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Treatment Decision Making Involvement and Informational Support Needs Among Older Adult Caregivers

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APOS Annual Conference, Albuquerque, NM
March 8, 2024

BACKGROUND AND METHODS



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Background and Purpose

- Caregivers often collaborate with patients in their cancer treatment decision making (TDM)
- TDM involves significant logistical, physical, emotional, and financial considerations
- Healthcare shifts towards patient centricity have increased opportunities for shared treatment decision making, yet rapid advances in cancer diagnosis and treatment have led to added complexities in the decision process
- Despite growing awareness of the support provided by caregivers, the TDM experiences and informational support needs and preferences of caregivers are understudied

(CancerCare 2022; Dionne-Odom et al., 2023; Hobbs et al., 2015; Ozdemir et al., 2022)

Aging and Cancer

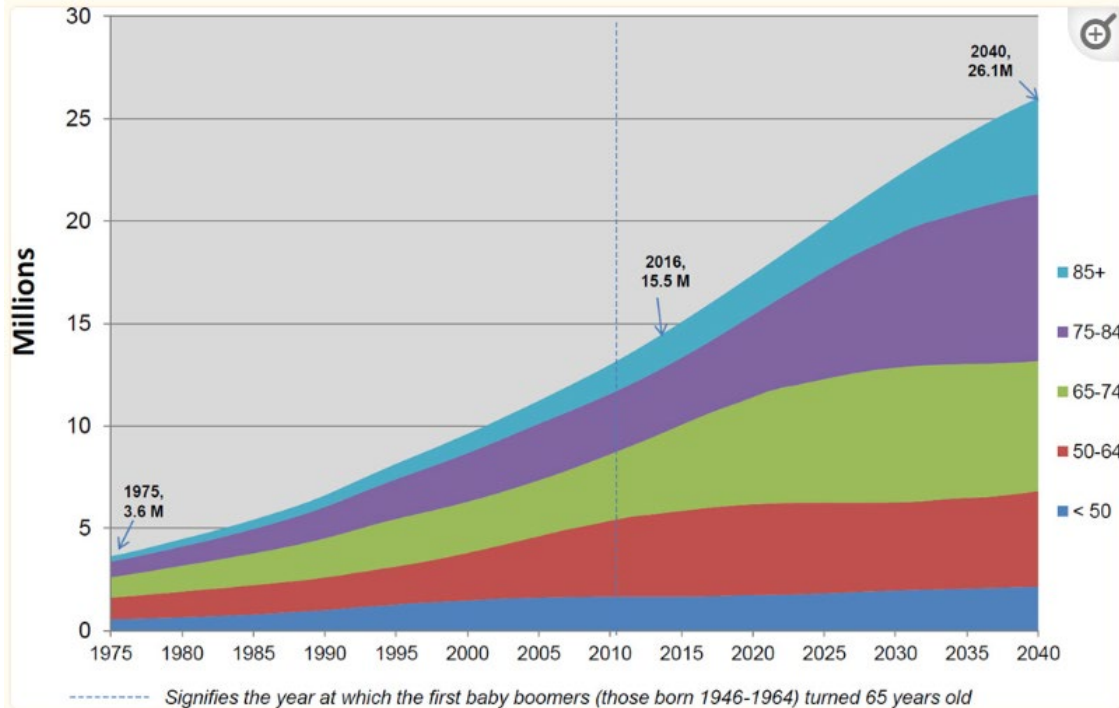


Figure 1

Source: Bluethmann, Mariotto, & Rowland, 2017

Estimated cancer prevalence by age in the US population from 1975 (216 M) to 2040 (380 M)

Even less is known about TDM among **older cancer caregivers**, despite older adults being the largest and fastest growing cancer population:

By 2030, 70% of all cancers will be diagnosed in adults ages 65+

By 2040, 73% of cancer survivors are projected to be ages 65+

(Bluethmann, Mariotto, & Rowland, 2017; Kadambi et al, 2020)

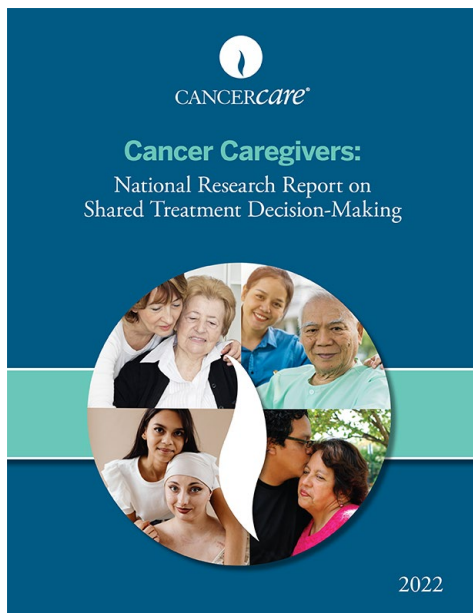
Aging and Cancer: TDM and Caregiving

- Older adults are at risk for medical comorbidities that exacerbate the complexity of cancer-related TDM and information support needs
- Older adults are underrepresented in cancer clinical trials due to inclusion criteria restrictions (upper age limits, comorbidities) and other barriers, resulting in more limited evidence to inform effective TDM
- Older adults are at risk for aging stigma, which can interfere with care delivery and is associated with poorer health outcomes and worse psychological well-being
- Collectively, this increased complexity can create increased TDM support needs for older adult caregivers as well as risk for increased psychological distress

(Allen & Sikora, 2023; Kadambi et al., 2020; Ludmir et al, 2020; Nelleke Seghers et al, 2023)

1. Describe the involvement and informational support needs of older adult caregivers engaged in TDM
2. Examine the relationships between TDM involvement and informational support needs with older adult caregiver depression and anxiety
3. Document older adult caregivers' preferred resources to improve TDM support gaps

- We conducted a secondary analysis of CancerCare's cross-sectional National Research Survey on Cancer Caregiver Treatment Decision-Making



N = 2700

Primary Areas of Focus:

- Decision-making roles of caregivers
- Caregivers' information sources for TDM
- Challenges in TDM
- Psychosocial correlates of TDM

Intended Impact:

- Increase public awareness of caregiver TDM roles and needs
- Evolve and enhance caregiver support
- Inform healthcare policy change

Family and friend caregivers recruited through consumer research panels vetted by PureSpectrum (Feb-July 2021) and completed online survey

<https://www.cancercare.org/cancer-caregivers>

Funding for the Cancer Caregiver Treatment Decision Making study was provided to CancerCare by: Amgen, Astellas US LLC, Eisai Inc, GSK, Jazz Pharmaceuticals, Merck & Co Inc, Pfizer, and Regeneron

Inclusion Criteria

- Caregivers were eligible to take part if they currently provided support to someone close to them with cancer (excluding non-melanoma skin cancer), for at least 6 months
- We limited our analytic sample to **N=164** caregivers ages 65+ who reported caring for an adult 65+ with cancer, who supported at least one cancer treatment-related decision
- A subset of respondents ($n=129$) also answered in-depth questions about specific aspects of TDM



Caregiver 65+ Patient 65+

- Descriptive statistics were calculated for socio-demographic, clinical, and TDM experience variables
- Multivariable regression analyses were conducted to examine the associations of:

Predictors

caregiver involvement (sum of 9 types of TDM support)
caregiver informational support needs
perceived age-related support bias

with

Outcomes

caregiver depression (PHQ-2) and caregiver anxiety (GAD-2)
(controlling for gender and education)

PARTICIPANTS



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Caregiver Socio-Demographics

AGE		GENDER IDENTITY		RACE AND HISPANIC ETHNICITY			
65-74	88%	Woman	73%	Alaskan Native or American Indian, Non-Hispanic	1%		
75+	12%	Man	26%	Asian, Non-Hispanic	4%		
		Missing	1%	Black or African American, Non-Hispanic	9%		
				Hispanic	6%		
				White, Non-Hispanic	80%		
				Two or more races, Non-Hispanic	1%		
EMPLOYMENT		INCOME		EDUCATION		MARITAL STATUS	
Full or Part Time	31%	< \$50K	27%	HS, Voc Tech, or less	24%	Married/Partnered	83%
Retired	64%	\$50K-\$99K	45%	Some College or more	76%	Not Partnered	17%
Not Employed	5%	≥ \$100K	26%				
Missing	1%	Prefer NS	2%				

Care Relationship Characteristics

CARE RECIPIENT RELATIONSHIP

Spouse/Partner	50%
Parent	20%
Sibling	12%
Friend	11%
Extended Family	7%
Child	1%

CARE RECIPIENT LIVING SITUATION

Home, with caregiver	60%
Home, without caregiver	32%
ALF/Nursing Home	7%
Other	<1%

N=164

DURATION OF CAREGIVING

< 1 Year	22%
1 to < 3 Years	33%
3 to < 5 Years	18%
5 to < 10 Years	16%
10+ Years	11%

DISTANCE IF NOT COHABITATING (n=65)

< 5 – 15 minutes	51%
16 – 30 minutes	23%
31 – 60 minutes	11%
More than 60 minutes	14%
Missing / Prefer not to share	<1%

Care Recipient Clinical Characteristics

MOST FREQUENT CANCER TYPES

Prostate	20%
Breast	17%
Hematologic	16%
Lung	14%
Colon or Rectal	10%
Bladder	5%
Melanoma	4%
Kidney	3%

**As reported by caregiver survey respondents*

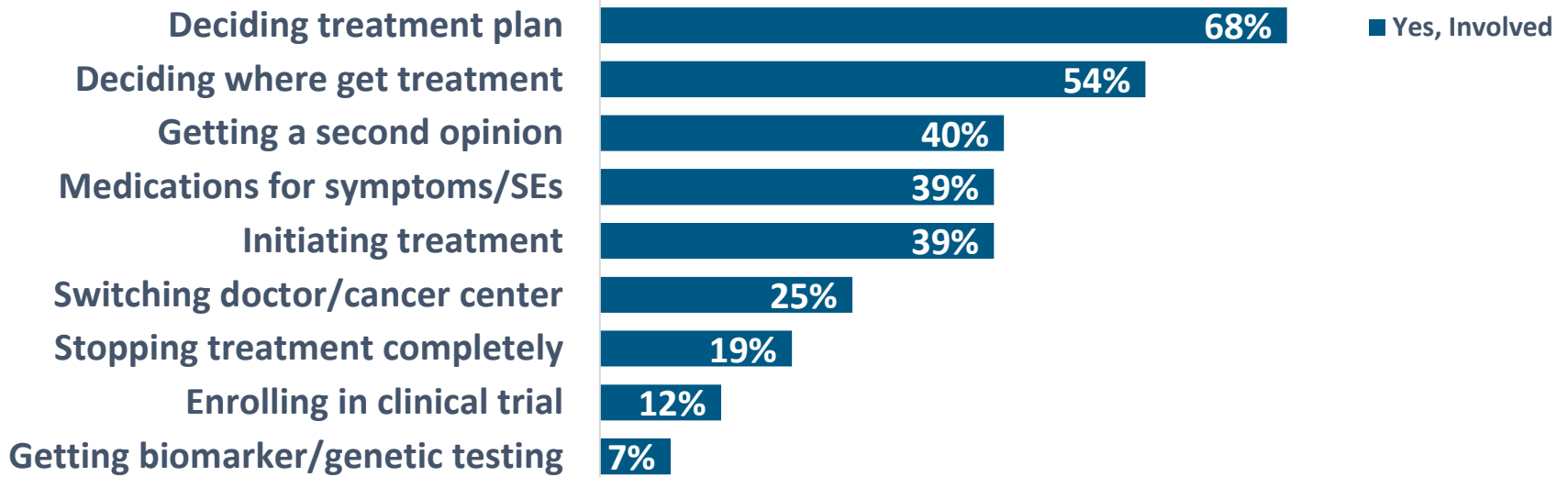
CAREGIVER DECISION INVOLVEMENT



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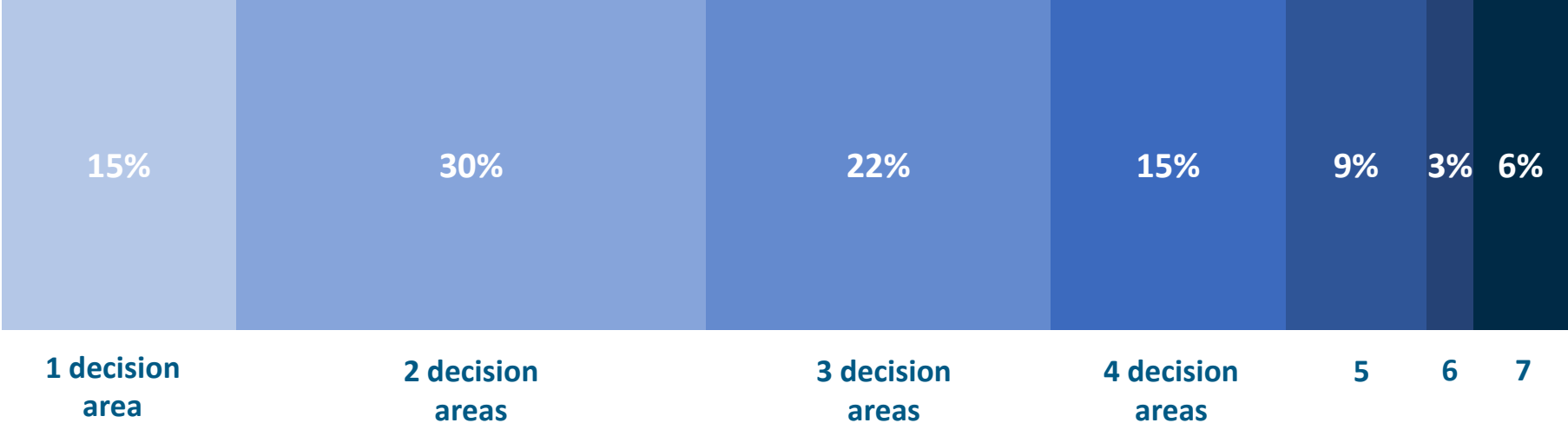
Types of Treatment Decision Involvement by OA Caregivers



Older adult caregivers were most frequently involved in deciding on a treatment plan, followed by deciding where to get treatment

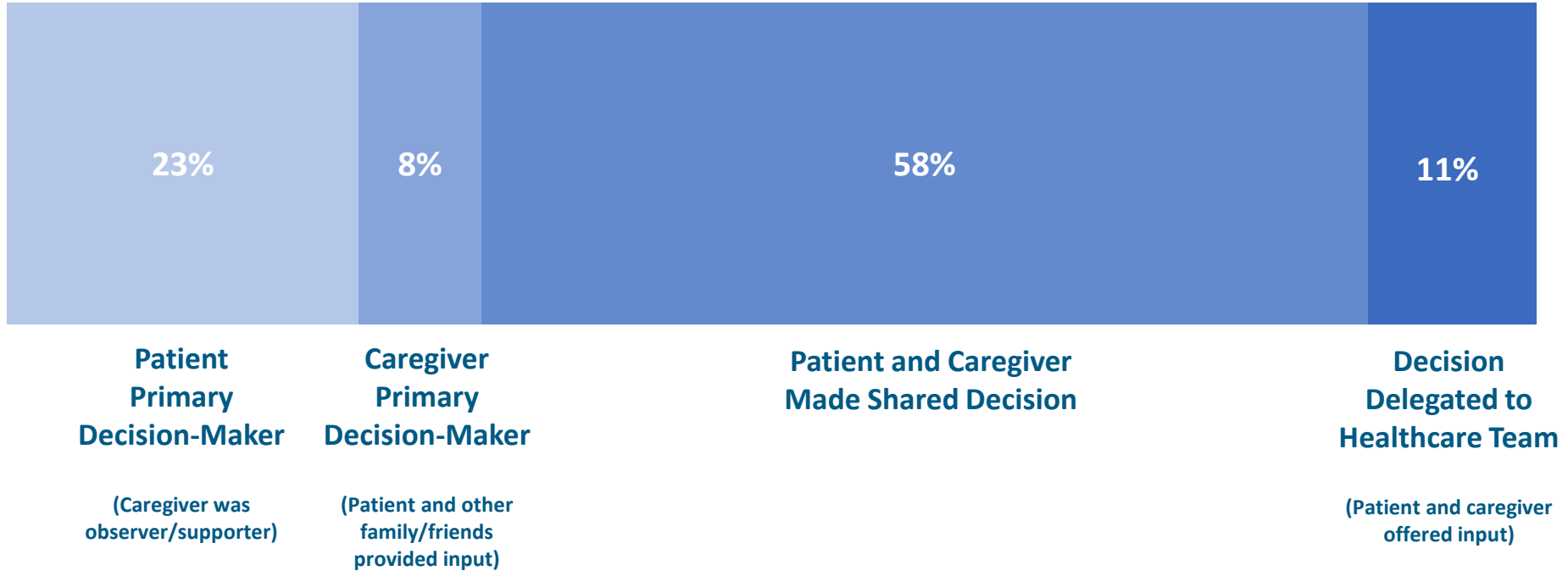
They were least frequently involved in clinical trial enrollment and biomarker testing, although it is unclear how many care recipients were ever offered these options

Number of Treatment-Related Decisions Supported by OA Caregivers



85% of OA caregivers were involved in 2 or more areas of treatment decision support

Caregiver Support Role Across All Treatment-Related Decisions



Note: Data from subsample of caregivers who reflected on their role in supporting a specific treatment-related decision

N=129

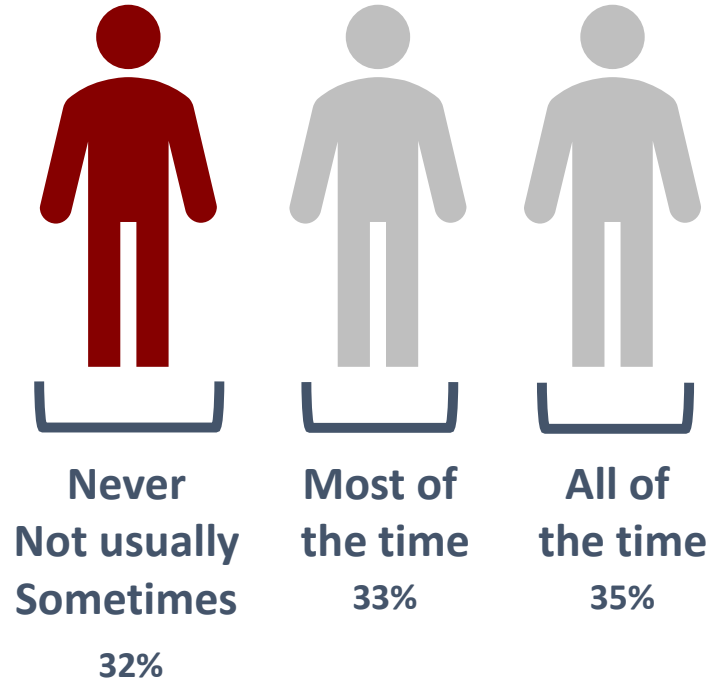
INFORMATIONAL SUPPORT NEEDS AND EXPERIENCES



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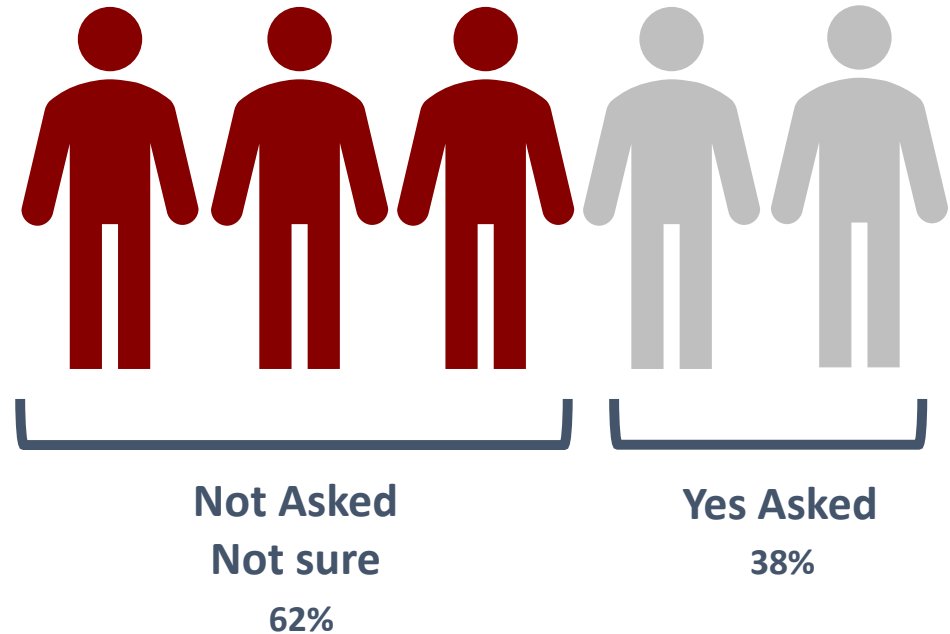
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1 in 3 OA caregivers reported the patient could not routinely communicate effectively with cancer doctors without assistance



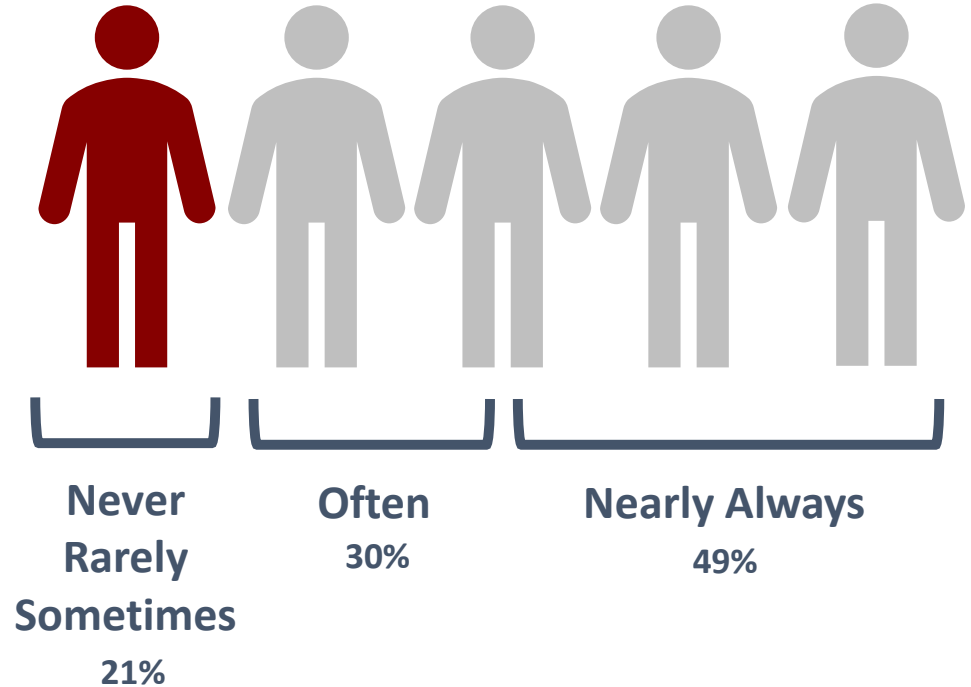
Asked about Decision Support Needs

3 in 5 OA caregivers said they were not asked by the doctor, nurse, or social worker about what they needed to help take part in making decisions



Adequately Informed about Illness

1 in 5 OA caregivers
felt “never” to “sometimes”
adequately informed
about the patient’s illness



“Have you felt that the support you and the patient have received from the doctor or healthcare team for making cancer-related decisions has been negatively affected by age?”

15% Yes
85% No

ASSOCIATIONS WITH DEPRESSION & ANXIETY



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Depression and Anxiety

		Model Statistics at Final Step				
DV	Predictor Variables	ΔR^2	<i>F</i>	Model <i>R</i> ²	Significant Predictors	β
Depression (Model 1)	Step 1: Gender identity Education	.001				
	Step 2: Total # decisions involved Adequately informed about illness Asked about decision support needs Care negatively affected by age	.159***	4.81***	.16	Total # decisions involved Adequately informed about illness	.17* -.31***
Anxiety (Model 2)	Step 1: Gender identity Education	.003				
	Step 2: Total # Decisions Involved Adequately Informed Asked about decision support needs Care negatively affected by age	.117***	3.43**	.12	Total # decisions involved Adequately informed about illness	.18* -.25**

p* < .05; *p* < .01; ****p* < .001

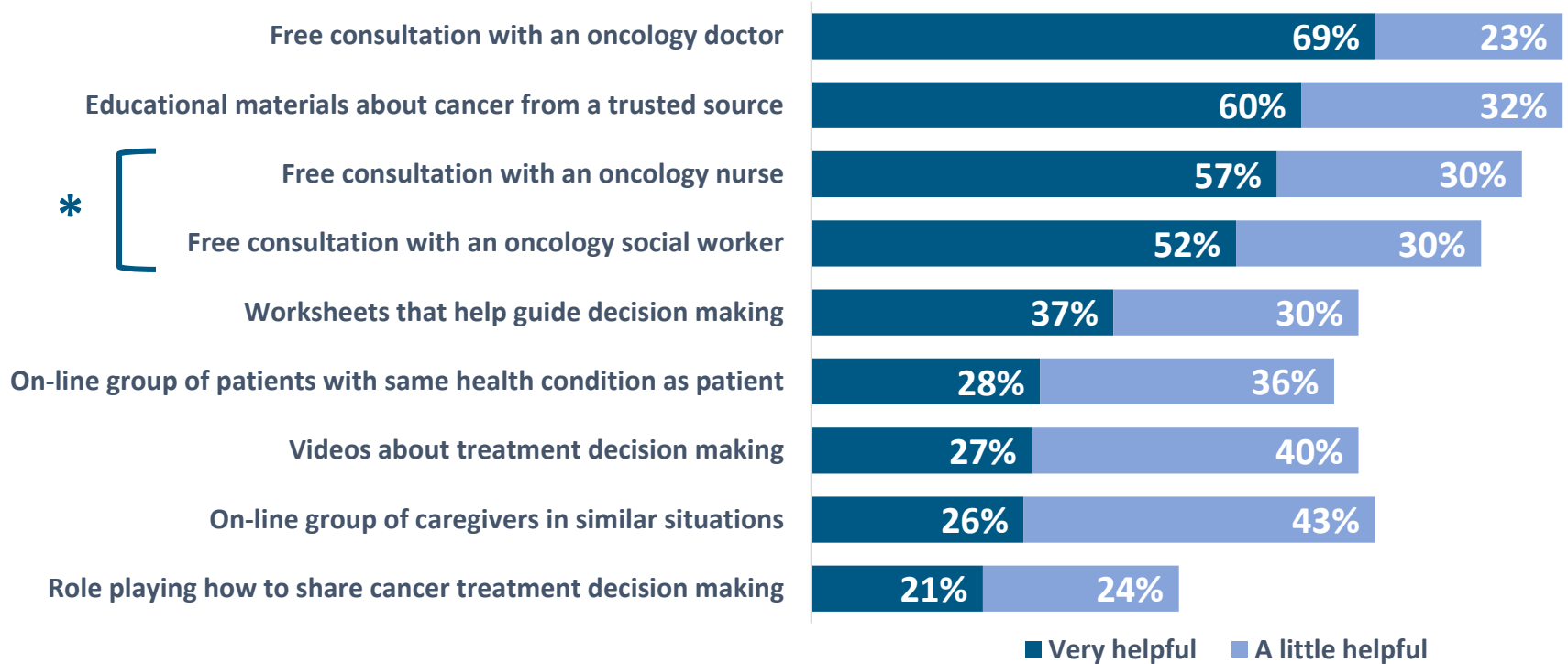
DESIRED CAREGIVER TDM SUPPORT RESOURCES



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What Resources Would be Helpful to Support Caregiver TDM?



*Note: To date, nursing and social work not included in new CY2024 CMS Caregiver Training Services CPT codes

Conclusions and Implications

- Older adult caregivers engage in a range of cancer treatment decision making, yet they report unmet informational support needs that, along with their engagement, were associated with greater caregiver depression and anxiety
- Caregivers identified multiple support resources they believed could assist TDM, yet access and sustainability of resources are challenging under current reimbursement practices and available funding
- Evidence-based programs tailored to support older cancer caregivers' TDM and informational needs remain a critical practice and policy priority

Cancer & Aging SIG

Let's continue the discussion on aging and cancer...

Meeting Today!

12-12:45PM in Fiesta Room

More Info:

<https://dev.apos-society.org/cancerandaging/>

Chair:

Rebecca Saracino, PhD

jamesr@mskcc.org



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