UCLA CENTER FOR HEALTH POLICY RESEARCH

HEALTH DISPARITIES

January 2014

"Angie" - A Case Study

77:	*Age*
52:	*Number of IHSS hours currently received each month.*

Other formal supports received: *Visiting nurse once a week*

Informal supports: *Daughter and son-in-law, extended family during visits to country of origin*

Reduction of supports in recent years: *IHSS cut by 5 hours per month; reduction of monthly income; no longer authorized for Lantus pens for insulin injection*

Introduction

Angie is a 77 year-old woman living with her daughter and only child, Julia, and son-in-law in a metropolitan region of California. Angie has Parkinson's disease, diabetes, heart disease, arthritis and osteoporosis. She was diagnosed with lymphoma one year ago, and has now concluded her treatment.

Angie requires assistance with bathing, grooming, and administering daily insulin injections. All of this help is provided by Julia, who is also her paid IHSS provider. Julia also does the shopping, housework and laundry, and manages her mother's medical care, although Angie continues to manage her own bills.

As the result of her health conditions, walking short distances is difficult for Angie, even with a walker. As a result, she does not leave the house without the assistance of her family members, who also work full time outside of the home. This leaves her isolated for many hours of the day.

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The HOME Project

(**H**elping **O**lder- adults **M**aintain independenc**E**)

...is an ongoing qualitative study that is documenting the experiences of older Californians with disabilities, who depend on fragile arrangements of paid public programs and unpaid help to live safely and independently at home.

In-depth interviews are being conducted with older adult consumers of In-Home Supportive Services (IHSS) and their caregivers. All are insured through both Medicare and Medi-Cal (dual eligible) and most receive other public supports and/or informal help as well. The following case study illustrates how changes in need and supports impact older adults in the state.

See the related policy brief:

"Disconnected?: Challenges of Communicating Cal MediConnect to Low-Income Older Californians"

http://healthpolicy.ucla.edu/hometoo

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Background

Angie immigrated to the United States on her own in the 1970s. She worked to support her family and lived independently until she was diagnosed with Parkinson's disease and her overall health started to decline. At that point, she moved in with her only child, Julia, and her son-in-law, and depended on them for many of her care needs. At the beginning of our study, Angie was under treatment for non-Hodgkin's Lymphoma and her daughter was busy managing her treatment. By the third interview Angie was declared cancer-free, but was still being closely monitored for any recurrence of the cancer.

Continuity of Care

Angie highly values the ability to continue seeing the same doctors that have been treating her medical conditions for the last couple of years and, in particular, the oncologist who oversaw her cancer treatment. Because Julia works during the day, she briefly considered enrolling Angie in a Community-Based Adult Services (CBAS) program, but decided against it because it would have meant automatic enrollment in a Medi-Cal managed care plan and a switch to new providers. Of her mom, Julia says:

> She doesn't want to change doctors, especially the oncologist and cardiologist because they know about cancer and they still see her, and she feels comfortable.

Julia is aware of the upcoming transition to managed care. When asked about how she thinks her mom might respond to a change in her medical providers, Julia says that she is concerned about the quality of care Angie would receive from providers who are not familiar with her medical history:

> I believe she's going to think if any of the other doctors can detect any return of the cancer, because those doctors that she has right now, they are very on top of it, any spread or return. They are on top of the illnesses that she had before.

Family members contribute to care continuity

As a result of her illness, Angie has lost her ability to speak English — her second language — and is now unable to communicate with her medical providers directly because none of her doctors speak Spanish. Angie's daughter Julia is critical to her continuity of care, as she is fluent in English and has a great amount of medical knowledge, having been trained as a medical doctor in her country of origin.

Even with Julia's dedicated efforts to coordinate her mother's care, there remain significant gaps in her network of medical care and long-term services and supports. For example, Julia reports that she has tried to arrange mental health care for her mother, but has not been able to find appropriate services:

> I requested [a therapist], but that doctor doesn't speak Spanish, so it's hard to get that… and it's not possible with my [work] condition. I think the main problem is the Spanish, and also I don't remember if Medi-Cal does not cover the mental health…I really don't know…

In addition to struggling to find mental health care for her mom, Julia also works to arrange transportation to medical appointments. This is no small task, given that Julia works full-time, and sometimes has to rely on her husband (Angie's son-in-law) to help out when he can. She says:

> We had trouble with transportation. I don't know if insurance covers it, because I usually end up paying for the transportation. I always give a ride to my ma, always take her to the doctors… she needs help; she could take a taxi but it would be hard for her, she needs a companion.

In the absence of any formal transportation services to medical appointments, and given limited

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availability on the part of family members, Julia has to arrange medical appointments for weekends when she is available. She expresses concern about how dependent her mother is on her to ensure continuous access to medical care:

> Sometimes I worry about it because I need to go everywhere and schedule everything and some times I worry that if I have an accident or some thing I don't know what she's going to do.

This concern has become more acute given recent changes in coverage for the medical supplies necessary to manage Angie's diabetes:

> They cut the Lantus pen, and they don't authorize any more for the Medicare, Medi-Cal patients. The doctors changed me for the vials. You know, it's a little more complicated in case, if she wants to inject by herself to use the vial, it's easier to use the pen. But the Medicare has cut that benefit… I always inject her, but in case of emergency, she can inject by herself, but using the pen, not the vial.

Other key gaps in Angie's medical network are dental and eye care.

> I took [my mom] to get new glasses, but she paid for that...because Medicare doesn't cover. She receives Medi and Medi. But they don't cover that. For the dentist they don't cover too, I don't understand why, as that is the time that they need it.

In the absence of covered dental care, Angie has gone out of the country to receive and fix her crowns, paying out of her pocket and relying on family members to help.

Care Coordination

Because Angie has forgotten how to communicate in English, she is completely dependent on Julia to communicate and coordinate all of her medical and long-term services and supports. Even a visiting nurse that comes once a week to visit Angie while Julia is away at work does not speak Spanish, meaning that Angie relies on Julia to communicate with medical providers even when she is not physically present. Julia arranges medical appointments and all other communication with Angie's doctors, coordinates her prescription medication, and schedules her transportation between her own work schedule and one or two other family members.

Despite Julia's efforts, there are significant gaps in Angie's care that result in part from her providers' lack of responsiveness beyond a limited set of medical concerns. When asked whether or not Angie's doctors are responsive to her unmet mental health needs, Julia says:

> Nutrition, yes, they have a nutritionist in my office, and they tell her how much she should eat, weigh, etc. Mentally -- no not really. If she says she's depressed, they say okay and try to get some support and if she feels bad she can go on medication but she hasn't really referred us to a counselor or anything like that.

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Information Sources and Engagement

Angie receives information about her medical and IHSS benefits primarily through the mail, although all of this information is managed by her daughter Julia; both report that they rarely receive information written in Spanish.

Julia says that she wished that information about medical and LTSS benefits were in Spanish and in larger fonts so that her mother could be engaged in coordinating her own care. Julia also learns about changes, including the upcoming transition to managed care, through news on TV.

Given that Angie's doctors pay little attention to her mental health needs, and the fact that her daughter Julia struggles with finding a provider who speaks Spanish and sees patients at times that work with her full-time work schedule, Angie's needs for mental health services are left unmet. She continues to experience depression and social isolation.

Information about changes evokes concern

Although Angie is not yet aware of upcoming changes to her medical and non-medical benefits, these changes are a source of concern for Julia:

> We are worried because there will be a change, I think in 2013 or 2014 for Medicare patients, which we will go onto health plans. I'm worried that be cause of her condition she needs to go to the physician – especially the hospital doctors, some doctors don't have any health plan, so I'm worried now… [I found out through] some letters from Medi-Cal and also I was receiving brochures from the health nurses. I think it's the following year, they need to be assigned a plan… [The information is] just in English.

Julia is also concerned about the cuts to her mother's IHSS hours. Julia plans to go back to school to continue her medical education and advance her career in the healthcare field. She would like to hire another caregiver to help her mother, but is worried that the cuts in hours will limit her ability to hire a non-family caregiver to work enough hours to adequately care for her mother.

The stress of coordinating her mother's medical care while providing in-home care, as well as working a full-time job, is starting to affect Julia's health. She describes herself as having only "fair" health, when asked whether she considers her health to be excellent, very good, good, fair, or poor:

> I went to the hospital last Friday because I had too much stress… the doctor told me it was a complex migraine and it looked like a stroke so I was very worried when I felt the symptoms. So I went to the emergency room and the doctor helped me. But I just have to be less stressed, I need to relax myself, and at this moment I think it's not good.

Conclusion

For Angie, a transition to managed care holds promise, as it may expand and strengthen her care network, especially to the extent that behavioral health benefits are integrated into the delivery of care. A successful transition might also ease some of the burden of coordinating and ensuring continuity of care that is currently being handled almost solely by Angie's daughter, Julia. To the extent that Angie would have an easier time finding providers that communicate in Spanish, and a mental health care provider in particular, the transition may represent a positive change in terms of medical care continuity and coordination. However, given Angie's attachment to her current doctors, and her concern that a new group of providers may not be as diligent in monitoring her health conditions, any change to managed care and to a new set of providers needs to be handled with care.

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