



Article from

Long-Term Care News

April 2019

Issue 50

Understanding How Families Search for Long-Term Services and Supports

By Eileen J. Tell

While many articles in this publication address how to manage the costs of long-term care (LTC) or efforts to design better products to pay for care, what many people find equally, if not more challenging, is finding and maintaining appropriate care when they or a loved one need it. Indeed, I will gladly help friends and family make decisions about whether and which LTC insurance product to purchase and how to craft coverage choices that best fit their needs. But when they call with an urgent need for help choosing a nursing home, or understanding what type of care would be best for their long-distance loved one, my industry expertise quickly becomes almost useless. I know the service landscape, but not how to navigate it. And I certainly do not know how to do so during a care crisis. So imagine how the typical consumer feels!

This is what motivated the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE) to study how families manage their way through this process. The research included a series of focus groups with consumers who had recently gone through the process of finding LTC services to explore the challenges they encountered and identify any helpful resources they may have encountered. This article summarizes findings from the consumer focus groups.

DYNAMICS OF THE CONSUMER EXPERIENCE

The focus group discussions revealed that, whether there was a sudden or gradual decline in the health of a family member, for most, an acute incident such as a fall, a stroke, or the sudden illness or loss of the primary caregiver such as a spouse precipitated the need for broader family involvement in the process of finding LTC service and formal care options. A common theme heard in all the groups was the lack of awareness of the decline in either physical or cognitive health of their loved one until this acute episode occurred. Aging parents typically shielded their adult children from the realities of

their limitations. Even families where some individuals tried to engage loved ones in conversations about planning ahead, should LTC needs emerge, these conversations were generally shut down, especially if these inquiries involved talking about finances. Some of the illustrative statements from the groups include the following:

“You don’t need to know. ... We’re fine. ... We’re handling everything.”

“My mom fell and there was a lot going on that we weren’t aware of. She was living by herself and we just did not know ... or recognize the signs of Alzheimer’s.”

“... whenever we called, mom said dad was out or busy. So we never talked to him on the phone. ... otherwise we would have realized how bad off he’d gotten.”

WHERE TO START

For many families, trying to find LTC options was completely new terrain. Even those who had been through the experience before in some capacity with another family member felt unprepared since each situation was unique. Most felt that they had no road map and that it is not a “once and done” process since changing care needs over time also means continually finding new solutions.

While consumers in the focus groups used the internet for research as an entry point to defining care needs and looking for long-term services and supports (LTSS), few found useful information in either the public or private sector online resources.

“I googled ‘long term care’ and her sickness, like what to expect ... but I didn’t really know what I was looking for.”

“I’m on the internet and I think ... what do I do? Where do I go? How do I start?”

“I looked up nursing home, I looked up assisted care ... but I didn’t know what to look for.”

Despite the large and growing presence of web-based information resources and their prominence in search results when consumers are looking for information about long-term care, very few of the focus group participants mentioned using or even being aware of these online resources. One or two of the heavily advertised services were mentioned, but many were skeptical that they would have the expertise or reliability to be worth trying. Those that did try one or two of the online services either could not understand why the recommended service options were not more convenient or understood that the service only included providers willing to “pay to play.”



“They’re getting the recommendation of the ones that are gonna pay for the referral. It wasn’t a good fit for us.”

“I did sign up ... I went through all the steps. And they did call me and took a lot of my dad’s information. But they recommended places that were not really close by.”

Many consumers looked largely to their family physician, hospital discharge planner or to the recommendations of family and friends as the most valued source of information on finding LTSS. In particular, for in-home care, word of mouth from others who had used that type of care was especially valued as a way to find a care provider. Families relied upon recommendations from friends, a religious organization with which they were affiliated or their healthcare provider.

“I searched out from word of mouth, and you know, people that I knew who had elderly parents that went through this ... that’s how I found out.”

“I really relied on doctors and my friends.”

Interestingly, familiarity with a facility simply in terms of having driven past it, seen advertising, or knowing it as part of one’s community was also important to peoples’ comfort in choosing a facility. Of course, that also corresponded to the desire to select a facility for a loved one nearby so that visits and other logistics are less complicated.

“My family is born and raised here. It was just a place we’ve driven by and then that just came to mind. I don’t want to tell you it was recommended. It was just a place we knew.”

None of the focus group participants was aware of the type of assistance that can be provided by a geriatric care manager. But when it was discussed, many found the idea of hiring a

professional familiar with local providers and able to match care needs with local resources to be a great service, and one they wished they had known about.

There was some familiarity with public-sector resources such as the Area Agencies on Aging (AAA) and Eldercare Locator. But those that had reached out found them to be of limited value. Respondents felt these options are not well positioned to serve the private pay population and are also not typically in a position to make provider recommendations. Indeed, many public agencies have long waiting lists and a mandate to serve a defined population. They also are often not permitted to offer provider recommendations but can provide lists, which these consumers did not find particularly helpful.

“When you call the AAA, they can’t give you a straight answer. ... They tell you ... ‘well this is here and this is here.’ ... If you ask, ‘what’s the best?’ ... they say ‘well they’re all good.’ ... Well, no, they’re not all good.”

“They gave me lists ... I wanted recommendations.”

The experience with Eldercare Locator was especially disappointing for those who reached out—expecting that it would help them “locate eldercare.” The toll-free number provides information about the Area Agency on Aging near where one lives which, as shown above, does not currently adequately address the needs of the typical private pay population, although the public sector is interested in doing so but can’t, both because of current mandates and limited resources.

EVALUATING OPTIONS

Once a care facility was identified, some participants talked about using the internet to learn how that facility compared with others with regard to staffing, complaints, services,

features and other indicators that might shed light on the facility's quality or suitability for their loved one. While many said that they did online research including looking up quality ratings or state certification information, for most the critical next step was to actually visit the facility.

"The internet will give you direction. But I'm hands-on. You have to go to the facility, look at the people and eyeball them when you're there. You have to check on the meals."

"It's a good starting point. But it's not an end-all. You still have to see it for yourself or know someone who had a good experience there."

None of the participants in these focus groups were aware of the CMS websites www.NursingHomeCompare.gov or www.HomeCareCompare.gov, both of which provide quality ratings data on those services. When shown samples of the information available there, consumers were interested, although there was still some skepticism about how current the data are, how reliably it is collected and whether providers are able to game the system.

"You never know if the nursing home knows when the inspectors are coming and if they 'spruce up' for it."

MAKING A CHOICE

Many of the participants expressed frustration at the process of finding LTSS because—in the end—all that matters is cost and availability. Despite doing extensive research, the ultimate factors driving provider selection were availability, convenience and cost.

"Even if you find a great place, you have to think about money, availability and the convenience of the place."

"We asked for recommendations in the area, and they did give us five. But only two had beds available. So we chose the one that was closest."

IMPROVING THE PROCESS

The participants in these focus groups liked the concept of a public-sector, nonprofit entity that could help curate information on how to find and evaluate long-term care services. Some, however, were skeptical that even nonprofits might have an agenda and not truly represent individuals' needs. People wished they could rely more on their family physician, health plan or local hospital to get this type of time-sensitive support. While the concept of a geriatric care manager was appealing, few were familiar with this resource or how to use it. Interestingly, only one individual from across the three focus groups had a long-term care insurance policy; she spoke about the assistance she received from the care coordination feature of that coverage when it came to finding care for her husband.

While others in the group had some awareness of long-term care insurance, they did not realize it provided help finding care, along with paying for services.

"There needs to be a liaison, somebody to help people make informed decisions right when it happens."

"Maybe the health care companies need to take some responsibility ... develop something that could help us ... that we would know who to contact."

LIMITATIONS OF THE STUDY

It is important to note some of the limitations of the study upon which these findings are based. First and foremost is the qualitative and nonrepresentative nature of the focus group research design from which these findings are drawn. Additionally, while the groups included a diverse mix of individuals in urban, suburban and rural locations, the study was conducted within a single state. Also, the emotional and logistical impact of finding facility-based care dominated the caregiver conversation during these focus groups; therefore, the study did not provide sufficient insights into the process of defining and meeting in-home care needs.

CONCLUDING THOUGHTS

Consumers struggle as much with how to find and maintain in place good quality LTSS for their loved ones as they do with how to pay for care. The crisis nature of the need for care and the ever-changing nature of those care needs add to an already emotionally charged and challenging process. For the long-distance and/or working caregiver, there are additional emotional and logistical burdens. The emotions and guilt that loved ones experience also complicate the process. Families are trying to satisfy numerous constraints while they search for care options that are affordable, suitable, available, local and of good quality—all without having the knowledge and information they need to evaluate or identify care providers against these attributes. Trusted, easy-to-use and transparent resources that can help families identify and evaluate care resources are greatly needed. While long-term care insurance policies typically address these needs, expanding this type of care-finding support to the vast majority of the population without insurance would be a well-received and much-needed resource. ■



Eileen J. Tell, MPH, is principal and CEO of ET Consulting, LLC. She can be contacted at eileenjtell@gmail.com.