The Caregiver Factor

Understanding the Medical Journey of the Caregiver and their Information and Support Needs

Disclaimer

Presenter

Ann Moravick, President, Rx4good
Ann.Moravick@rx4good.com
www.Rx4good.com

Background and Purpose

Understand the Role of Caregivers in Medical Decisions and How Best to Support their Journey

Caregivers often play a vital role in treatment decisions for their loved one. The purpose of this research is to better understand the dynamics of this role and what caregivers need as they embark on the care journey and as they gain more confidence in their role.

While caregiver experiences and needs may vary based on a number of factors, the research is designed to identify commonalities across a wide range of people who provide voluntary care to patients (adults and children) with chronic conditions.

Methodology

IRB approved 15-20 minute online survey of 633 caregivers

U.S. residents age 18+
Provide voluntary care to adult or child with chronic condition
Involved in medical decisions/treatment choices

April 16 to May 31, 2018

Extent to which caregiver is involved in discussions about medical choices and/or treatment decisions for care recipient	
Very involved	91%
Somewhat involved	7%
Not very involved	1%
Not involved at all	*Not qualified for survey*

Methodology (continued)

To ensure a wide representation of U.S. caregivers, a variety of online recruitment methods were used:

- Distribution of the survey link to partner organizations' membership (email, newsletters, social media)
- Outreach to diverse disease, caregiver groups and social media influencers
- Targeted Facebook advertisements

Survey results are representative of caregivers who were reached by these methods and who responded to the survey

Our Partners

- Acres Global
- Alagille Syndrome Alliance
- Alkermes
- American Cancer Society – Cancer Action Network
- American Chronic Pain Association
- American Heart Association
- American Medical Women's Association
- American Syringomyelia and Chiari Alliance Project
- Amgen
- Angelman Biomarkers and Outcome Measures Alliance
- Cancer Support Community
- CancerCare
- Caregiver Action Network
- Charlotte and Gwenyth Gray Foundation to Cure Batten Disease
- Cholangiocarcinoma Foundation
- Colorectal Cancer Alliance
- Critical Mass
- DC Outreach
- EMD Serono
- The End Brain Cancer Initiative
- Enzyvant
- Epilepsy Foundation
- Evans Syndrome Foundation
- Family Voices
- First Descents
- Food Allergic Adults Support Group
- g6pd Deficiency Foundation
- Global Genes
- HealthyWomen.org
- Hereditary Neuropathy Foundation (HNF Cure)
- Hermansky-Pudlak Syndrome Network
- Horizon Pharma
- Ionis Patient Advocacy
- Kite Pharma
- Les Turner ALS Foundation
- Leukemia & Lymphoma Society
- Luck Fupus
- Medical Education Institute
- Mended Hearts
- Mended Little Hearts
- Merck
- MS Focus
- National Alliance for Caregiving
- National Alliance on Mental Illness
- National Blood Clot Alliance
- National Osteoporosis Foundation
- National Register of Health Service Psychologists
- National Stroke Association
- NTMinfo
- Parent Project Muscular Dystrophy
- Parkinson's Resource Organization
- Patvocates
- Patient Empowerment Network (Powerful Patients)
- PTC Bio
- RUN - Rare & Undiagnosed Network
- Sage Therapeutics
- Santhera
- Sharsheret
- Short Bowel Syndrome Foundation
- Sofia Sees Hope
- Spark
- Teen Cancer America
- Tesaro
- The Samfund
- Ulman Cancer Fund for Young Adults
- US Pain Foundation
- Vestibular Disorders Association
- Wilsons Disease Association

Caregiver and Care Recipient Characteristics

Caregivers

	n=633
Gender	
Female	**82%**
Male	**18%**
Age	
<40	**9%**
40-49	**15%**
50-59	**30%**
60-69	**31%**
70+	**16%**
Married	**78%**
College grad +	**79%**
Employed full/part time	**48%**
Race/ethnicity	
White or Caucasian	**81%**
Black or African-American	**3%**
Hispanic, Latino, or Spanish	**9%**
Other	**3%**
Prefer not to say	**4%**

Care Recipients

	n=633
Patient relationship to caregiver	
Spouse / Significant other / Partner	**52%**
Parent/parent in-law	**27%**
Child or stepchild	**9%**
Adult child	**6%**
Someone else	**6%**
Patient Gender	
Female	**41%**
Male	**59%**
Patient Age	
<20	**8%**
20-29	**6%**
30-39	**4%**
40-49	**6%**
50-59	**13%**
60-69	**21%**
70-79	**19%**
80+	**23%**

Caregivers Represented Patients with Wide Variety of Conditions

	n=633
Condition that most drives care recipient's needs *(top mentions)*	
Stroke, Trans Ischemic Attack (TIA), or post-stroke symptoms	**39%**
Alzheimer's disease, mild cognitive impairment or dementia	**20%**
Chronic Pain	**14%**
Heart disease, including heart failure, post-heart attack care	**14%**
Blood cancers such as Leukemia, Lymphoma, Myeloma	**13%**
Mental health, including depression, anxiety disorders, bipolar disorder, schizophrenia, etc.	**12%**
Diabetes or related complications	**12%**
General age-related issues / elder care	**11%**
Cancer, other than blood cancers	**9%**
Muscular Dystrophy, Duchenne Muscular Dystrophy	**7%**
Kidney disease	**6%**
Osteoporosis	**6%**
Bowel disorders	**6%**
Disability due to trauma/accident or neuromuscular disease	**5%**
Autoimmune disease (lupus, rheumatoid arthritis)	**5%**
Seizure disorder	**5%**

Care Dynamics

Nearly three-quarters of surveyed caregivers live in the same household as their care recipient; the majority of those who do not live within close proximity.

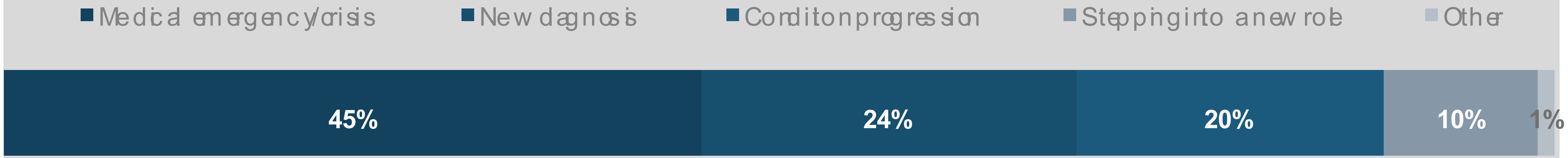
Most have been involved in care choices/treatment decisions for more than 3 years.

	n=633
Caregiver and care recipient currently live in same HH	**74%**
Among those who do not live in the same household **Distance to care recipient**	n=158
Walking distance/10-15-minute drive	**49%**
1 hour drive	**26%**
1-4 hour drive	**8%**
4+ hour drive	**5%**
Not within driving distance	**12%**

	n=633
Years of involvement in making care choices and treatment decisions	
Less than 1 year	**6%**
Between 1 and 2 years	**14%**
Between 3 and 5 years	**25%**
Between 6 and 10 years	**24%**
Between 11 and 20 years	**20%**
More than 20 years	**12%**

Most caregivers are thrust into the role suddenly with a medical emergency or new diagnosis

Situation When Care Role First Became Apparent
One response permitted, among all answering, n=632



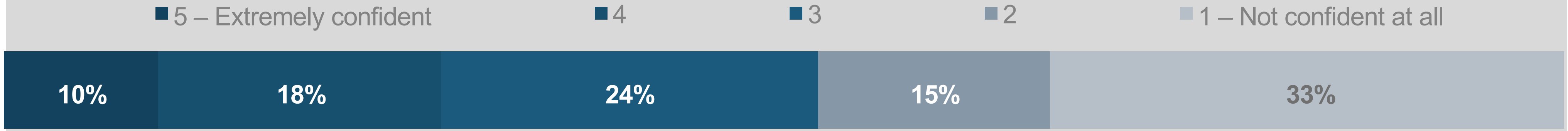
69% stepped into their caregiving role based on an emergency or new diagnosis

Caregivers are not fully prepared for their role in medical decisions at the outset

Caregiver Confidence in Having All Information Needed to Make Medical Decisions/Treatment Choices:

When first involved as caregiver

One response permitted, among all answering, n=631



Only **28%** felt they had the information they needed to medical decisions/treatment choices at the outset

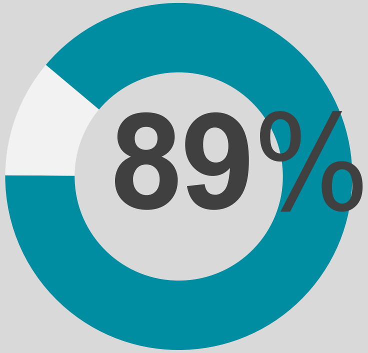
While actively seeking information, few could claim expertise when they moved into the caregiver role

Caregiver Agreement with Statements: When first involved as caregiver

% Strongly/somewhat agree

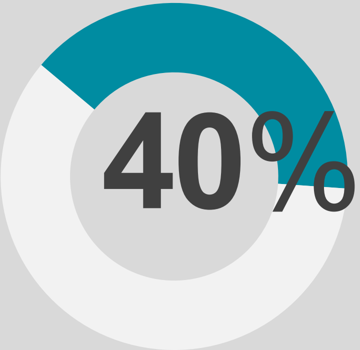
I was frequently searching for more information about their medical condition(s), medications and treatment options

Among all answering, n=631



I considered myself to be an expert on their medical condition(s), medications and treatment options

Among all answering, n=631



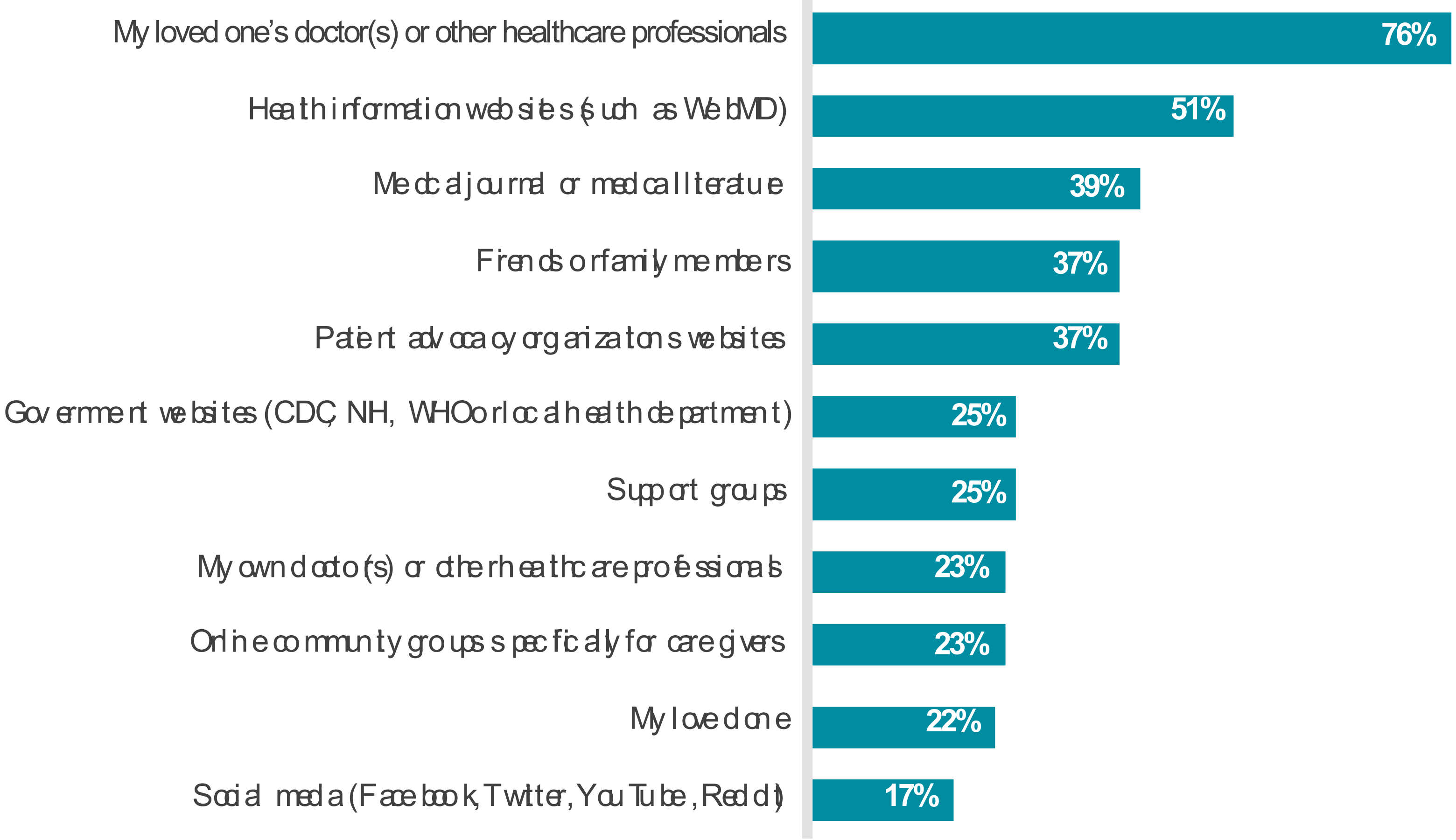
Q22. Still thinking about when you first became involved as a caregiver, please indicate the degree to which you agree or disagree with the following statements.

Scale: Strongly disagree. Somewhat disagree, Somewhat agree, Strongly agree

HCPs play an important role in helping caregivers learn about care options and treatment choices

Sources used to learn more about care options/treatment choices when first became involved as caregiver

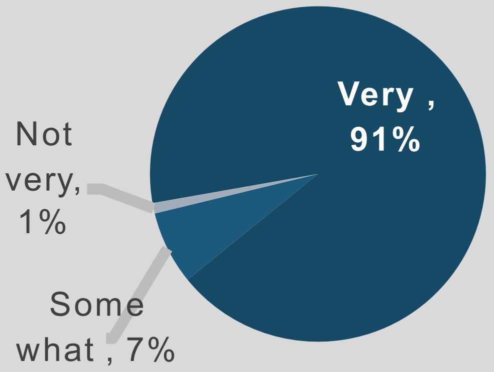
Multiple responses permitted, top mentions shown, n=631



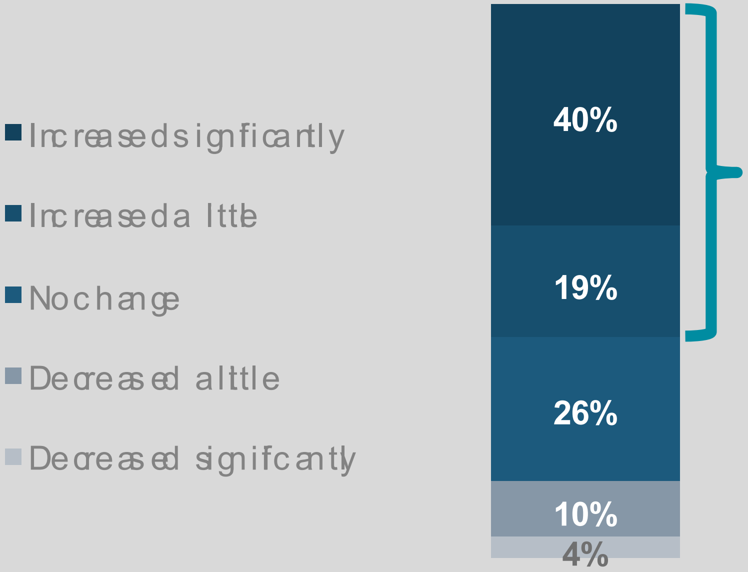
Q21. Still thinking about the time when it became apparent that you would be playing a role in caregiving...Where did you turn to learn more about the available care options and treatment choices?

Caregivers are highly involved in treatment decisions and are becoming more so

Extent of involvement in medical choices and/or treatment decisions
Among all answering, n=633



Change in role in medical choices and/or treatment decisions over past year
Among all answering, n=630



59% report an increasing role in medical decisions

Q7. To what extent are you involved in discussions about medical choices and/or treatment decisions the person you care for?
Q32. Over the past year or so, how has your role in medical and/or day-to-day support and decision making changed (if at all)?

Caregivers are often the "point person" for care, participating in HCP appointments, coordinating across specialists, and responding to emergencies

17

Average # times caregiver visited HCP with their care recipient in the past year

n=627

6

Average # HCPs care recipient has seen in the past 2 years

n=629

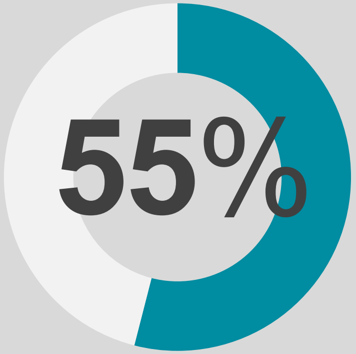
2

Average # ER/ICU trips in past year

n=631

Agree: I often need to remind healthcare professionals of the other health conditions affecting my care recipient

Among all answering, n=625



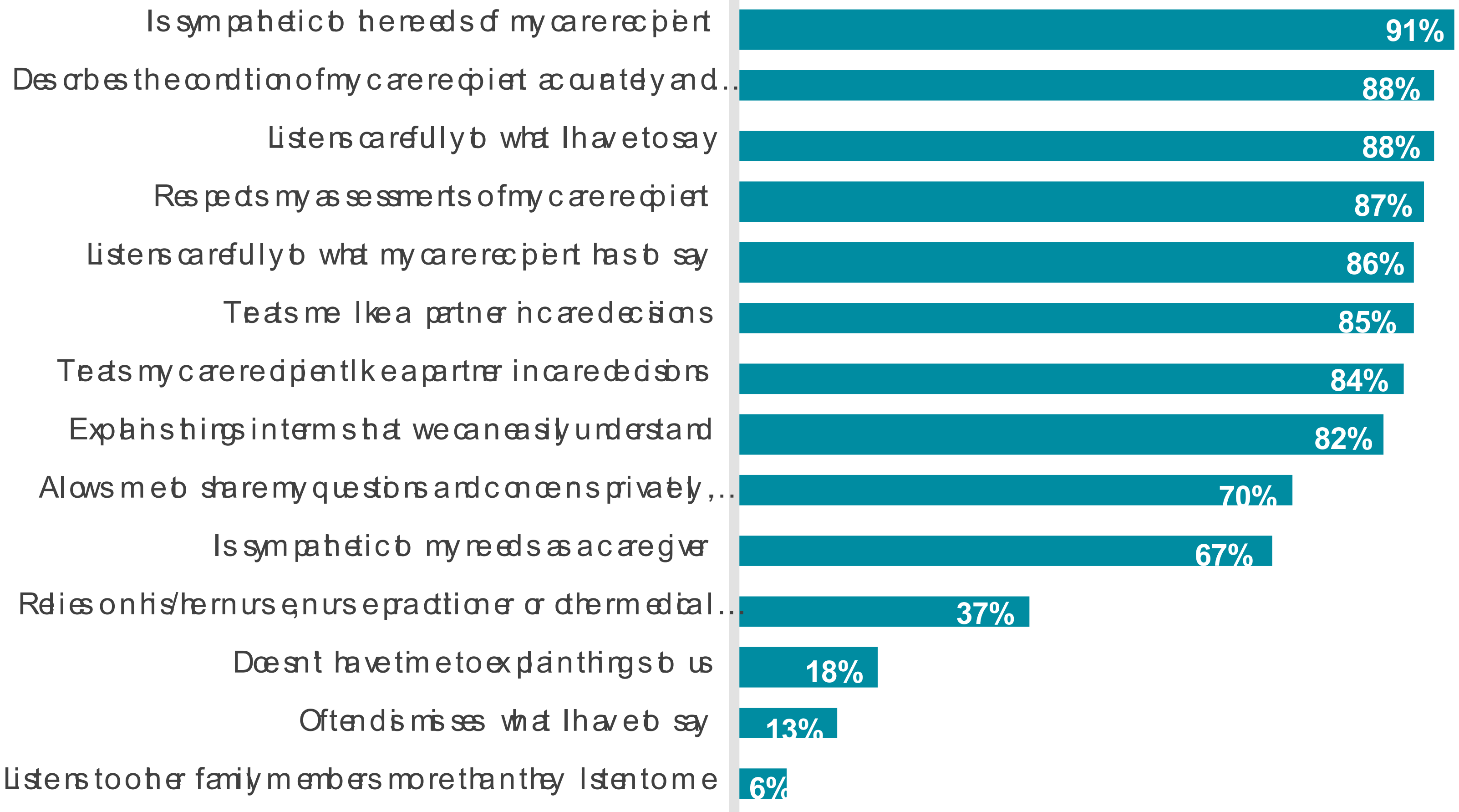
Q38. In the past two years, which of the following types of healthcare professionals have seen the person you care for in any setting – including office visits, hospital stays, etc.? Please choose all that apply.
Q39. In the past year, how many times have you visited a doctor or healthcare professional with the person you care for – excluding trips to the hospital or emergency room? Your best estimate is fine.
Q39. In the past year, how many times have you visited a doctor or healthcare professional with the person you care for – excluding trips to the hospital or emergency room? Your best estimate is fine.

Q41. On the scale below, please indicate how much you agree or disagree with the following statements about the healthcare professionals of the person you care for. Scale: Strongly disagree. Somewhat disagree, Somewhat agree, Strongly agree

Overall, caregivers have very positive perceptions of their care recipient’s primary physician

Agree: The doctor who is most knowledgeable about my care recipient…

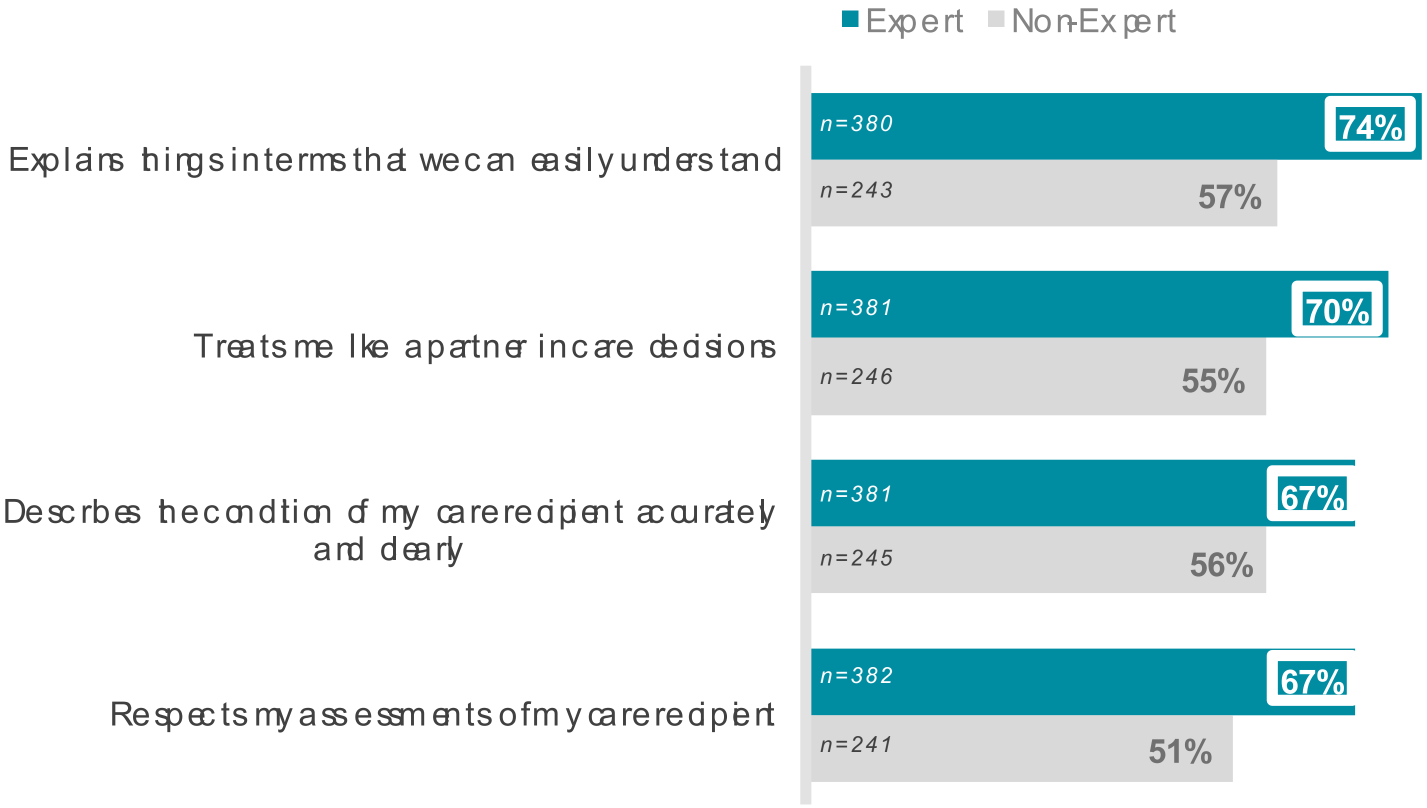
Among all answering, n=620-626



Q21. Still thinking about the time when it became apparent that you would be playing a role in caregiving...Where did you turn to learn more about the available care options and treatment choices?
Scale: Strongly disagree. Somewhat disagree, Somewhat agree, Strongly agree

Caregivers who are confident in their condition/treatment expertise report better communication with their care recipient’s doctor

Strongly Agree: The doctor who is most knowledgeable about my care recipient…



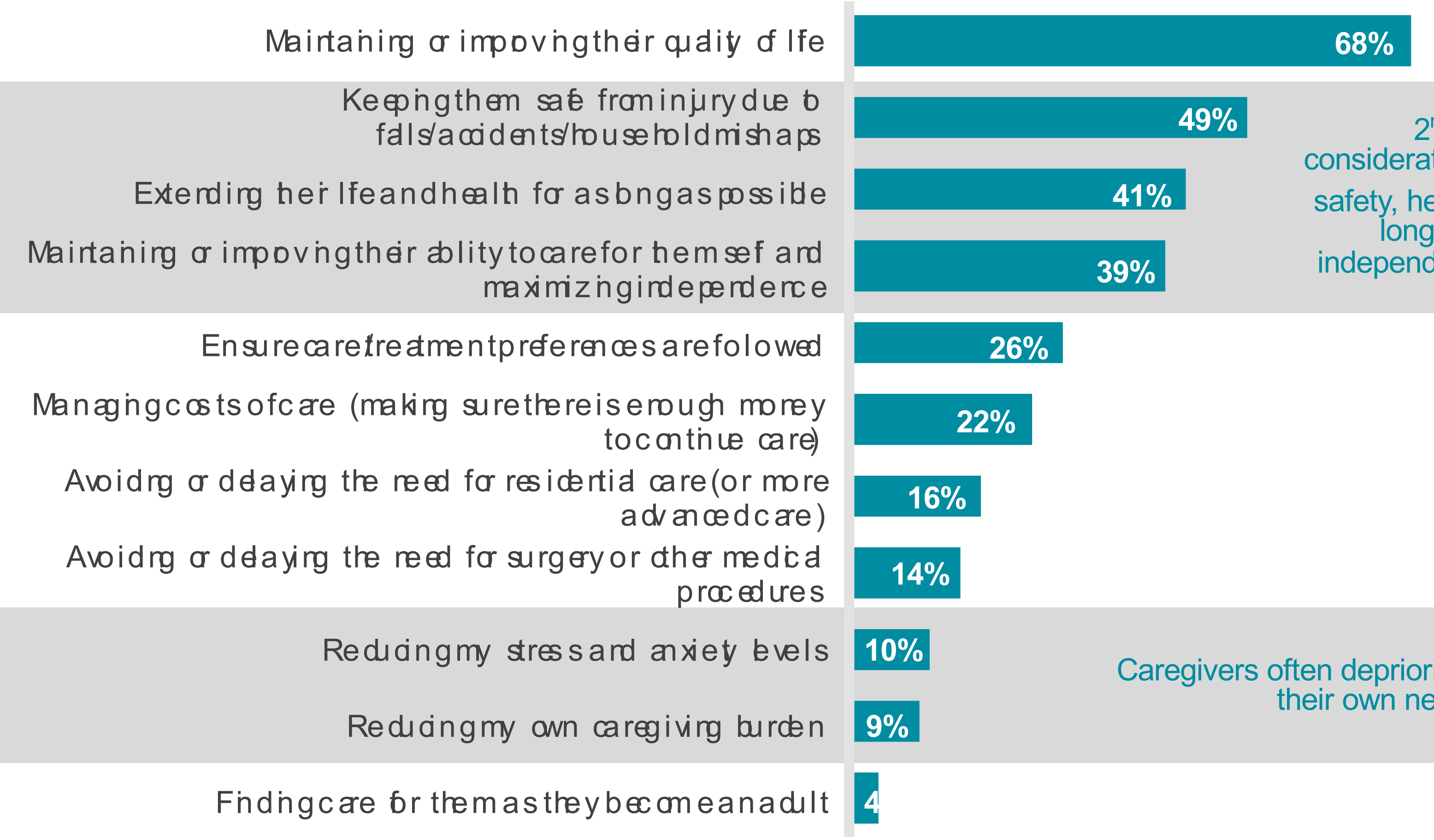
Boxes indicate statistically higher percentages at the 95% level of confidence

Expert = agree with statement: I consider myself to be an expert on their medical condition(s), medications and treatment options
Q42. Please indicate how much you agree with the following statements about the physician who is most knowledgeable about your care recipient.
Scale: Strongly disagree. Somewhat disagree, Somewhat agree, Strongly agree

Top priority patient quality of life, lowest priority caregiver burden

Care Priorities: Rank Ordered #1/#2/#3

Among all answering,
Base: total answering,
n=635



2nd tier considerations:

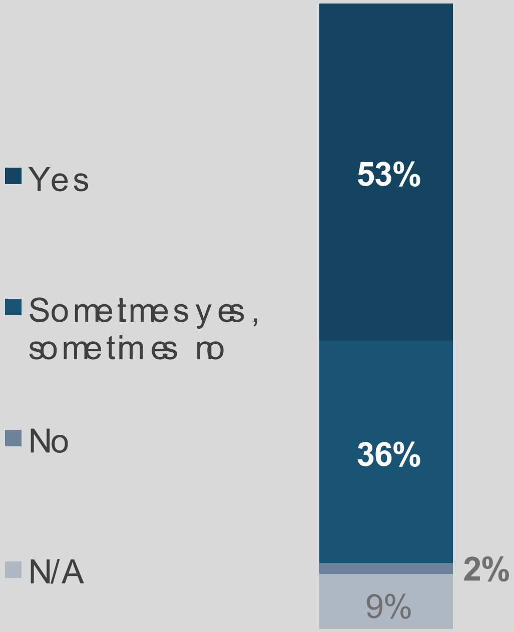
safety, healthy longevity, independence

Caregivers often deprioritize their own needs

Q34. We would like to know what factors you personally consider when deciding on care and treatment options for your care recipient. Please rank order the items below by placing a "1" next to the one that is the most important, a "2" next to the second most important factor, etc. If you are not actively involved in these decisions, please rank order based on what your priorities would be if you were involved.

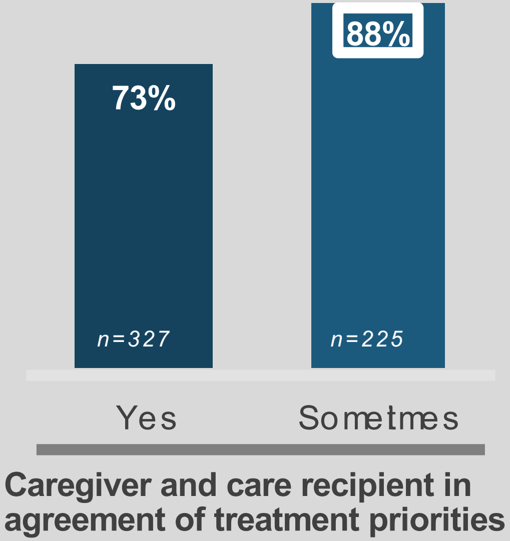
Caregivers and recipients are often in agreement on care priorities

Caregiver and care recipient in agreement of treatment priorities
Among all answering, n=630

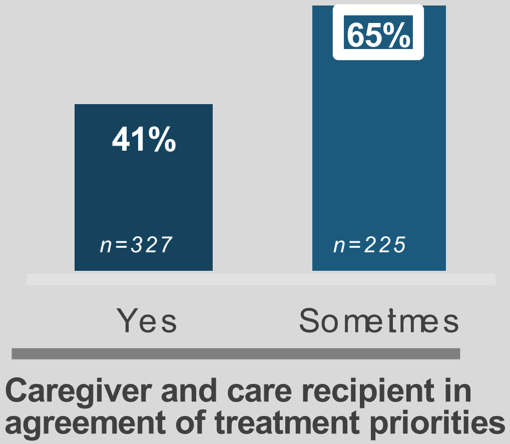


Agreement on priorities lessens stress on the caregiver and on the relationship

Agree: Care decisions put a great deal of stress on me
Among all answering



Agree: Care decisions put a great deal of stress on my relationship with the person I care for
Among all answering

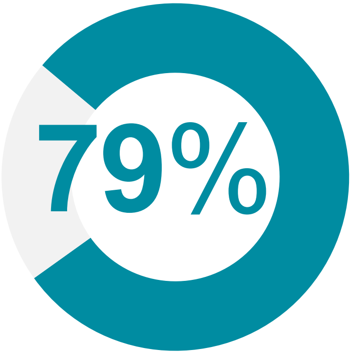


Boxes indicate statistically higher percentages at the 95% level of confidence

Q35. Are you and the person you care for in agreement with these care priorities?
Q37. On the scale below, please indicate the degree to which you agree or disagree with the following statements. *Scale: Strongly disagree. Somewhat disagree, Somewhat agree, Strongly agree*

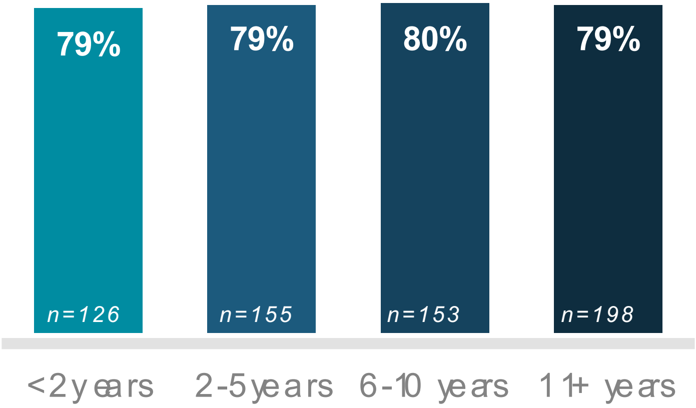
Caregivers continue to seek information throughout their journey

Agree: I am frequently searching for more information about their medical condition(s), medications, and treatment options
Among all answering, n=632



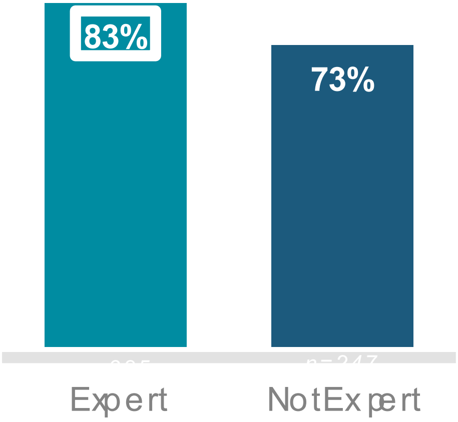
… regardless of years of experience with medical decisions

By years of involvement in making care choices and treatment decisions



… or their perceptions of their own expertise. In fact, "experts" are even more likely to be information seekers.

By perceptions of condition expertise



Boxes indicate statistically higher percentages at the 95% level of confidence

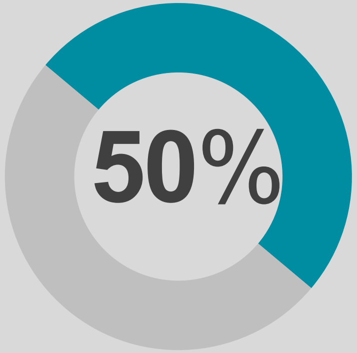
Expert = agree with statement: I consider myself to be an expert on their medical condition(s), medications and treatment options
Q17. For how many years have you been involved in medical care choices and treatment decisions for your care recipient?
Q29. On the scale below, please indicate the degree to which you agree or disagree with the following statements. *Scale: Strongly disagree. Somewhat disagree, Somewhat agree, Strongly agree*

Caregivers will continue to seek information to help them in the next step of their journey

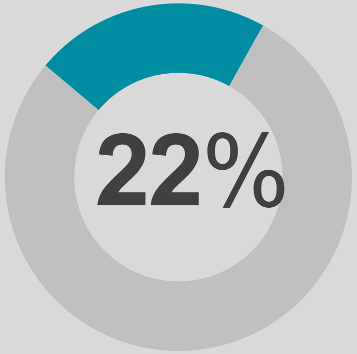
Information about…	**Information Sought in the Past**	**Information Helpful for Future**
New treatment options and medications	57%	69%
Support programs for caregivers like me	53%	63%
Alternative treatment options	45%	56%
Treatment options being studied in clinical trials	44%	55%
In-home caregivers, assisted living or skilled nursing facilities	43%	54%
Information about temporary or respite care facilities	30%	51%

Caregivers express interest in clinical trial information, but few claim expertise in this area

Agree: I am frequently searching for more information about clinical trials and drugs in development
Among all answering, n=631



Agree: I consider myself to be an expert on clinical trial options and drugs in development for them
Among all answering, n=630



Q30. What types of information have you sought in the past, and what types of information would be most helpful to you in planning for future caregiving needs?
Q29. On the scale below, please indicate the degree to which you agree or disagree with the following statements. *Scale: Strongly disagree. Somewhat disagree, Somewhat agree, Strongly agree*

Executive Summary

4 Key Takeaways from the Research

Crisis Leads to Central Role in Decision Making

Most caregivers are thrust into the role suddenly, increase their role over time, are very involved in medical decisions and doctor visits and are on point in a crisis.

Respect for Physician Grows with Knowledge and Confidence

Caregivers who are confident in their overall condition/treatment expertise report better communication with their care recipient's doctor. Overall, very positive perceptions of physician.

Treatment Goals for Patient More Important than Personal Goals

Caregivers put their patient's needs and goals first and work to gain consensus when decisions need to be made. Decisions put stress on the caregiver, their relationship with their care recipient, and others in the family – but agreement on care priorities lessens these stress levels.

Caregivers Constantly Searching Throughout Journey

Even those who feel confident – even "expert" -- in their knowledge of their care recipient's condition continue to seek information that can help them be more confident in medical decisions. They will continue to do so as they move to the next step in their journey, whether that involves new/different treatments for their care recipient, additional care options, or ways in which they can find support for themselves in their care role.

Implications

4 Key Implications from the Research

- Need for crisis support and education at time of diagnosis to help caregiver adjust to unforeseen role
- Physicians have an ally in an informed caregiver and could benefit from engaging them in shared decision-making
- Providing patient and caregiver tools to gain consensus on treatment paths could ease stress and decision-making
- Triaging information to the caregiver aligned with various stages of medical decision making would ease the caregiver journey

Ann Moravick, President, Rx4good
Ann.Moravick@rx4good.com
www.Rx4good.com