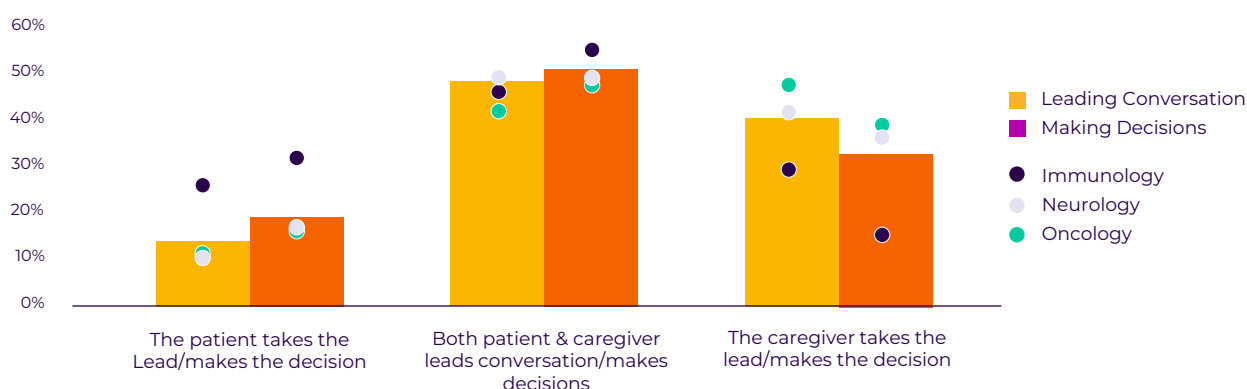


Support Our Unsung Heroes – The Case for Greater Caregiver Engagement

Treatment for a chronic disease induces stress, anxiety, and additional behavioral health challenges for both patients and caregivers. The caregiver study, conducted in partnership between the PURE Report and PatientsLikeMe, focuses on the needs of the caregiver community and is stratified by caregiver-patient relationships and therapeutic areas to deliver actionable insights that the pharmaceutical industry can act upon.

The pivotal impact and involvement of caregivers during a patient’s treatment course are frequently overlooked, leading to unheard voices and unaddressed needs. This caregiver study serves as a tool for the pharma/biotech industry, providing guidance to incorporate caregiver support and preferences into the design of support services. By acknowledging and understanding the unique challenges and perspectives of caregivers, the industry can develop more targeted and effective solutions that enhance the overall patient experience and outcomes.

Figure 1. The role of the caregiver vs. the patient.



Introduction: The PURE Report & PatientsLikeMe’s caregiver study highlights the needs, perceptions, and experiences of 164 caregivers across immunology, neurology, and oncology. With two-thirds of the caregivers reporting spending 20 hours or more per week caring for their loved ones, the caregiver community voices the perspectives of partners, children, and parents of patients, thereby conveying a holistic overview of the varying roles and challenges in the community.

Needs & Perceptions: Caregivers are involved at every stage of the treatment journey and are pivotal in shaping patient success and outcomes. They have equal or more say than the patients in the conversations with healthcare providers or management of healthcare-related decisions for the patient (see Figure 1).

While the role itself is demanding and at times, incessant, their perspective and outlook can anchor how patient services can assist the caregiver community. Caring for a loved one comes with a myriad of challenges to the health of caregivers. Having no breaks from responsibilities results in caregivers ignoring their health and bearing the consequences of it, which in turn adds to their healthcare burden. They often experience a sense of resentment towards the patient and feel like they are putting their life on hold.

The fatigue and emotional toll the caregiver encounters drive a need to connect with others in similar situations. Figure 2 illustrates a need the caregivers have where they feel the pharmaceutical industry can step up and do a better job.

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Figure 2. How caregivers want pharma to support them.

Be forthcoming with side effects & their impact	Lower drug prices
Support to manage the patient's suffering	Be empathetic when communicating with us
Caregiver support to reduce burden & fatigue	Reduce barriers to financial assistance
Provide better on-call support	Streamline prescription refill process
Provide caregiver specific guidelines for drugs	Improve drug efficacy and inform caregivers about new drugs with better outcomes

Pharma can support caregivers by:

- Further educate them on financial support offerings that are available to the patient
- On-call support like hotlines for in-the-moment support to the caregivers
- Guidelines on how caregivers best can support the patient
- General empathy and understanding of their situation are an appreciated element

Patient Adherence Impact: Neurological disorders, for example, create higher dependencies from the patient on the caregiver and adherence is a crucial need for support. Medication management is challenging and without adequate support and vigilance, can inversely affect patient outcomes.

Caregivers rely on several resources and systems to support their loved one's treatment, with most utilizing their own method of record-keeping for medications but also relying on text reminders and apps.

Patients, on the other side, tend to rely more on apps and reminders from patient support programs/specialty pharmacies even though nudges from their support people also play a big role in keeping them adherent to their medications.

Call to Action: A caregiver is a critical group of people that many organizations are discussing how to best support, but very few are doing anything for the caregivers. Providing support is not only the right thing to do for an exposed stakeholder but will indirectly help the patient given the prominent role the caregiver has in healthcare decision-making for the patient. According to the research, The two most important areas in which pharma can support the caregivers are:

1. Educate the caregivers on how to best care for their loved one, e.g., tips on symptoms and side effect management, disease education, and administrative & logistical advice.
2. Emotional support which can either be during direct engagement with caregivers or guide them to caregiver groups/networks for peer-to-peer support.

About the PURE Report: This white paper focuses on just a small part of the broader PURE Report (Patient services Utilization, Recognition, and Experience), an independent, syndicated study of patient and HCP satisfaction with manufacturers' patient support services, along with manufacturer rankings across 7 PURE indices in Oncology, Neurology, Rheumatology, Dermatology, and Gastroenterology and is powered by Nuvera.

About PatientsLikeMe: PatientsLikeMe (PLM) is one of the world's largest consumer engagement and activation platforms with a reach of over 45 million patients/healthcare consumers. PLM's Patient Support Program (PSP) solution supports brands to drive adherence, enhance the patient/caregiver experience, and drive brand awareness.



For more information, contact:

Jens Kulstad

jens.kulstad@nuveraconsulting.com:

Darcy Duckenfield

dduckenfield@patientslikeme.com