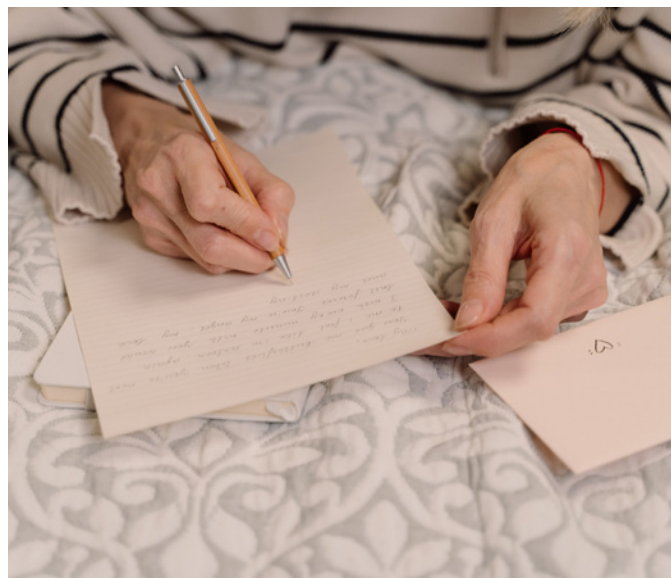


The survey's findings align with other research on Hispanic caregivers. The *Caregiving in the U.S. 2020* report finds that Hispanic adults make up 17% of family caregivers in the U.S. They tend to be younger (average age: 43) and take on greater care responsibilities than non-Hispanic white caregivers: 26 hours of care on average per week, with nearly half of Hispanic caregivers living with the person they care for (48%) and handling high-intensity care situations (49%). Often without help from other family or paid caregivers, 52% of Hispanic caregivers shoulder these responsibilities solo.⁶

Depression and general anxiety—Hispanic vs. non-Hispanic caregivers



Higher screener scores that suggest depression and general anxiety in this sample of Hispanic caregivers may be related to several factors. Hispanic communities have been deeply impacted by COVID-19 and rates of depression and distress have spiked among Hispanic adults during the pandemic,⁷ within the same timeframe that survey data was collected. The complex dynamics of *familismo* may also be involved: while some theorize that such beliefs mediate the stress of providing care,⁸ other studies have linked *familismo* to higher rates of Hispanic caregiver burden and depression.⁹ One study found that Hispanic caregivers who were less satisfied with their social networks were more likely to score higher for burden and depression.¹⁰ Another concluded that, “Although relatives provide affective support [for Hispanic caregivers], the burden of instrumental assistance rests on the primary caregiver.”¹¹ Interviews with Mexican American



caregivers add further nuance: a caregiver's ability to put the cancer patient's needs first while balancing other responsibilities—either “becoming stronger” or “hurting too much”—depends on whether other family members shift priorities as well (e.g., a spouse covering more childcare duties).¹²

Factors important to Hispanic respondents' decision-making

All caregivers in the survey sample shared details about their involvement in one specific decision-making situation, including the factors they considered important to making that decision. Looking at aggregate data across all decision-making situations, Hispanic caregivers and non-Hispanic caregivers had different perspectives on which factors were “Very important.” For all comparisons, the first figure given is for Hispanic caregivers and the second is for non-Hispanic caregivers (i.e. X% vs. Y%). All differences are at a 95% confidence level. (Factors not discussed did not show significant differences between groups.)

Patient's well-being

While both groups prioritized the patient's well-being, Hispanic caregivers did so to a lesser degree. They gave significantly less weight to **the patient's quality of life** (60% vs. 69%), **the patient's physical well-being** (59% vs. 69%), **the patient's emotional well-being** (38% vs. 56%), and **how long the patient is likely to live** (54% vs. 65%).

Expert opinions

The **opinions of the patient's oncologist and health-care team** were of high importance to Hispanic caregivers, though less so than non-Hispanic caregivers (49% vs. 57%). When rating the helpfulness of various support programs in the context of future decision-making, Hispanic caregivers also scored a free consultation with an oncology doctor significantly lower (62% vs. 70%). Why is unclear, but this may be related to experiences of bias from healthcare professionals, health literacy and/or other decision-making barriers reported by Hispanic caregivers (discussed below).

Personal relationships

Hispanic and non-Hispanic caregivers placed near-equal importance on the **opinions of other family members and/or friends**. Yet in the information Hispanic caregivers shared about who else was involved in the decision-making group, other family and close friends were significantly less likely to be mentioned compared to non-Hispanic caregivers (31% vs. 38%). This may relate to the higher portion of Hispanic caregivers who served as Primary Decision Makers.

Maintaining "normal life"

Compared to non-Hispanic caregivers, Hispanic caregivers place more importance on several factors related to maintaining "normal life." These included **the patient being able to attend special events** (38% vs. 30%), **the patient's ability to keep working** (36% vs. 29%), and **the patient's ability to take care of others** (34% vs. 27%). This again may be related to the value many Hispanic caregivers place on *familismo*

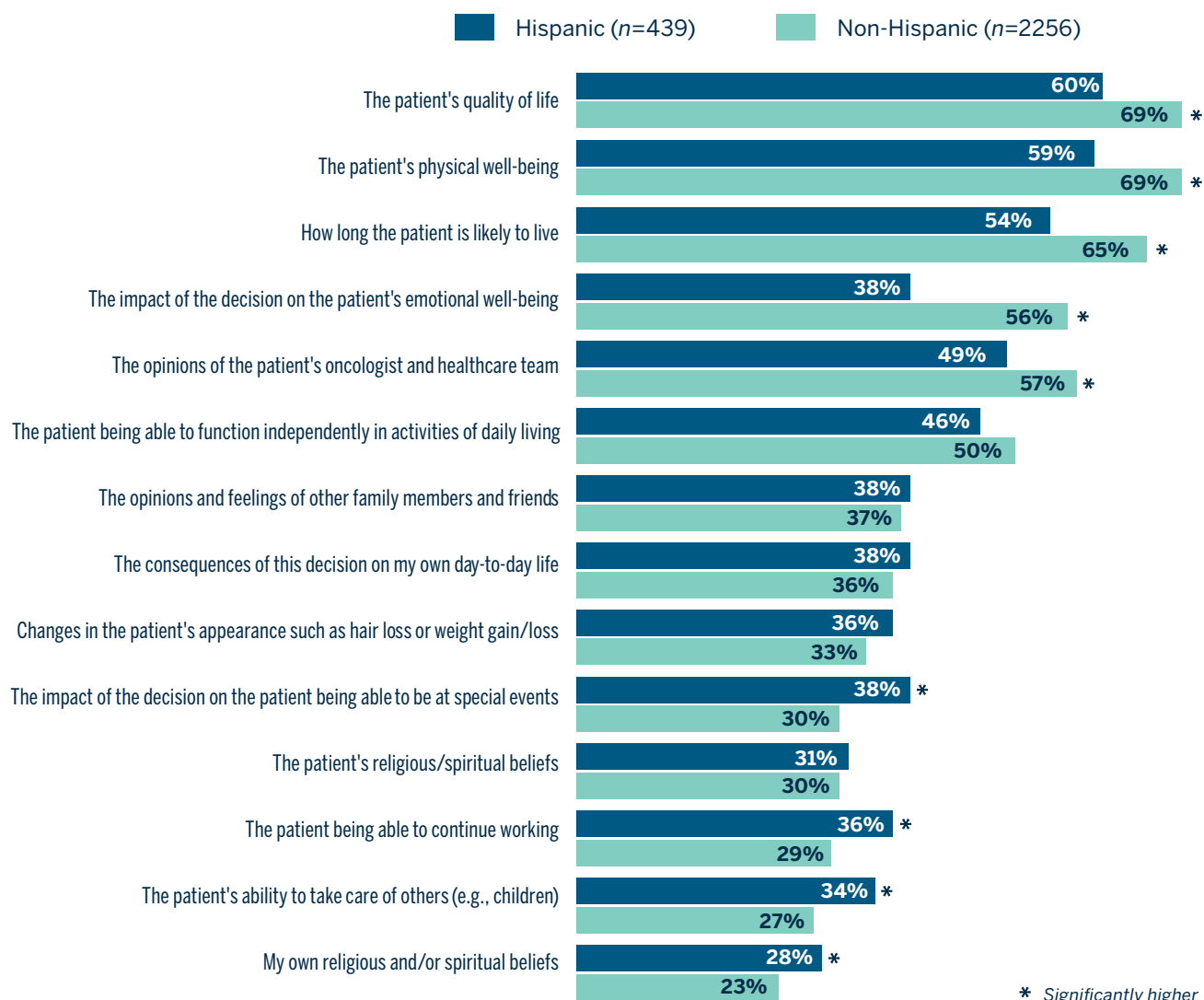


and networks of reciprocal care—for instance, grandparents helping to care for grandchildren and adult children providing support for their parents and older relatives.¹³ Hispanic and non-Hispanic caregivers alike placed the patient’s needs ahead of consequences to their own daily life.

Religious/spiritual beliefs

Compared to non-Hispanic caregivers, Hispanic caregivers were more likely to place importance on **their own religious and/or spiritual beliefs** (28% vs. 23%), a finding in keeping with studies that note the significance of religious beliefs in shaping many Hispanic caregivers’ perspectives

Factors considered “very important” to decision-making—Hispanic vs. non-Hispanic caregivers



on providing care. Albeit at low levels, Hispanic caregivers were more likely to involve faith or spiritual counselors in decision-making (13% vs. 9%) and significantly more likely to feel they received less support from the healthcare team due to bias toward their or the patient's religious beliefs (11% vs. 8%).

Decision-making barriers encountered by Hispanic respondents

Hispanic caregivers faced numerous barriers in making treatment decisions. Nearly a third reported they “did not have enough information to make the decision,” compared to 18% of non-Hispanic caregivers. Hispanic caregivers were also significantly more likely to say that the information they found or received was not helpful (36% vs. 21%). Both groups used similar sources of information in decision-making; Hispanic caregivers, however, were more likely to use social media (20% vs. 15%).

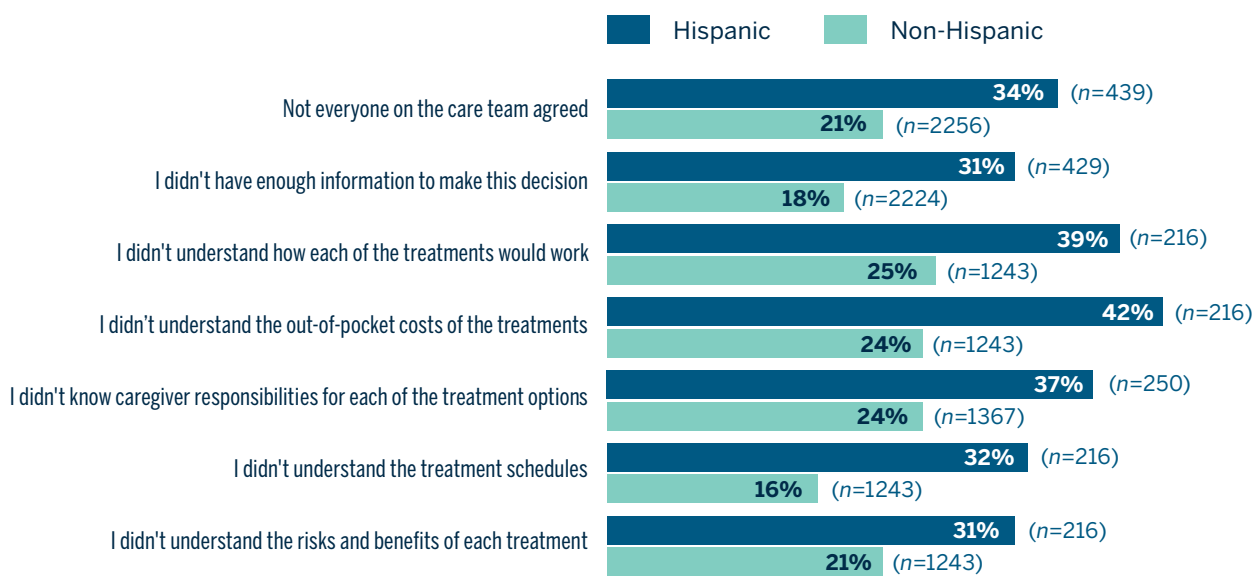
Hispanic caregivers were more likely than non-Hispanic caregivers to report decision-making challenges due to limited knowledge or understanding of treatment and testing options. This included feeling that they “didn’t understand how each of the treatments would work” (39% vs. 25%) and “didn’t understand the risks and benefits of each treatment” (31% vs. 21%). Many were also uncertain as to how treatments or testing would be implemented, with Hispanic caregivers more likely to say they “didn’t know the caregiver’s responsibilities for each of the treatment options” (37% vs. 24%), “didn’t understand the treatment schedule” (32% vs. 16%) and lacked information about out-of-pocket costs for treatments (42% vs. 24%).

Amplifying the stress of decision-making, Hispanic caregivers were more likely to experience situations where “not everyone on the care team agreed” (34% vs. 21%). These conflicting views may have influenced how they perceived the decision that was ultimately made. Hispanic caregivers were more likely than non-Hispanic caregivers to express regret about the choice (26% vs. 17%) and worry that it was harmful to the patient (30% vs. 17%).



Decision-making challenges—Hispanic vs. non-Hispanic respondents

Aggregate data from relevant decision-making situations; all differences statistically significant at 95%



In Hispanic caregivers' recollections of past treatment decisions, we see a troubling lack of resources and support, including from the healthcare team. Compared to non-Hispanic caregivers, they were significantly more likely to report that bias from the patient's doctor or healthcare team negatively impacted the decision-making support provided. Hispanic caregivers reported bias related to multiple factors, including their or the patient's race, health or disability, language, education level, gender/sex, sexual orientation, and religion; they were significantly more likely to perceive bias on all factors included on the survey except for age, body weight, and household income.¹⁴

It is well documented that many Hispanic patients and caregivers encounter a lack of cultural responsiveness from non-Hispanic healthcare professionals.¹⁵ For Hispanic patients with limited English proficiency, professional translators and Spanish-language materials in healthcare settings are rarely available, unreliable, or overly technical; family members often get pressed into service as ad hoc translators.¹⁶ Compared to non-Hispanic white, African American, or Asian American caregivers, Hispanic caregivers report having less access to information and resources that support care.¹⁷ Culturally relevant resources for treatment decision-making are unfortunately no exception.

Case study: A young Hispanic caregiver-turned-translator carries a heavy burden

At 19 years old, Sara* has become the de facto translator and constant companion for her mother, Elena, a 45-year-old metastatic breast cancer patient whose first language is Spanish. Sara lives at home with Elena and two adolescent siblings.

Elena initially requested a professional translator for appointments, but she never received one. By default, Sara became the conduit for all communication between her mother and the medical team. Sara attends every healthcare appointment and spends her time being a caregiver to Elena; she is not currently in school or working.



As her mother’s “voice” in treatment decisions with the medical team, Sara serves as an Observer/Supporter and as a Primary Decision Maker. She does her best to provide her mother with a summary of the discussions; Elena admits, however, that she is unclear how treatment decisions are made and reports that the medical team chose the treatment plan.

Along with translating her mother’s concerns and questions, Sara must listen to, understand, and translate for her mother all the medical and scientific information related to a metastatic breast cancer diagnosis. Sara does not have any medical training, and it is possible that she misses important information or nuances in instructions. Beyond being technically challenging, the information carries devastating weight. Through Sara, Elena has learned she has an aggressive cancer that has spread to her bones, lungs, and brain. Sara has had to repeatedly break the news that the latest treatment protocol has not worked and explain to her mother what might come next.

Without a professional translator, Sara must carry life-and-death messages between the medical team and a stage 4 cancer patient—a patient who is the teenager’s mother and only available parent. As Elena’s oncology social worker points out, “The level of responsibility put on the shoulders of this young adult is inappropriate.”

**Caregiver and patient names have been changed.*



References for Section 7: Hispanic caregivers & treatment decision-making

- 1 Yennurajalingam, Sriram, et al. "A Multicenter Survey of Hispanic Caregiver Preferences for Patient Decision Control in the United States and Latin America." *Palliative Medicine*, vol. 27, no. 7, 2013. *SAGE Journals* DOI: 10.1177/0269216313486953.
- 2 Hobbs, Gabriela S., et al. "The Role of Families in Decisions Regarding Cancer Treatments." *Cancer*, vol. 121, no. 7, 2015, pp. 1079-1087. *ACS Journals*, DOI: 10.1002/cncr.29064.
- 3 See: Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.; Floríndez, Lucía I., et al. "Differing Interpretations of Health Care Encounters: A Qualitative Study of Non-Latinx Health Care Providers' Perceptions of Latinx Patient Behaviors." *PLoS ONE*, vol. 15, no. 8, 2020. *PLoS ONE*. DOI: 10.1371/journal.pone.0236706.; Miyawaki, Christina E. "Caregiving Practice Patterns of Asian, Hispanic, and Non-Hispanic White American Family Caregivers of Older Adults Across Generations." *Journal of Cross-Cultural Gerontology*, vol. 31, 2016, pp. 35-55. *SpringerLink*. DOI: 10.1007/s10823-016-9281-5.; Wells, Jo Nell, et al. "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger." *Journal of Transcultural Nursing*, vol. 19, no. 3, 2008, pp. 223-233. *SAGE Journals*, DOI: 10.1177/1043659608317096.; Losada, Andres, et al. "Cross-cultural Study Comparing the Association of Familism with Burden and Depressive Symptoms in Two Samples of Hispanic Dementia Caregivers." *Aging and Mental Health*, vol. 10, no. 1, 2006, pp. 69-76. *Taylor & Francis Online*. DOI:10.1080/13607860500307647.; Cox, Carole and Abraham Monk. "Hispanic Culture and Family Care of Alzheimer's Patients." *Health & Social Work*, vol. 18, no. 2, May 1993, pp. 92-100. *Oxford Academic*. DOI: 10.1093/hsw/18.2.92.
- 4 Floríndez, Lucía I., et al. "Differing Interpretations of Health Care Encounters: A Qualitative Study of Non-Latinx Health Care Providers' Perceptions of Latinx Patient Behaviors." *PLoS ONE*, vol. 15, no. 8, 2020. *PLoS ONE*. DOI: 10.1371/journal.pone.0236706.
- 5 Wells, Jo Nell, et al. "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger." *Journal of Transcultural Nursing*, vol. 19, no. 3, 2008, pp. 223-233. *SAGE Journals*, DOI: 10.1177/1043659608317096.
- 6 See: National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>. Accessed March 5, 2022.; Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.
- 7 McGinty, Emma E., et al. "Psychological Distress and Loneliness Reported by US Adults in 2018 and April 2020." *JAMA*, vol. 324, no. 1, July 2020, pp. 93-94. *JAMA Network*. DOI:10.1001/jama.2020.9740.
- 8 See: Falzarano, Francesca, et al. "Family Matters: Cross-Cultural Differences in Familism and Caregiving Outcomes." *The Journals of Gerontology: Series B*, September 2021. *Oxford Academic*. DOI: 10.1093/geronb/gbab160.; Losada, Andres, et al. "Cross-cultural Study Comparing the Association of Familism with Burden and Depressive Symptoms in Two Samples of Hispanic Dementia Caregivers." *Aging and Mental Health*, vol. 10, no. 1, 2006, pp. 69-76. *Taylor & Francis Online*. DOI:10.1080/13607860500307647.; Cox, Carole and Abraham Monk. "Hispanic Culture and Family Care of Alzheimer's Patients." *Health & Social Work*, vol. 18, no. 2, May 1993, pp. 92-100. *Oxford Academic*. DOI: 10.1093/hsw/18.2.92.
- 9 See: Cox, Carole and Abraham Monk. "Hispanic Culture and Family Care of Alzheimer's Patients." *Health & Social Work*, vol. 18, no. 2, May 1993, pp. 92-100. *Oxford Academic*. DOI: 10.1093/hsw/18.2.92.; Luchsinger, José A., et al. "Characteristics and Mental Health of Hispanic Dementia Caregivers in New York City." *American Journal of Alzheimer's Disease & Other Dementias*, vol. 30, no. 6, 2015, pp. 584-590. *SAGE Journals*. DOI:10.1177/1533317514568340.; Losada, Andres, et al. "Cross-cultural Study Comparing the Association of Familism with Burden and Depressive Symptoms in Two Samples of Hispanic Dementia Caregivers." *Aging and Mental Health*, vol. 10, no. 1, 2006, pp. 69-76. *Taylor & Francis Online*. DOI: 10.1080/13607860500307647.
- 10 Luchsinger, José A., et al. "Characteristics and Mental Health of Hispanic Dementia Caregivers in New York City." *American Journal of Alzheimer's Disease & Other Dementias*, vol. 30, no. 6, 2015, pp. 584-590. *SAGE Journals*. DOI:10.1177/1533317514568340.



References for Section 7: Hispanic caregivers & treatment decision-making

- 11** Cox, Carole and Abraham Monk. "Hispanic Culture and Family Care of Alzheimer's Patients." *Health & Social Work*, vol. 18, no. 2, May 1993, pp. 92-100. *Oxford Academic*. DOI: 10.1093/hsw/18.2.92.
- 12** Wells, Jo Nell, et al. "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger." *Journal of Transcultural Nursing*, vol. 19, no. 3, 2008, pp. 223-233. *SAGE Journals*. DOI: 10.1177/1043659608317096.
- 13** Karlin, Nancy J., et al. "Comparisons Between Hispanic and Non-Hispanic White Informal Caregivers." *SAGE Open*, Oct-Dec 2012, pp. 1-10. *SAGE Journals*. DOI: 10.1177/2158244012470108.
- 14** Dionne-Odom, J. Nicholas, et al. "Bias Reported by Family Caregivers in Support Received When Assisting Patients With Cancer-related Decision-making." Submitted to *The Journal of Clinical Oncology*, March 26, 2022.
- 15** See: Floríndez, Lucía I., et al. "Differing Interpretations of Health Care Encounters: A Qualitative Study of Non-Latinx Health Care Providers' Perceptions of Latinx Patient Behaviors." *PLoS ONE*, vol. 15, no. 8, 2020. *PLoS ONE*. DOI: 10.1371/journal.pone.0236706.; Niranjana, Soumya J., et al. "Bias and Stereotyping Among Research and Clinical Professionals: Perspectives on Minority Recruitment for Oncology Clinical Trials." *Cancer*, vol. 126, no. 9, 2020, pp. 1958-1968. *ACS Journals*. DOI: 10.1002/cncr.32755.
- 16** See: Riera, Antonio, et al. "Latino Caregiver Experiences With Asthma Health Communication." *Qualitative Health Research*. September 2014. *SAGE Journals*. DOI: 10.1177/1049732314549474.; Zamora, Eduardo R., et al. "The Impact of Language Barriers and Immigration Status on the Care Experience for Spanish-speaking Caregivers of Patients with Pediatric Cancer." *Pediatric Blood & Cancer*, vol. 63, no. 12, 2016, pp. 2173-2180. *Wiley Online Library*. DOI: 10.1002/pbc.26150.; Floríndez, Lucía I., et al. "Differing Interpretations of Health Care Encounters: A Qualitative Study of Non-Latinx Health Care Providers' Perceptions of Latinx Patient Behaviors." *PLoS ONE*, vol. 15, no. 8, 2020. *PLoS ONE*. DOI: 10.1371/journal.pone.0236706.
- 17** Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.

Ways to Improve Support for Caregiver Decision-Making

To better understand what resources might best support caregivers in assisting with cancer-related decisions, the survey presented a list of possible services and asked caregivers to rate how helpful or unhelpful each would be to them. Services selected for the survey included patient-focused options (e.g. an online group of patients with the same health conditions as my friend/family member), caregiver-focused options (e.g. role playing how to share cancer treatment decision-making) and combination patient-/caregiver-focused options (e.g. free consultation with an oncology social worker). Three of these services specifically addressed treatment decision-making, while others related more broadly to cancer care.

Perceived helpfulness of services

The survey's service options received positive scores from caregivers overall. Seven of the nine were scored as "Very helpful" to decision-making by at least half of respondents. When we look at combined scores ("Very helpful" + "A little helpful"), more than 75% of caregivers found each

of the nine options helpful, with several services exceeding 90%. Some significant differences in perceived helpfulness of services occurred among psychosocial segments and Hispanic vs. non-Hispanic caregivers.

Two-thirds of caregivers indicated a **free consultation with an oncology doctor** would be very helpful (68%). This likely speaks to caregivers' significant information needs concerning their patient's cancer diagnosis and treatment options, also evident in respondents' "Very helpful" rating for **educational materials about cancer from a trusted source** (66%). Wanting a free oncology consultation may also hint at frustrations regarding access to doctors—long waits, divided attention, feeling rushed—which unfortunately are common themes in caregiver interviews.¹ The reality is that caregivers don't often have confidential, independent access to the clinical team to voice their questions, concerns, and fears. Respondents were interested as well in time with other cancer care professionals to support decision-making, awarding a "Very helpful" rating to a **free consultation with an oncology nurse** (59%) or **with an oncology social worker** (58%).

"Very helpful" services for decision-making

n=2703



Caregivers rated opportunities for peer support and guidance below the professional cancer consults. Roughly half indicated an **online group of patients with the same health conditions as their care recipient** (52%) and an **online group of caregivers in similar situations** (51%) would be very helpful.

Services specifically focused on treatment decision-making scored lowest, but were still considered very helpful by nearly half of caregivers surveyed. These included **videos about treatment decision-making** (50%), **worksheets that help guide decision-making** (48%), and **role playing how to share cancer treatment decision-making** (44%). Similar resources that have been tested with patients, caregivers, and clinicians are discussed below.

Differences in perceived helpfulness of services among psychosocial segments

Looking at caregivers according to the psychosocial segments discussed in Section 6, variations in perceived helpfulness emerge. Most notably, those in Segment 3 (High needs for self-care + Low support) ranked caregiver-focused services as more helpful than patient-focused ones. In contrast, caregivers overall and in all other segments gave top ranking to patient- and caregiver-/patient-focused options.





Segment 1: Low needs + Moderate support (22% of caregiver respondents)

Segment 1 caregivers responded positively to all the services, with each option considered “Very helpful” by more than half to three-quarters of the segment. They scored every service significantly higher than caregivers not in Segment 1, except the **free consultation with an oncology nurse**, which they only scored significantly higher than Segment 3 (61% vs. 51%). Segment 1’s highest-rated services focus on better understanding cancer, including **educational materials about cancer from a trusted source** (76%) and a **free consultation with an oncology doctor** (75%).

Segment 2: Moderate needs + Low support (25% of caregiver respondents)

Like Segment 1, the majority of Segment 2 caregivers indicated that **educational materials from a trusted source** would be very helpful (83%), followed closely by a **free consultation with an oncology doctor** (79%). Compared to caregivers not in Segment 2, they gave significantly lower scores to almost all the caregiver-focused services, including an **online group of caregivers** (41% vs. 55%), **worksheets that help guide decision-making** (43% vs. 50%), and **role playing how to share cancer treatment decision-making** (35% vs. 48%). As the caregivers who were less likely to feel overwhelmed, out of control, depressed, or anxious, they may have more personal bandwidth for decision-making and perceive less need for caregiver-focused services.

Segment 3: High needs for self-care + Low support (37% of caregiver respondents)

A desire for personal support comes through in Segment 3’s scores. Services specific to caregiver needs were seen as most helpful, with scores significantly higher than caregivers not in Segment 3. These included **worksheets that help guide decision-making** (54% vs. 45%), an **online group**

for caregivers (54% vs. 50%), **videos about treatment decision-making** (54% vs. 49%), and **role playing how to share cancer treatment decision-making** (54% vs. 39%). Conversely, Segment 3’s “Very helpful” scores were significantly lower for **educational materials about cancer** (53% vs. 73%), a **free consultation with an oncology doctor** (52% vs. 78%), an **oncology nurse** (51% vs. 63%), and an **oncology social worker** (53% vs. 61%).

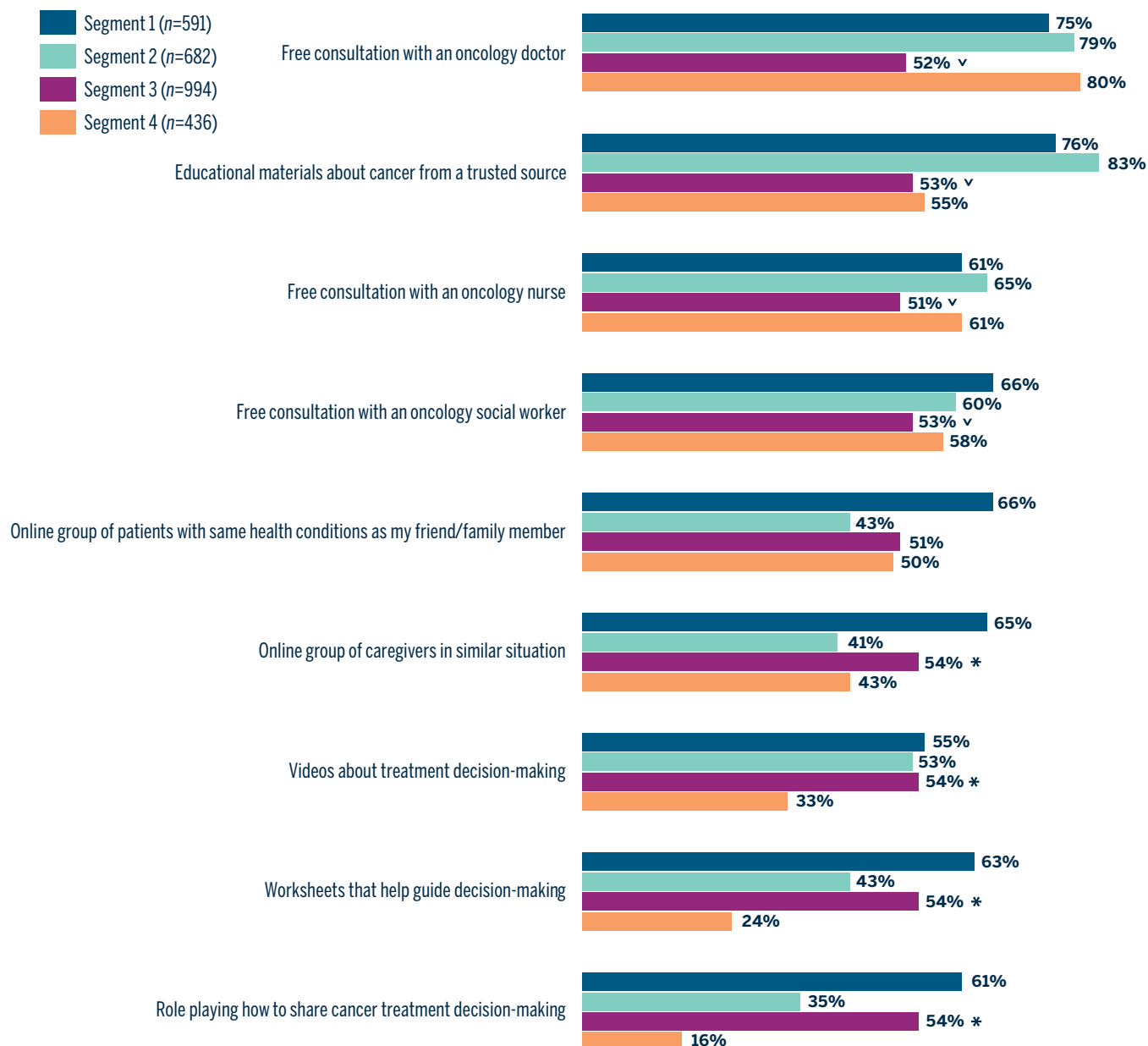
Although all the services were “Very helpful” to roughly half of Segment 3, scores were low overall and clustered in a narrow range from 54% to 51%. In contrast, Segment 1’s lowest score is actually higher than Segment 3’s top score for helpfulness.

Segment 4: High needs for patient care + Low support (16% of caregiver respondents)

Segment 4 caregivers seek expert guidance to address their patient’s needs. Their top three selections all offer contact with oncology professionals: a **free consultation with an oncology doctor** (80%), an **oncology nurse** (61%), and an **oncology social worker** (58%). Compared to caregivers not in Segment 4, they were significantly less likely to say **educational materials about cancer** would be very helpful (55% vs. 68%). Segment 4 also gave significantly lower scores to all of the caregiver-focused services, including an **online group for caregivers** (43% vs. 53%), **videos about treatment decision-making** (33% vs. 54%), **worksheets to guide decision-making** (24% vs. 53%), and **role playing how to share treatment decision-making** (16% vs. 50%).

Segment 4’s patient-focused, healthcare-oriented choices align with the practical challenges they face supporting older patients with advanced cancer. The lower scores for caregiver- and decision-making support raise some questions, however. Segment 4 caregivers expressed significant distress, anxiety, and lower self-confidence, and would no doubt benefit from services that offer more guidance and support.

Services perceived as “very helpful” for future decision-making by psychosocial segments



* Significantly higher than caregivers not in Segment 3

v Significantly lower than caregivers not in Segment 3

Hispanic caregivers' perceived helpfulness of services

Hispanic caregivers gave significantly lower scores to the top two services selected by their non-Hispanic counterparts: **a free consultation with an oncology doctor** (62% vs. 70%) and **educational materials from a trusted source** (60% vs. 67%). This might be related to their past experiences in the healthcare system. Compared to non-Hispanic caregivers in this survey, they rated the information they received as less helpful, encountered more decision-making barriers, and were more likely to report incidents of bias by healthcare professionals.



Services that best support caregivers in cancer treatment decision-making

While organizations like CancerCare offer many of the services presented in the survey, reaching caregivers in need is a challenge; only 16% of caregivers surveyed reported seeking help or information from non-profit organizations when making cancer-related decisions. Below is an overview of current CancerCare services that support cancer treatment decision-making, along with some areas it seeks to enhance or develop based on the findings of this survey. Hopefully, this report will encourage more organizations, medical associations, and healthcare systems to develop programs and materials with a similar aim to support patients and caregivers.

Free consultations with cancer care professionals

CancerCare provides free counseling in English or Spanish with licensed oncology social workers for patients and caregivers. This includes building skills to improve communication with the medical team and family members, as well as strategies to enhance coping skills and reduce anxiety and distress. These social workers provide practical information about cancer treatment, such as navigating through the process, managing expenses, and other challenges faced by patients and caregivers. To get started, caregivers can contact CancerCare's Hopeline (1-800-813-HOPE) or email info@cancercare.org.

CancerCare's live Connect Education Workshops offer caregivers and patients opportunities to learn from doctors, nurses, and other oncology experts. Each hour-long, over-the-phone or online program includes time for participants to submit questions to and get answers from the panel of experts. Past workshops tailored to caregivers have addressed specific cancer diagnoses, participation in decision-making,

and coordination of care; others have examined treatment options (such as clinical trials), treatment planning, and communication with the clinical team. In addition to the live events, all workshops are available as podcasts. Future workshops will include more opportunities for caregivers to consult with oncology experts.

Beyond CancerCare, free consultations with oncology doctors and nurses may be available through medical centers, health systems, and medical societies and associations. Without delving into prescriptive advice, clinical experts can explain cancer types and treatment options and direct caregivers to other vetted resources.

Educational materials about cancer

CancerCare's growing online library includes booklets, fact sheets, videos, and podcasts on cancer-related topics. As the survey results showed, caregivers often need information and do not always understand the materials they have been given by the healthcare team. CancerCare publications are developed with health literacy in mind, so they are relatively simple to read without sacrificing accuracy. This emphasis on accessible information extends to the CancerCare website, which can be read in English and Spanish, as can many of the publications. In addition, the website offers Recite Me, an accessibility assistive toolbar solution that allows website visitors to customize a site in ways that work best for them. With one click, the Recite Me toolbar provides text-to-speech functionality, fully customizable styling features, reading support aids, and a translation tool with over 100 languages, including 35 text-to-speech voices and many other features.²

Support groups for caregivers and people with cancer

CancerCare's oncology social workers host support groups for patients, caregivers, and those grieving a cancer-related loss. Groups aligned by shared experiences and concerns—such as “Caregivers for young adults” or “Ovarian Cancer Patients”—meet online or face to face for weekly,

multi-month sessions. Members-only online message boards can be accessed at any time, providing greater flexibility and removing barriers to participation for caregivers already juggling work and care responsibilities.

While the survey did not ask respondents about language preferences, expanding Spanish-language support groups provides Hispanic caregivers more opportunities to connect. Currently, CancerCare coordinates a four-month Spanish-language workshop for patients and caregivers that focuses on resiliency and communication.

Worksheets, videos, and role playing about cancer treatment decision-making

Based on these survey results, CancerCare hopes to produce and make available new materials related to shared decision-making. The website currently includes a few printable worksheets with recommended questions to ask the healthcare team. Additional worksheets, such as decision-making aids (discussed below), could be produced in both English and Spanish. New videos could cover different aspects of treatment decision-making, including sample conversations among clinicians, caregivers, and patients that model effective communication techniques, approaches to challenging topics, and conflict resolution.



Other ways to support caregivers in cancer treatment decision-making

Based on survey findings, CancerCare has identified several opportunities to better support and engage caregivers in treatment decision-making. Examples of existing tools, programs, and initiatives are briefly discussed.

Improve communication with the clinical cancer care team

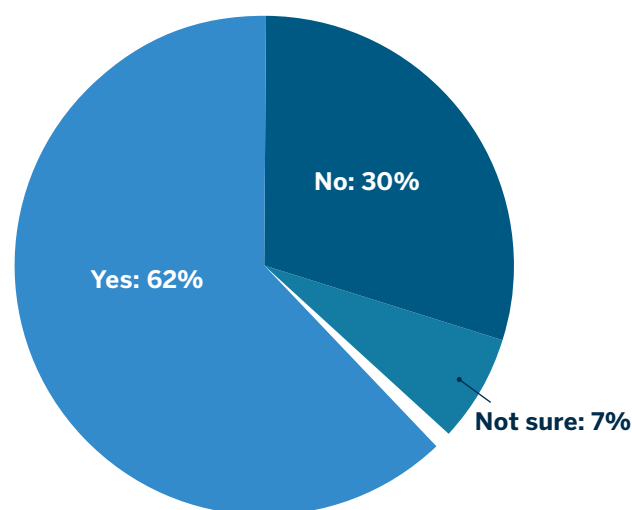
Clear communication with the clinical cancer care team is essential to informed treatment decision-making. The majority of caregivers in this survey relied on communication with the patient's clinical team and the education materials they provided to inform decisions. Yet nearly a third of caregivers reported they had not been asked by a doctor, nurse, or social worker about what they needed to help share in making decisions. The *Caregiving in the U.S. 2020* report revealed a similar disconnect, with only 29% of caregivers surveyed reporting being asked by a healthcare professional about their caregiving needs.³

Caregivers in our survey also reported concerning information gaps regarding treatment options, their potential impact on the patient, and what to expect during treatment, in addition to disagreements among the care team regarding doctors' recommendations. Other studies have found that perceptions of communication differ greatly among clinicians and their patients and caregivers, with healthcare professionals underestimating information needs and overestimating comprehension.⁴

One way to improve communication among clinicians, caregivers, and patients is the active use of patient portals (also called information technology platforms and interactive health communication systems/IHCS). As a hub for all information, portals have the potential to support more timely communication, reduce ambiguity about what has been shared, and ease pressure on patients and caregivers to recall or record information in the moment during appointments. Patient portals can be expanded in numerous ways to include further resources and support specifically for caregivers. One example is CHESS, the Comprehensive Health Enhancement Support System, which brings together communication tools, cancer and caregiving information, and coaching services to build positive communication techniques, manage emotional distress, and support decision-making.⁵

Clinician inquiry regarding caregiver's needs in shared decision-making

n=2703



Results do not total 100% due to rounding



Studies find that caregivers give patient portals and similar information platforms positive scores for usability⁶ and that technology-mediated interventions, including portals, may improve cancer caregivers' knowledge, confidence, satisfaction, burden, emotional well-being, and quality of life.⁷ For patient portals to be truly successful, however, the clinical care team must actively participate with timely notes, responses to questions and concerns, health-literate education materials, and links to vetted information sources. In addition, the portal must be easy to read and navigate regardless of device and screen size.

Critically important in this context are the implications of the digital divide and health literacy levels. "Patients with low cognitive functioning and/or low health literacy skills could have difficulty in understanding [information regarding] clinical results, leading to heightened anxiety and confusion when the appropriate medical interpretation is not available."⁸ Digital communication between

clinicians and patients/caregivers must be culturally appropriate, user friendly, and supported by a "help desk" that is responsive to questions and can appropriately triage any confusion and concerns.

Improving communication with caregivers also requires clinical organizations to update patient forms to include caregivers' names, use their scheduling systems to invite caregivers to attend appointments, create space for them in consultation rooms (or teleconference equipment for remote participation), and ensure policies define the word "family" to include friends, neighbors, and other "chosen family" that serve as caregivers.⁹ Legislation such as the Caregiver Advise, Record, and Enable (CARE) Act¹⁰ and the RAISE Family Caregivers Act¹¹ can make it easier for patients, caregivers, and providers to designate caregivers, share healthcare information, and address the care needs of patients and caregivers in tandem.

Proactive communication about the impact of treatment and patients' quality-of-life priorities

As noted in Sections 4 and 5, the factors that caregivers consider most important to treatment decision-making are too often the same areas where they lack information and understanding—particularly when it comes to patients' well-being. This tension between what they value and what they don't know seems to have been especially challenging for caregivers in this survey who were involved in making decisions about medications for symptoms/side effects and decisions about whether to end treatment.

Past research by CancerCare and others indicate that challenges related to limited information about side-effect management actually start during treatment plan

decision-making. Patients and caregivers value having information on side effects and other quality-of-life issues associated with different treatment options.¹² When this information is not fully communicated by clinicians and/or understood by caregivers, treatment decision-making is more difficult. In one survey, 35% of cancer patients ages 25 to 44 felt “very” or “somewhat dissatisfied” with how well their clinical care team prepared them for symptoms and side effects.¹³ Focusing solely on efficacy and extending life, without addressing trade-offs for quality of life, may not align with a patient's values. Healthcare professionals should explain treatment risks and benefits in a way that is health literate and understandable for patients and caregivers, since technical explanations involving probability and clinical uncertainty can make it difficult to fully share in decision-making with the clinical team.¹⁴

Open communication about prognosis, illness progression, and potential for control or cure is also crucial to inform treatment decisions, including whether to stop treatment. Value assessment surveys find that many people with advanced cancer believe it's “very valuable” to be told by their doctor if they're dying.¹⁵ Yet research has found that cancer clinicians often “consciously overestimate” survival, if they share prognosis at all,¹⁶ and delay addressing end-of-life care until treatment options run out or symptoms advance.¹⁷ This can lead to patients receiving aggressive treatment at end of life, despite its negligible benefit and devastating impact on quality of life. In contrast, frankly discussing prognosis earlier allows for treatment decisions that consider patients' quality-of-life priorities. Studies show that conversations about prognosis and treatment options are associated with greater patient well-being; less depression, stress, and regret among caregivers; and increased use of hospice care and lower incidents of unwanted aggressive treatments in the final weeks of life.¹⁸



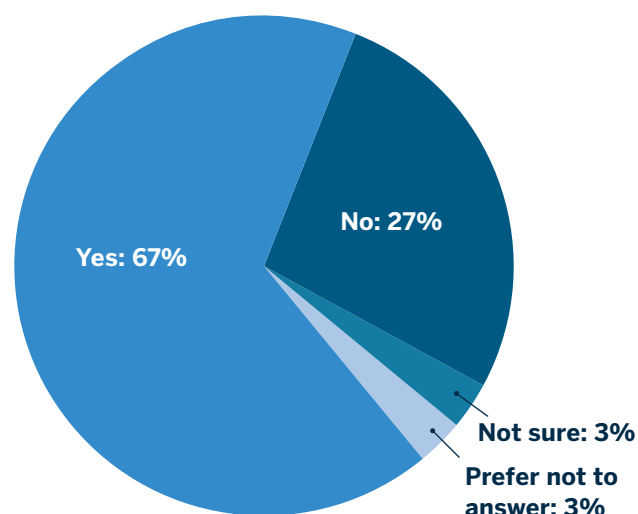
Often it falls to caregivers to ensure patients' quality-of-life values are heard and respected regarding the late-stage care they receive. Researchers note that "effective communication is probably the most important contributing factor in the prevention of end-of-life conflicts."¹⁹ Still, just over a quarter (27%) of caregivers in our survey had not discussed any particular wishes the patient has about the care they would want to receive if they were dying.

There are numerous resources available to help caregivers and patients navigate these difficult conversations. *The Conversation Project*, developed by the Institute for Healthcare Improvement, provides workbooks, guides, videos, recommended talking points for engaging healthcare providers, and other resources to help patients deliberate, communicate, and document end-of-life wishes.²⁰ Patients can formalize these decisions with an Advance Directive, which includes designating a caregiver to be their healthcare proxy. The American Bar Association's Commission on Law and Aging offers guidance on taking this legal step and on serving as a healthcare proxy.²¹ Many states now use Portable Orders for Life-Sustaining Treatment (POLST) forms to include end-of-life wishes in patients' medical records.

Clinicians can also make use of end-of-life conversation frameworks, such as the Family Conference model and the mnemonic device "VALUE": **V**alue and appreciate what family members say; **A**cknowledge the family's emotions; **L**isten; **U**nderstand the patient as a person; and **E**licit questions from the family members.²² The "My Choices, My Wishes" Advance Care Planning program and Values Assessment tool is offered at numerous cancer centers in the US Oncology Network.²³

Caregiver/patient discussion regarding care if dying

n=2703



Incorporate shared decision-making tools for caregivers, patients, and clinicians

Scholars note that as cancer treatment options and delivery methods multiply, decision-making difficulties will likely grow as well.²⁴ The need to consider multiple options and outcomes can lead to decisional conflict, “a state of uncertainty about which course of action to take when choices among competing actions involve risk, loss, regret, or challenge to personal life values.”²⁵ Evidence-based decision aids can provide a more manageable structure and help people make strategic, informed choices by “providing accurate, balanced, and tailored information” about possible options and outcomes; “by clarifying patients’ values” and helping them “better forecast their futures”; and “by augmenting skills in shared decision-making.”²⁶ Decision aids help cue patients and caregivers to their roles in shared decision-making and help clinicians better support their active involvement.



A systematic review of decision aids for health treatment or screening found that their use improved knowledge of treatment options, decreased decisional conflict, and resulted in users feeling better informed and clearer about personal priorities.²⁷ Data suggest aids may also foster more realistic perceptions of risks and benefits and encourage more active discussions with clinicians about the decision.²⁸

Decision aids can be accessed on paper or online as worksheets, question lists, and/or flow charts; they can be self-administered by patients and caregivers or completed with clinicians, providing a bridge to more in-depth decision-making conversations. The Ottawa Hospital Research Institute offers an A-to-Z online inventory of decision aids; a search for “cancer” calls up several dozen resources.²⁹ In addition, the Ottawa Personal Decision Guide for Two offers general support for patient-caregiver discussions.³⁰

Decision aids are also available through multimedia platforms that bundle together a variety of services, similar to the CHESS system discussed above. Some incorporate videos, informal or formal coaching, and role-playing exercises. For example, the TRIO Framework for shared decision-making has informed the development of eTRIO, a suite of interactive digital learning modules targeted to patients, caregivers, and clinicians. The clinician modules include training videos that simulate communication challenges that can negatively impact decision-making and model techniques to mediate them, based on the TRIO Guidelines.³¹



Connect caregivers who have high needs for self-care with oncology social workers

The majority of the caregivers we surveyed reported low levels of support for providing care and elevated scores in the screens for depression and anxiety. In particular, Segment 3 caregivers expressed distinctive and significant needs related to self-care. These caregivers make up more than a third of our sample, suggesting a large population of caregivers nationwide in need of similar support, such as counseling with an oncology social worker. The TRIO Guidelines reinforce this, recommending that clinicians “attempt to meet the emotional needs of family caregivers, including referring family caregivers to relevant support services where required (psychologist, counselor, social worker).”³² Social workers assist cancer caregivers in developing healthy techniques for coping, relating, and communicating, and can provide connections to support groups and services to help address specific caregiving burdens and practical concerns.

Research suggests that counseling services for caregivers are underutilized, however, and may be impeded by the current healthcare system.³³ When a caregiver voices emotional needs to the patient’s clinical team, they are typically referred to their primary care doctor; how many caregivers follow through is unclear. The National Alliance for Caregiving notes that “standards for handling family-level data [such as including results from a caregiver burden assessment with a patient’s files] are not developed or integrated into the commonly used electronic record systems,”³⁴ nor are standard ways to reimburse healthcare providers for “treating” caregivers. An AARP survey of primary medical providers confirms that payment and legal/privacy issues, along with time constraints, are barriers to engaging caregivers about their needs.³⁵

Several programs present new approaches to dismantle these barriers and redesign healthcare systems. The Caregiver Health and Well-Being Initiative (CGI) at Rush University Medical Center includes the caregiver in a patient's electronic medical record (EMR); the record also links to a separate EMR for the caregiver with their insurance information, setting them up as a patient in the system. Caregiver support services include coaching on treatment planning, skill building, and diagnostic assessments for depression, anxiety, and burden. Early evaluation shows program participation has significantly lowered depression, anxiety, and caregiver burden.³⁶ At Memorial Sloan Kettering Cancer Center, caregivers can self-refer or be referred by the healthcare team to the Cancer Caregiver Clinic. The Clinic coordinates mental health assessments, in-house counseling, and peer support groups. The program now includes online resources that make it possible to provide support regardless of insurance barriers. Data is being collected to determine whether healthcare costs are lower for patients whose caregivers receive mental health services through the Clinic.³⁷



Cultivate culturally responsive practices, including professional translation services and preferred-language resources

A significant finding of this survey was the heightened distress and decision-making barriers experienced by Hispanic caregivers in our sample. Numerous scholars cite a need for greater cultural responsiveness among healthcare workers.³⁸ More broadly, caregiver studies point to the ways that diverse cultural norms may shape caregiver involvement and decision-making dynamics and suggest that culturally responsive healthcare professionals can support more successful interactions.³⁹ Healthcare inequities related to race, ethnicity, and sexual orientation/gender identity also impact caregivers and patients,⁴⁰ as shown by the higher incidence of perceived clinical team bias reported by non-white caregivers in this survey.

While not specific to cancer care, the “Meeting the Needs of Diverse Family Caregivers” series developed by the Diverse Elders Coalition is a helpful starting point. One of its recommendations is to “assess for difficulty with cultural tasks”—i.e. “language barriers, translating health materials, [and/or] legal issues with immigration/naturalization.”⁴¹ They find that caregivers who report high levels of difficulty with cultural tasks tend to have higher levels of strain and depression and the quality of care they provide rates lower. Other recommendations include developing in-language caregiver support groups, translating healthcare materials for both language and cultural meaning, providing “culturally competent, trained Medical Interpreters,” and removing barriers to services by ensuring there are in-language provider options. Studies also indicate that the use of inclusive decision aids can help to counter implicit bias and assumptions from healthcare professionals that might otherwise lead to disparities in how treatment options and other health-related information is presented.⁴²



National support organizations for cancer caregivers

As we saw in this survey and past focus groups, caregivers often look online for information to better understand a cancer diagnosis and to help with treatment decision-making.⁴³ Healthcare professionals can recommend the list below as a starting point. It is by no means comprehensive, as there are many more organizations offering high-quality resources and support. Healthcare professionals might further suggest that caregivers focus on “.org” and “.edu” sites to locate web-based materials that tend to be reliable.

CancerCare

Services include counseling with oncology social workers (offered in English and Spanish), support groups, financial assistance, expert answers to monthly FAQs, and education workshops, podcasts, videos, and publications.
<https://www.cancercare.org/tagged/caregiving>
support hotline: 1-800-813-HOPE

National Alliance for Caregiving

Services include Circle of Care guidebooks and fact sheets, links to aid organizations and caregiver services, research on national caregiver data, and local, national, and global advocacy efforts, including social interventions for workplaces and healthcare systems.
<https://www.caregiving.org/>

ASCO

Services include education materials on a range of cancers and cancer-related topics, including a suite of resources on Caring for a Loved One (linked below) that cover self-care, sharing responsibilities, caregiving in different contexts (long-distance, in home, in a hospital), and the “ASCO Answers Guide to Caring for a Loved One With Cancer” in English and Spanish.
<https://www.cancer.net/coping-with-cancer/caring-loved-one>

AARP

Services include online caregiver community groups, news about legislative efforts to support caregivers, and tools and guides for such topics as coordinating care, financial planning, life balance, in-home and extended care, and Advance Directives and other legal measures.
<https://www.aarp.org/caregiving/>
support hotline: 1-877-333-5885 (English)
1-888-971-2013 (Spanish)

Caregiver Action Network

Services include a virtual “help desk” with live chat, caregiver discussion forums and personal stories from caregivers, caregiver-related news and statistics, links to agencies and organizations for further support services, and education articles, checklists, FAQs, “how to” guides, and instructional videos, including a series on in-home hands-on care.
<https://www.caregiveraction.org/>
support hotline: 1-855-227-3640

National Institutes of Health: National Cancer Institute

Services in English and Spanish include education publications for patients, caregivers, and families; cancer topic fact sheets, articles, and e-dictionaries; and links to other vetted resources. The National Cancer Institute also provides a database of organizations that offer cancer support services (<https://supportorgs.cancer.gov/>).
<https://www.cancer.gov>
support hotline: 1-800-422-6347
live chat and email contact also available

References for Section 8: Ways to improve support for caregiver decision-making

- 1 Garvelink, Mirjam M., et al. "A Synthesis of Knowledge About Caregiver Decision Making Finds Gaps in Support for Those Who Care for Aging Loved Ones." *Health Affairs*, vol. 35, no. 4, 2016, pp. 619-626. *Health Affairs*, DOI: 10.1377/hlthaff.2015.1375.; Kimberlin, Carole, et al. "Cancer Patient and Caregiver Experiences: Communication and Pain Management Issues." *Journal of Pain and Symptom Management*, vol. 28, no. 6, 2004, pp. 566-578. DOI: 10.1016/j.jpainsymman.2004.03.005.; Hashemi, Maryam, et al. "Caregivers Needing Care: The Unmet Needs of the Family Caregivers of End-of-Life Cancer Patients." *Supportive Care in Cancer*, vol. 26, no. 3, 2018, pp. 759-766. *SpringerLink*, DOI: 10.1007/s00520-017-3886-2.; Harrison, Reema, et al. "Preparing for Partnerships in Cancer Care: An Explorative Analysis of the Role of Family-based Caregivers." *BMC Health Services Research*, vol. 21, no. 1, 2021. DOI: 10.1186/s12913-021-06611-0.; Wells, Jo Nell, et al. "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger." *Journal of Transcultural Nursing*, vol. 19, no. 3, 2008, pp. 223-233. *SAGE Journals*, DOI: 10.1177/1043659608317096.; CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercare.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.
- 2 Recite Me. "Website Accessibility Assistive Toolbar." *Recite Me*, <https://reciteme.com/product/assistive-toolbar>. Accessed April 29, 2022.
- 3 National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>. Accessed March 5, 2022.
- 4 Hancock, Karen, et al. "Discrepant Perceptions About End-of-Life Communication: A Systematic Review." *Journal of Pain and Symptom Management*, vol. 34, no. 2, 2007, pp. 190-200. DOI:10.1016/j.jpainsymman.2006.11.009.
- 5 See: DuBenske, Lori L., et al. "Web-Based Cancer Communication and Decision Making Systems: Connecting Patients, Caregivers, and Clinicians for Improved Health Outcomes." *Medical Decision Making*, vol. 30, no. 6, 2010, pp. 732-744. *PubMed.gov*, DOI: 10.1177/0272989X10386382.; DuBenske, Lori L., et al. "CHESS Improves Cancer Caregivers' Burden and Mood: Results of an eHealth RCT." *Health Psychology*, vol. 33, no. 10, 2014, pp. 1261-1272. *PubMed.gov*, DOI: 10.1037/a0034216.
- 6 See: Heynsbergh, Natalie, et al. "Feasibility, Useability and Acceptability of Technology-based Interventions for Informal Cancer Carers: A Systematic Review." *BMC Cancer*, vol. 18, no. 244, 2018. DOI: 10.1186/s12885-018-4160-9.; Shin, Ji Youn, et al. "Supporting Caregivers of Patients with Cancer: A Summary of Technology-Mediated Interventions and Future Directions." *American Society of Clinical Oncology Educational Book*, vol. 38, 2018, pp. 838-849. DOI: 10.1200/EDBK_201397.
- 7 Shin, Ji Youn, et al. "Supporting Caregivers of Patients with Cancer: A Summary of Technology-Mediated Interventions and Future Directions." *American Society of Clinical Oncology Educational Book*, vol. 38, 2018, pp. 838-849. DOI: 10.1200/EDBK_201397.
- 8 Coughlin, Steven S., et al. "A Review of Web Portal Use by Oncology Patients." *Journal of Cancer Treatment and Diagnosis*, vol. 2, no. 6, 2018. DOI: 10.29245/2578-2967/2018/6.1154.
- 9 See: Diverse Elders Coalition. "Resources for Providers: Meeting the Needs of Diverse Family Caregivers" from the *Caring for Those Who Care Curriculum*, March 2021. <https://diverseelders.org/caregiving/>. Accessed April 24, 2022.; Laidsaar-Powell, Rebekah, et al. "Facilitating Collaborative and Effective Family Involvement in the Cancer Setting: Guidelines for Clinicians (TRIO Guidelines-1)." *Patient Education and Counseling*, vol. 101, no. 6, 2018, pp. 970-982. *ResearchGate.net*, DOI: 10.1016/j.pec.2018.01.019. Accessed April 24, 2022.
- 10 AARP. "State Law to Help Family Caregivers." *AARP.org*, 2014, <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>. Accessed April 24, 2022.
- 11 See: 115th Congress of the United States of America. *Public Law 115-119: Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017*. January 22, 2018. <https://acl.gov/sites/default/files/about-acl/2018-10/PLAW-115publ119%20-%20RAISE.pdf>. Accessed April 24, 2022.; RAISE Family Caregiving Advisory Council with assistance from Administration for Community Living. "RAISE Family Caregivers Act Initial Report to Congress." September 22, 2021, *Administration for Community Living, U.S. Department of Health and Human Services*, https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf. Accessed April 24, 2022.
- 12 See: CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancercare.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.; Verini, Christine, et al. *Improving Support in Treatment Decision Making for Patients with Metastatic Breast Cancer*. CancerCare, February 2020. https://media.cancercare.org/publications/original/396-396-2020_mbcroundtable.pdf. Accessed March 5, 2022.
- 13 CancerCare. *CancerCare Patient Access and Engagement Report*. 2016, <https://media.cancercare.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.



References for Section 8: Ways to improve support for caregiver decision-making

- 14** See: Reyna, Valerie F., et al. "Decision Making and Cancer." *American Psychologist*, vol. 70, no. 2, 2015, pp. 105–118. *PubMed.gov*, DOI: 10.1037/a0036834.; Shelton, Rachel C. "Decision-Making Under Clinical Uncertainty: An In-depth Examination of Provider Perspectives on Adjuvant Chemotherapy for Stage II Colon Cancer." *Patient Education and Counseling*, vol. 102, no. 2, 2019, pp. 284–290. *PubMed.gov*, DOI: 10.1016/j.pec.2018.09.015.
- 15** Hoverman, J. Russell, et al. "If We Don't Ask, Our Patients Might Never Tell: The Impact of the Routine Use of a Patient Values Assessment." *Journal of Oncology Practice*, vol. 13, no. 10, 2017. *ASCOpubs.org*, DOI: 10.1200/JOP.2017.022020.
- 16** Lamont, Elizabeth B. and Nicholas A. Christakis. "Prognostic Disclosure to Patients with Cancer Near the End of Life." *Annals of Internal Medicine*, vol. 134, no. 12, 2001, pp. 1096–1105. *ResearchGate.net*, DOI: 10.7326/0003-4819-134-12-200106190-00009. Accessed May 5, 2022.
- 17** Keating, Nancy L., et al. "Physician Factors Associated with Discussions about End-of-Life Care." *Cancer*, vol. 116, no. 4, 2010, pp. 998–1006. DOI: 10.1002/cncr.24761.
- 18** See: Wright, Alexi A. et al. "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment." *JAMA*, vol. 300, no. 14, 2008, pp. 1665–1673. *PubMed.gov*, DOI: 10.1001/jama.300.14.1665.; Detering, Karen M., et al. "The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomized Controlled Trial." *BMJ*, vol. 340, c. 1345, 2010. DOI:10.1136/bmj.c1345.; Mack, Jennifer W., et al. "Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study." *Journal of Clinical Oncology*, vol. 30, no. 35, 2012, pp. 4387–4395. DOI:10.1200/JCO.2012.43.6055.; Hoverman, J. Russell, et al. "If We Don't Ask, Our Patients Might Never Tell: The Impact of the Routine Use of a Patient Values Assessment." *Journal of Oncology Practice*, vol. 13, no. 10, 2017. *ASCOpubs.org*, DOI: 10.1200/JOP.2017.022020.
- 19** Hillman, Ken and Jack Chen. *Conflict Resolution in End of Life Treatment Decisions: An Evidence Check Rapid Review Brokered by the Sax Institute for the NSW Department of Health*. The Sax Institute, November 2008. https://www.saxinstitute.org.au/wp-content/uploads/REPORT_ConflictResEndOfLife.pdf. Access April 24, 2022.
- 20** Institute for Healthcare Improvement. *The Conversation Project*. <https://theconversationproject.org/>. Accessed April 24, 2022.
- 21** The American Bar Association Commission on Law and Aging. *Making Medical Decisions for Someone Else: A How To Guide*. 2009, American Bar Association, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2011_aging_bk_proxy_guide_gen.pdf. Accessed April 24, 2022.
- 22** See: Hillman, Ken and Jack Chen. *Conflict Resolution in End of Life Treatment Decisions: An Evidence Check Rapid Review Brokered by the Sax Institute for the NSW Department of Health*. The Sax Institute, November 2008. https://www.saxinstitute.org.au/wp-content/uploads/REPORT_ConflictResEndOfLife.pdf. Accessed April 24, 2022.; University of Washington End-of-Life Care Research Program at Harborview Medical Center. "V.A.L.U.E." *Reference Card*. <http://depts.washington.edu/eolcare/products/communication-tools/>. Accessed April 24, 2022.
- 23** See: Hoverman, J. Russell, et al. "If We Don't Ask, Our Patients Might Never Tell: The Impact of the Routine Use of a Patient Values Assessment." *Journal of Oncology Practice*, vol. 13, no. 10, 2017. *ASCOpubs.org*, DOI: 10.1200/JOP.2017.022020.; McKesson. "Innovative Advance Care Planning Program Gives Cancer Patients a Voice in Care Decision While Supporting Quality and Mitigating Costs." June 24, 2013. *McKesson.com*. <https://www.mckesson.com/About-McKesson/Newsroom/Press-Releases/2013/Innovative-Advance-Care-Planning-Program-Gives-Cancer-Patients-a-Voice-in-Care-Decisions-While-Supporting-Quality-Care-and-Mitigating-Costs/#:~:text=%22My%20Choices%2C%20My%20Wishes%20is.of%20The%20US%20Oncology%20Network>. Accessed April 24, 2022.
- 24** See: Kates, Jeannette M. "Treatment-related Decisional Conflict, Quality of Life, and Comorbidity in Older Adults with Cancer." *Asia-Pacific Journal of Oncology Nursing*, vol. 5, no. 4, 2018, pp. 421–429. *ScienceDirect.com*, DOI: 10.4103/apjon.apjon_32_18.; Hoerger, Michael, et al. "Values and Options in Cancer Care (VOICE): Study Design and Rationale for a Patient-centered Communication and Decision-making Intervention for Physicians, Patients with Advanced Cancer, and Their Caregivers." *BMC Cancer*, vol. 13, 2013. DOI: 10.1186/1471-2407-13-188.
- 25** LeBlanc, Annie, et al. "Decisional Conflict in Patients and Their Physicians: A Dyadic Approach to Shared Decision Making." *Medical Decision Making*, vol. 29, no. 1, 2009, pp. 61–68. *ResearchGate.net*, DOI: 10.1177/0272989X08327067.



References for Section 8: Ways to improve support for caregiver decision-making

- 26** See: O'Connor, Annette M., et al. "Decision Aids for Patients Considering Options Affecting Cancer Outcomes: Evidence of Efficacy and Policy Implications." *Journal of the National Cancer Institute Monographs*, vol. 25, 1999, pp. 67-80. https://www.researchgate.net/publication/12465027_Decision_Aids_for_Patients_Considering_Options_Affecting_Cancer_Outcomes_Evidence_of_Efficacy_and_Policy_Implications/link/0deec517e5d6f7d106000000/download. Accessed April 24, 2022.; Reyna, Valerie F., et al. "Decision Making and Cancer." *American Psychologist*, vol. 70, no. 2, 2015, pp. 105-118. *PubMed.gov*, DOI: 10.1037/a0036834.
- 27** Stacey, Dawn, et al. "Decision Aids for People Facing Health Treatment or Screening Decisions." *Cochrane Database of Systematic Reviews*, version published April 12, 2017, DOI: 10.1002/14651858.CD001431.pub5.
- 28** Stacey, Dawn, et al. "Decision Aids for People Facing Health Treatment or Screening Decisions." *Cochrane Database of Systematic Reviews*, version published April 12, 2017, DOI: 10.1002/14651858.CD001431.pub5.
- 29** Ottawa Hospital Research Institute. "A to Z Inventory of Decision Aids." *Ottawa Hospital Research Institute*, <https://decisionaid.ohri.ca/AZinvent.php>. Last modified June 26, 2019; accessed April 24, 2022.
- 30** Stacey, Dawn, et al. *Ottawa Personal Decision Guide for Two*. Ottawa Hospital Research Institute and University of Ottawa, Canada, 2015. <https://decisionaid.ohri.ca/docs/das/OPDGx2.pdf>; for the guide in additional languages, visit <https://decisionaid.ohri.ca/decguide.html>. Accessed April 24, 2022.
- 31** Bonnaudet, Melanie. "An Usability Evaluation of TRIO's E-Learning Modules Enhancing the Communication Between Cancer Patients, Clinicians and Carers." Degree Project - KTH Royal Institute of Technology, School of Electrical Engineering and Computer Science, 2020. URN:nbn:se:kth:diva-280704. <http://kth.diva-portal.org/smash/get/diva2:1466296/FULLTEXT01.pdf>. Accessed April 24, 2022.
- 32** Laidsaar-Powell, Rebekah, et al. "Facilitating Collaborative and Effective Family Involvement in the Cancer Setting: Guidelines for Clinicians (TRIO Guidelines-1)." *Patient Education and Counseling*, vol. 101, no. 6, 2018, pp. 970-982. *ResearchGate.net*, DOI: 10.1016/j.pec.2018.01.019. Accessed April 24, 2022.
- 33** See: CancerCare. *CancerCare Patient Access and Engagement Report*. 2016. <https://media.cancercare.org/accessengagementreport/FINAL-CancerCare-CAPER-10May2016-hsp.pdf>. Accessed March 5, 2022.; National Alliance for Caregiving. *Caring for the Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team*. National Alliance for Caregiving, November 2021, https://www.caregiving.org/wp-content/uploads/2021/11/NAC_CaringForCaregiver_Paper_111921.pdf. Accessed April 24, 2022.; Skufca, Laura. *Primary Care Providers' Experiences with Family Caregivers*. AARP Research, 2018, https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2019/primary-care-provider-on-family-caregiver-role.doi.10.26419-2Fres.00273.001.pdf. DOI: 10.26419/res.00273.001.
- 34** National Alliance for Caregiving. *Caring for the Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team*. National Alliance for Caregiving, November 2021, https://www.caregiving.org/wp-content/uploads/2021/11/NAC_CaringForCaregiver_Paper_111921.pdf. Accessed April 24, 2022.
- 35** Skufca, Laura. *Primary Care Providers' Experiences with Family Caregivers*. AARP Research, 2018, https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2019/primary-care-provider-on-family-caregiver-role.doi.10.26419-2Fres.00273.001.pdf. DOI: 10.26419/res.00273.001.
- 36** See: National Alliance for Caregiving. *Caring for the Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team*. National Alliance for Caregiving, November 2021, https://www.caregiving.org/wp-content/uploads/2021/11/NAC_CaringForCaregiver_Paper_111921.pdf. Accessed April 24, 2022.; Pelton, Leslie, et al. "The Rush Caregiver Initiative: A Model for Caregiver Health and Wellness in Age-Friendly Health Systems." *Innovation in Aging*, vol. 5, no. S-1 (GSA 2021 Annual Scientific Meeting - Session 3165 Symposium), 2021. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8679208/pdf/igab046.1189.pdf/?tool=EBI>. Accessed May 5, 2022.
- 37** See: National Alliance for Caregiving. *Caring for the Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team*. National Alliance for Caregiving, November 2021, https://www.caregiving.org/wp-content/uploads/2021/11/NAC_CaringForCaregiver_Paper_111921.pdf. Accessed April 24, 2022.; Applebaum, Allison. "Caregivers Clinic at Memorial Sloan Kettering Cancer Center." *Innovation in Aging*, vol. 5, no. S-1 (GSA 2021 Annual Scientific Meeting - Session 3165 Symposium), 2021. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8679457/pdf/igab046.1188.pdf/?tool=EBI>. Accessed May 5, 2022.



References for Section 8: Ways to improve support for caregiver decision-making

- 38** See: Floríndez, Lucía I., et al. "Differing Interpretations of Health Care Encounters: A Qualitative Study of Non-Latinx Health Care Providers' Perceptions of Latinx Patient Behaviors." *PLoS ONE*, vol. 15, no. 8, 2020. *PLoS ONE*. DOI: 10.1371/journal.pone.0236706.; Wells, Jo Nell, et al. "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger." *Journal of Transcultural Nursing*, vol. 19, no. 3, 2008, pp. 223-233. *SAGE Journals*, DOI: 10.1177/1043659608317096.; Riera, Antonio, et al. "Latino Caregiver Experiences with Asthma Health Communication." *Qualitative Health Research*. September 2014. *SAGE Journals*. DOI: 10.1177/1049732314549474.; Zamora, Eduardo R., et al. "The Impact of Language Barriers and Immigration Status on the Care Experience for Spanish-speaking Caregivers of Patients with Pediatric Cancer." *Pediatric Blood & Cancer*, vol. 63, no. 12, 2016, pp. 2173-2180. *Wiley Online Library*. DOI: 10.1002/pbc.26150.
- 39** See: Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf. Accessed March 5, 2022.; Miyawaki, Christina E. "Caregiving Practice Patterns of Asian, Hispanic, and Non-Hispanic White American Family Caregivers of Older Adults Across Generations." *Journal of Cross-Cultural Gerontology*, vol. 31, 2016, pp. 35-55. *SpringerLink*. DOI: 10.1007/s10823-016-9281-5.; Diverse Elders Coalition. "Resources for Providers: Meeting the Needs of Diverse Family Caregivers" from the *Caring for Those Who Care Curriculum*, March 2021. <https://diverseelders.org/caregiving/>. Accessed April 24, 2022.
- 40** See: Bose, M., et al. *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. National Alliance for Caregiving. November 2021. https://www.caregiving.org/wp-content/uploads/2021/12/NAC_AmgenDiverseCaregiversReport_FinalDigital-112121.pdf.; Niranjana, Soumya J., et al. "Bias and Stereotyping Among Research and Clinical Professionals: Perspectives on Minority Recruitment for Oncology Clinical Trials." *Cancer*, vol. 126, no. 9, 2020, pp. 1958-1968. *ACS Journals*. DOI: 10.1002/cncr.32755.; Floríndez, Lucía I., et al. "Differing Interpretations of Health Care Encounters: A Qualitative Study of Non-Latinx Health Care Providers' Perceptions of Latinx Patient Behaviors." *PLoS ONE*, vol. 15, no. 8, 2020. *PLoS ONE*. DOI: 10.1371/journal.pone.0236706.; Eggly, Susan, et al. "Development of a Question Prompt List as a Communication Intervention to Reduce Racial Disparities in Cancer Treatment." *Journal of Cancer Education*, vol. 28, no. 2, 2013, pp. 282-289. *PubMed.gov*, DOI: 10.1007/s13187-013-0456-2.
- 41** Diverse Elders Coalition. "Resources for Providers: Meeting the Needs of Diverse Family Caregivers" from the *Caring for Those Who Care Curriculum*, March 2021. <https://diverseelders.org/caregiving/>. Accessed April 24, 2022.
- 42** Eggly, Susan, et al. "Development of a Question Prompt List as a Communication Intervention to Reduce Racial Disparities in Cancer Treatment." *Journal of Cancer Education*, vol. 28, no. 2, 2013, pp. 282-289. *PubMed.gov*, DOI: 10.1007/s13187-013-0456-2.
- 43** CancerCare. *Cancer Caregivers and Treatment Decision Making: A Qualitative Research Assessment*. 2020, https://media.cancer.org/documents/270/original/CC_Caregiver-Treatment-Decision-Making-White-Paper-8.12.pdf. Accessed March 5, 2022.

TRIO Framework: Model scenarios for caregiver involvement in shared decision-making

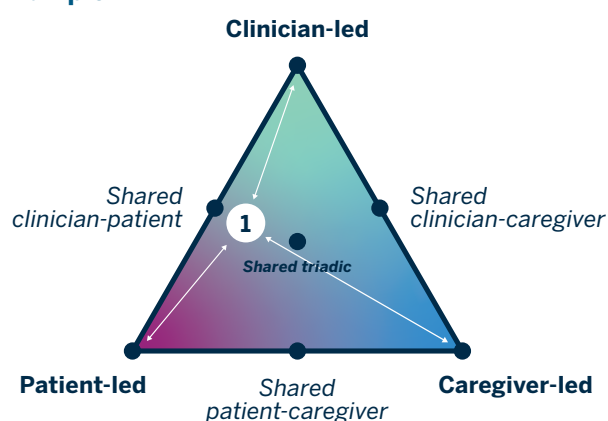
Originally published by Laidsaar-Powell, et al., 2017; reproduced with permission of the authors.

The variability of caregiver influence amongst different triads

Example 1: is plotted at a point which represents sharing of a decision between the patient and clinician, with a very small degree of caregiver influence.

Example 1 could be the case of a patient with advanced cancer facing a decision of whether to receive chemotherapy or no treatment. The patient and oncologist share information, each contribute their preferences during deliberation, and the decision is shared between the patient and clinician. The patient's adult daughter states that, while she wants her father to live as long as possible, she will support whatever his decision is. The patient and clinician have most influence over the decision, and the caregiver has a small amount of influence although she shares her general preferences.

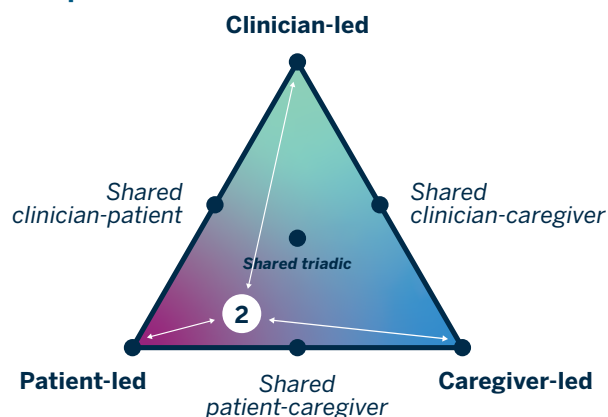
Example 1



Example 2: is plotted at a point which represents that the patient has greatest influence over the decision (as indicated by the shortest distance on the arrow leading from the patient-led anchor point), followed by the caregiver with limited input of the clinician.

Example 2 could be the case of a young adult woman diagnosed with breast cancer who is facing the decision of whether to delay chemotherapy to undergo fertility treatment. Whilst the patient retains most of the decision-making control, outside of the consultation she and her husband research and share information and deliberate together, where the husband shares his preferences of wanting children and his willingness to undergo IVF but clearly states that it is ultimately her body and her decision. The couple discuss the decision with a clinician, but feel strongly it is their own personal choice.

Example 2

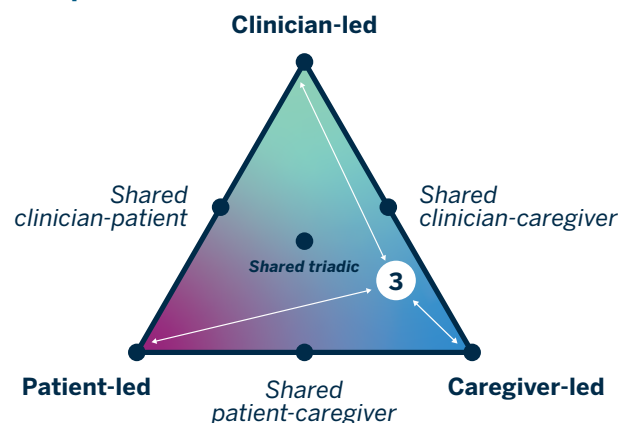


Laidsaar-Powell, Rebekah, et al. "The TRIO Framework: Conceptual Insights into Family Caregiver Involvement and Influence Throughout Cancer Treatment Decision-making." *Patient Education and Counseling*, vol. 100, no. 11, 2017, pp. 2035-2046. ScienceDirect, DOI: 10.1016/j.pec.2017.05.014.

Example 3: is plotted at a point which represents that the caregiver has greatest influence over the decision (as indicated by the shortest distance on the arrow leading from the caregiver-led anchor point), followed by the clinician with very limited influence of the patient.

Example 3 could be the case of a patient with limited English language proficiency who is diagnosed with lung cancer. His son (fluent in English) directs the information exchange with the clinician in all consultations and translates a small amount of the information for the patient. The son directs the deliberation process, not conveying the patient's wishes. The treatment decision is largely directed by the patient's son, to which the patient consents.

Example 3



The variability of caregiver influence within the one triad over time

The following is a case example of the variability of caregiver influence over a number of decisions within the one illness experience.

- A person suffers from a seizure and becomes unconscious at work and is brought to the emergency room where the responsible clinician orders a number of diagnostic tests and treatments on the patient's behalf (A).
- The patient's spouse is called and is informed that the patient has had a large brain bleed caused by a brain tumor and will require surgery. The clinician and spouse share the decision to operate immediately (B).
- The surgery is successful and after a period of time the patient regains consciousness. The patient is informed of their diagnosis of a brain tumor and radiotherapy is discussed and decided upon between the patient, clinician, and spouse (C).
- After the patient is discharged from hospital, the patient and spouse begin researching steroid therapy. They discuss this decision at length at home sharing their information, opinions and preferences. The patient and spouse make a decision together with limited input from a clinician (D).
- After a period of time, the patient's cancer recurs in the brain. The patient researches the implications of this recurrence, deliberates alone, and makes the decision, relatively independently of his spouse and clinician, to cease treatment (E).

