

Getting patients to talk

Long-term illnesses or conditions often have a profound impact on a person's quality of life. Pain, disfigurement, embarrassment, stigmatization, physical limitations or disability, death, depression, anxiety, poverty and impaired relationships are some of the common results of chronic illnesses reported by primary and secondary sources and clinicians, patients and caregivers alike. In some cases, the therapies themselves and associated side effects can be the culprits. In others, the patient's inability to adhere to a drug regimen allows their condition to spiral out of control. In still other cases, the patient is unable to comply with lifestyle recommendations and the medications alone are not enough to keep them out of trouble.

Because of the impact on quality of life, patients often find great comfort in sharing their experiences with others who are living with the same condition. This is evidenced by the many support-group offerings by different types of organizations or institutions representing different chronic illnesses. The support-group environment is one in which members educate one another, find and give strength in and to one another and validate each other's failures, fears, desires, needs, goals and successes. It is a safe environment that fosters sharing of feelings and an honest discourse.

The support-group environment has applications extending beyond patient therapy in creating an ideal forum for conducting market research. By encouraging patients to open up and discuss their shared experiences in dealing with their illness, key behaviors and attitudes are identified which are directly complicit in poor/non-compliance and persistency with taking prescription medication. It can also serve to

A support-group approach to qualitative research

identify products, product attributes and services that would fulfill unmet needs in the patient marketplace. Often, the information gathered in a support-group environment is richer and more honest than what is captured in a more traditional group or one-on-one setting.

In traditional qualitative market research, the moderator-respondent bond and configuration, while positive in many ways, can create an unseen barrier when investigating some chronic illnesses.



By Will Leskin

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While many patients are eager to share some of their experiences, certain critical feelings or behaviors may be left unsaid. In some cases, it may be because the patient has a hard time admitting them. In other cases, they may be buried at a subconscious level, so the patient may not even realize they exist. One of the most empowering things for a patient to know is that “other people out there” have been through or are going through exactly what they are. This creates a bond between patients and allows them to open up in ways they may not have been willing or able to otherwise.

A case study involving Type II diabetes serves as a good example. In a qualitative project interviewing patients whose diabetes was not well controlled, the client’s assumption going into the study was that the poor control was related to poor compliance with taking the medication. The objective of the study was to find out why patients were not taking the medication as they should and what could be done to affect their behavior.

The study revealed, however, that the patients were highly compliant with their medication. In fact, we heard from quite a few of participants that they took their medication “religiously.” Interestingly, the reason for their high compliance was that they could not stick to their diet. They hoped (in some cases, believed) that talking their medication exactly as prescribed would offset their inability to stick to a diet low in sugars. Some of these patients were both embarrassed by and despondent over their “failure” with their lifestyle change.

As they discovered other patients in their group who were experiencing the exact same thing, their relief was evident. While it was gratifying to observe such catharsis during research, the most important aspect for the client and the outcome of the study was the richness of the ensuing discussion. In many cases, the patients had unrealistic

expectations of what the medications could achieve. They were afraid to face their medical provider and so were missing appointments and the opportunity to benefit from adjustments in their medication and other interventions.

These sessions provided essential information to the client on to how to focus marketing strategies that addressed the realities of the marketplace. The level of discovery during these sessions was made possible by setting them up to be more support-group oriented in nature rather than using a traditional market research approach.

While these kinds of “gems” may emerge whenever you bring a group of people together to talk about something, they are much more likely to be consistently observed if the research is set up to specifically foster such discoveries. In order to create the ideal environment, three key elements must be present: an ideal group size, a discussion-based room configuration, and a “group leader” approach to moderation.

In our experience, group size should be limited to four to five patients each. Smaller groups are more likely to achieve a group-wide bond than larger ones since it is harder for shyer respondents to fade into the background in small groups.

Another aspect of achieving a support-group type of setting is the physical arrangement of the research environment. Getting the participants out from behind the ubiquitous table and conducting the session in a circle of chairs is very important. By removing the table, a physical barrier between the respondents is eliminated, further encouraging a deeper level of sharing.

Most importantly, the moderator must foster a support-group type of discovery. The approach of the moderator who conducts these sessions should be that of a gentle and compassionate group leader. The moderator sets out with clear objectives in mind that seek to

uncover truths but are not dependent on a detailed guide. The group itself determines what in their lives is most impacted by their disease and treatment. By empowering the patients to drive the emotional agenda of the discussion, truths are uncovered that some patients will only share with other people in their situation. This leads to discovery of where the unmet needs are and how and in what ways patients are not being adequately served.

Due to the bond that is created between respondents, the support-group approach is not suitable for every study. For example, presenting these groups with a series of communication materials to get opinions about which execution they prefer would not be appropriate. However, conducting these groups to identify the core needs and drivers prior to the development of communications materials would be both highly appropriate and a very good use of this methodology.

Free to share

In sum, this type of research creates a safe environment in which patients feel free to share experiences, behaviors and attitudes they may not normally reveal. This, in turn, provides the ideal forum for uncovering the needs within a disease category of patients and providing clients with strategies for how best to meet those needs.

In a typical market research study involving patients, the client leaves with responses to a list of pre-determined questions and the respondent leaves with an honorarium check. In a support-group-based study, both parties end up with much more. The client takes away a deeper understanding of the world of the patient and, perhaps, answers to important questions he or she did not even think to ask. A patient often leaves with a feeling of fulfillment, answered questions and a sense of relief. Everyone gains from support-group-based research - the client, the patient and, most definitely, the market researcher. | Q