Most industries recognized long ago the value in learning from those who best understand and influence their consumers – in other words, the consumer’s friends, family members and peers. Friendship circles, mommy groups and interviews with married couples have for years provided consumer goods, technology and financial services industries deep insights into the drivers of decision-making. A group of friends engaged by a moderator, for example, quickly identify their ulterior motives for making emotionally-driven purchases during a shopping excursion, thereby isolating the underlying reason for a splurge outside the predetermined price range. In another instance, a husband and wife who debated their retirement plans with a market researcher promptly delved into the emotional quagmire of family spending – a factor which lies at the heart of retirement planning and investment decisions.

Each year, the pharmaceutical industry spends well over a billion

••• health care research

Patients don’t go it alone

The role of the caregiver in health care market research

| By Jennifer Gold

Researchers in many other industries solicit the input and perspectives of those inside their target consumers’ spheres of influence. It’s time health care and pharmaceutical marketing researchers did the same.
dollars on market research in the U.S. alone—most of it on health care providers (HCPs) and consumers. In particular, industry leaders have conducted in-depth research into the role of physician as decision-maker and patient as consumer.

As economic pressures in the U.S. health care system continue to increase, HCPs have less time to make thoughtful treatment decisions about each individual patient’s care. This, in turn, puts a greater burden on patients, who are sometimes ill-equipped to make complex decisions.

It is well-documented that patients find it difficult to digest information in the physician’s office—especially at the time of diagnosis.3 Even so, many market researchers don’t see this as a challenge and assume a patient will be able to be an active and informed decision maker once they recover from the initial shock of diagnosis and become more immersed in their disease.

As it turns out, however, patients are less likely to recall information related to the disease when the news or information is perceived to be even mildly negative.4 Even when only at risk, a patient’s recollection of relevant information decreases as they start to associate themselves with the risk group. For example, women at risk for breast cancer have trouble recalling information on breast cancer prevention, because they feel threatened about one day having breast cancer.5

As market researchers, we presume that a patient’s ability to recall events and information improves over time. This is not only incorrect—it seems to be the complete opposite.

Bringing a caregiver’s perspective into the equation, however, changes everything.

**Emotional and physical support**

Patients need emotional and physical support from their caregivers at each stage of the journey—from diagnosis to ongoing compliance and, in some cases, end-of-life decisions. A caregiver, such as a spouse, adult child, parent or friend, is chosen by the patient and brought into his or her most inner circle. They accompany the patient to doctor visits, conduct desk research on behalf of the patient, keep track of concerns and make pharmacy trips to fill prescriptions. In addition, they offer support and provide researchers a more accurate account of events, challenges and emotions involved throughout. Although a caregiver is closely connected to the patient, they do not self-identify with the affected group which, as identified earlier, can be a major barrier in accurately recalling information.6

To ultimately understand the patient, it is important to recognize the power of caregivers as research subjects, for they offer a rich and honest perspective of the patient and are active and often unbiased participants in the patient’s health journey. It should also be noted that the caregiver can also represent a powerful promotional channel and have incredible influence on a patient’s decision to seek care, choose a provider or manage a therapy.

Our firm, ZS Associates, recently reviewed impactful qualitative research across the company and found that several standout health care projects included a caregiver in the research sample. Some of these projects involved caregivers in standard situations with patients who were elderly, very young or were incapacitated and who could not easily make decisions. Others were more atypical situations in which it was assumed that the patient could recall and make all health care-related decisions.

In one instance, ZS grouped caregivers in a broad sample alongside primary care physicians, specialists, nurses and patients to understand the complex journey of a patient in a chronic and sometimes debilitating condition. The research objectives were to pinpoint the drivers and barriers each stakeholder faced in the decision-making process in order to identify and influence the ultimate adoption of the client’s new product. A major insight into the project was related to timing—how early in the journey did the caregiver help the patient and at which subsequent times did the patient interact with various HCPs? We found that the patients were unable to accurately recall the timing and series of events and the HCPs used inaccurate information reported to them by the patient in the initial consultation. Only the caregivers were able to remember the important who, what, when, where and whys of patient and HCP interaction.

In another project on a rare disease therapy for adolescents, researchers focused exclusively on the very-involved caregiver parents to identify unmet needs and design programs for both parents and their children through co-creation activities. The ultimate goal of the project was to create and prioritize support programs. In this case, the parents were recruited into an online open forum in which they could share their experiences and ideas. Surprisingly, the research found that the parents—through their interactions and support of each other—identified unique ideas for their children based on challenges many of them faced. The caregiver parents identified the need for an online support group for the children themselves as they learned to overcome challenges associated with their condition.

In addition to classic research approaches, such as qualitative and quantitative market research, several new tactics are available to consider—a perfect example being social media. At the advent of social media big data sources, most market researchers expected to find information from stakeholders they are used to studying, i.e., the physician and patient. However, in retrospect, it may not be surprising that one in three posts about breast cancer in social media channels are from caregivers and not patients or physicians.7

**Target patients and caregivers**

Several well-studied promotional campaigns target not just patients but also caregivers. This, for example, includes big-brand erectile dysfunction pharmaceuticals—which target spouses—and Kaiser’s “THRIVE” campaign, which encourages patients and their caregivers to select an integrated delivery network based on the support received by both parties.8 Even recent contributors to Quirk’s have identified the influence of caregivers on patient research.9

When designing a market research study, it is important to remember that the caregiver offers crucial and sometimes less-biased insight into understanding the patient; insights that drive marketing decisions for patients and HCPs. Increased recognition of the caregiver community and involvement in patient decision-making provides a more accurate and comprehensive view of the health care journey.
of caregivers in online forums provide a rich source of information to be studied.

For a strategic marketer, the caregiver is becoming an important stakeholder with associated stresses and challenges in helping to manage a loved one’s disease. An estimated 36.5 million households in the U.S. contain a caregiver who has been in their role for an average of 4.6 years.10 A Web search for “caregiver support” yields 5,040,000 results and a search for “caregiver burnout” yields 453,000 results, indicating a significant unmet need in this important group.

We believe that several trends will increase the importance of caregivers to provide a patient perspective:

- a shortage of HCPs, including primary care physicians and nurses, relative to the aging and increasing population;
- the role of decision maker being increasingly handed over to patients by HCPs;
- an aging population that drives the need for increased caregiver involvement;
- a growing online community of caregivers who reach out to each other for support and information; and
- increased research and interest in the area of caregivers and caregiver support.

Do not take their journey alone
As the health care industry continues to understand the patient as a consumer, it is important to recognize they do not take their journey alone – the caregiver has been invited and will continue to join along for the ride. Shouldn’t we ask the caregiver what the ride is like? Eventually, we might be equipped to offer them a map, extra legroom and snacks for their journey.

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