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Unmet needs and health-related quality of life impacts among family caregivers of people with metastatic bladder cancer

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BACKGROUND

Family caregivers provide critical support to people with cancer, yet research about the experiences and unmet informational and support needs of caregivers for people with metastatic bladder cancer (mBCP) is limited.

AIMS

We recruited caregivers of mBCP to complete a survey to understand:

1) caregiver support provided to mBCP,

2) caregivers' unmet needs and health-related quality of life,

3) feasibility of caregiver research engagement, including caregivers' perceptions of barriers/facilitators affecting their research participation.

METHODS

Recruitment occurred through advocacy networks (Cancer Support Community & Bladder Cancer Advocacy Network) and a physician clinic.

From July-Nov 2021, 15 current caregivers to mBCP completed an online survey including socio-demographics, mBCP clinical history, support provided, resources and unmet needs, and barriers/facilitators to caregiver research participation.

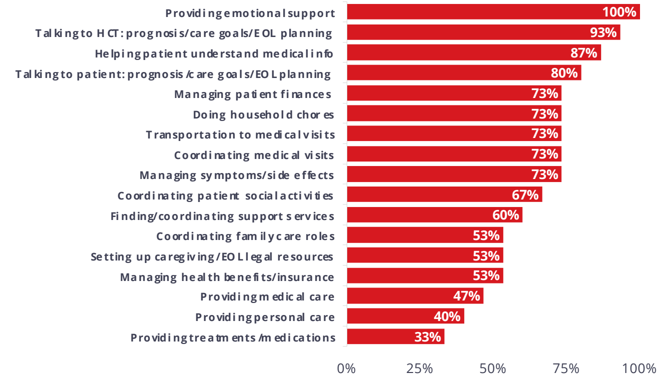
Caregivers received electronic gift cards for their participation.

PARTICIPANTS

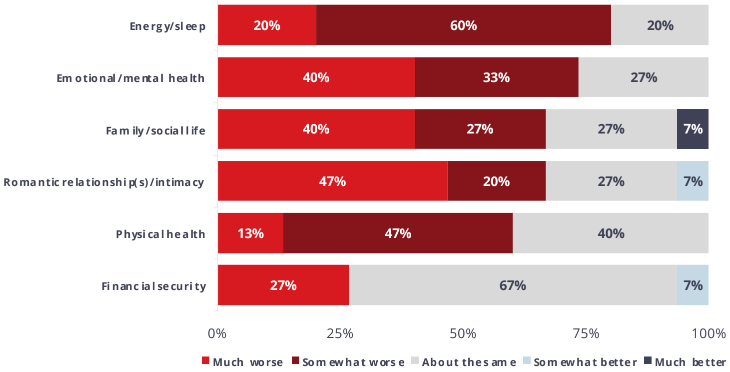
***N* = 15 Caregivers**	***Mean / n***	***SD / %***
Age (years) *(Range: 26–78)*	60	13
Race and ethnicity		
Non-Hispanic White	14	93%
Non-Hispanic Black	1	7%
Women	14	93%
Caregiver relationship to patient		
Caring for spouse	13	87%
Caring for parent	2	13%
Hours of care provided weekly		
≤20 hours	3	20%
40-85+ hours	3	20%
Constant care	5	33%
Don't know/Missing	4	27%
Years providing care		
<1 year	2	13%
1-2 years	7	47%
3-5 years	3	20%
6-10 years	1	7%
>10 years	2	13%
mBCP Years since diagnosis *(Range: <1–14)*	3	3.3
mBCP Years diagnosis to metastasis *(Range: 0-6)*	1	1.7
mBCP Bladder surgical history		
Full removal	7	47%
Partial removal	2	13%
No surgery	7	47%
mBCP Current treatment		
Chemotherapy	3	20%
Radiation	1	7%
Immunotherapy	6	40%
Targeted	2	13%
Supportive/Palliative	2	13%
Hospice	3	20%

RESULTS

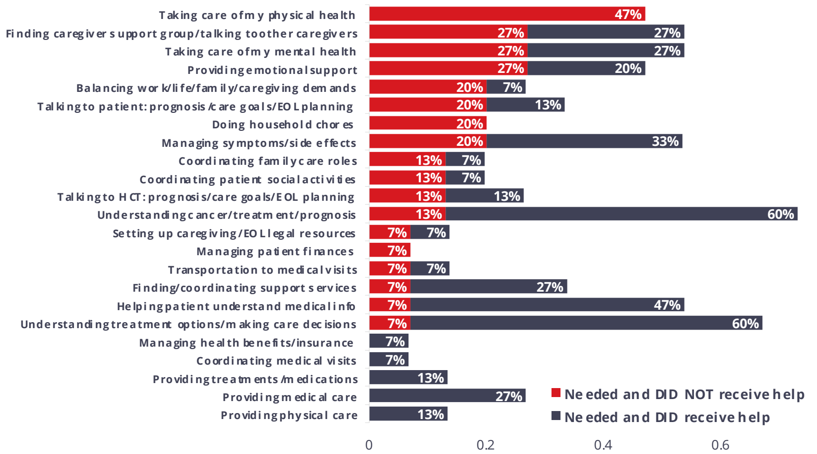
Caregiver Support: "Quite a Bit" or "Very Much" Involved



Health-Related Quality of Life Changes Due to Caregiving



Caregiver Help Needed vs. Help Received



Barriers/Facilitators to Research Participation

87% reported never taking part in caregiver-focused research because they were not aware of any studies

Suggestions to increase engagement included:

Increase Caregiver Awareness

"Awareness of such studies."
"Being informed about it."

Involve Oncologist / Health Care Team

"It could be part of the doctors' information that is available during the frequent visits."
"Maybe working through the hospitals."

Offer Fair Compensation for Time / Effort

"Compensation. We are living off of my husband's SSI retirement alone for a family of 4!"
"Probably money because our time is so limited and precious when caregiving…I really did it to be of some help to someone in my position in the future."

CONCLUSIONS AND IMPLICATIONS

- Caregivers are heavily involved in mBCP care, and experience substantial health-related quality of life impacts due to caregiving.
- While most receive support on clinical information and mBCP physical care, many do not receive vital support for the psychosocial needs of themselves or mBCPs.
- Awareness was the primary identified barrier to caregiver research participation.
- Our results provide an important foundation for enhancing education and support of caregivers for all people living with advanced cancer.

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