Filling the Gaps: In Support of Aging at Home

Sarah Jo Brown, RN(ret), PhD & Laurie Harding, RN, MS

Aging at home, that is continuing to live in one's residence of several or many years in contrast to moving to assisted living, a retirement community, or a long term care facility, is the preference of many older adults (Binette & Vasold, 2018). Yet, the reality is that aging at home encompasses a diverse range of experiences from comfortable and supported to anxiety-producing and lonely—and many in between. The quality of an older individual's experience while continuing to live at home is determined by many factors—health, finances, and social context being prominent among them. For those who have compromised health, limited finances, and/or scant social support, the mainstream United States health care system provides limited assistance. Often families, friends and local social service organizations try to fill the gaps of unmet needs, with varying degrees of success. Thus, a challenge in many communities is how to help older adults who are experiencing difficulties aging at home to attain a higher level of physical, psychological and social wellbeing.

This report describes a group of innovative, community-based programs that are addressing this challenge, the umbrella organization that supports them, and evolving changes in response to COVID-19. All of the programs are in counties designated as *rural* by the Health Resources and Service Administration Office of Rural Health (https://data.hrsa.gov/tools/rural-health?tab=StateCounty).

Community-based Programs

Sixteen communities in Vermont and New Hampshire have Community Nurse programs that support older adults who are struggling to continue living at home, be it by choice or by necessity. The programs are located in a town, city, or faith-based community, and provide their services at no cost to the client. The nurses these programs employ provide in-home assessment, chronic disease management, self-care education and guidance, care coordination, family support, medication reconciliation, and long-term follow up. They do not provide personal physical care. In one town of 2,600 residents, the community nurse, working 10 hours per week, provided service to 52 clients through 345 encounters in one year; 68 (20%) of these were home visits, 6% were office visits, and 73% were phone calls, texts or emails. This distribution was in part influenced by COVID-19. The number of home visits and calls to an individual client varied widely from just a single encounter to as many as 30 encounters during the year; the average was 7.

Importantly, the nurses are most often community residents, deeply familiar with the communities they serve and known to community residents, town officials and service organizations. This deep familiarity enables the nurse to suggest groups and individuals providing respite for caregivers, sources for obtaining at home personal care, transportation options, grocery delivery possibilities, pharmacies with prescription mail delivery, and local persons providing home maintenance services.

Referrals to the Community Nurse Program come mainly from the clients themselves, families and primary care providers, as well as neighbors and friends.   The proportion of referrals from primary care providers has gradually increased over time. Most of the clients seen by the Community Nurse programs are not eligible for visiting nurse services because they are

not homebound or do not required skilled care as defined by U.S. Medicare criteria. Other clients

have reached the end of their Medicare home care eligibility, thus the skilled home care nurse

hands them off to a Community Nurse. There are, however, situations in which the Community

Nurse and a home care agency or hospice nurse collaborate to more comprehensively address

issues.

Organization and Funding

Several towns with small populations banded together with another or several towns into one

program, whereas the larger towns (population 1700—11,000) and the only city (population

14,300) stand alone, resulting in 9 programs. One faith-based program makes services available

to all persons in its town, whereas another serves only members of its congregation. All

programs have boards of directors or steering committees. Most are independent 501(c)3

organizations; several are not.

Funding varies from entirely town or faith-based community-supported to cobbled

together from grants, town appropriations and donations. Nurse salary, transportation

reimbursement, phone, a devoted electronic device, and worker's compensation insurance are

major costs. All nurses carry their own liability insurance. Nurse hours worked vary from 4 to

24 hours per week, thus budgets range widely from $8,000 to $42,000 per year. The nurse's

designated hours are directly related to what the community can afford. The nurses'

reimbursement rate is below that of other employment situations because many of the nurses are

in a step-down phase of their career or have chosen for personal reasons to work part-time in a

program they view as worthy.

Clinical Documentation and Data

Health and wellbeing-related information is obtained via conversational interviewing with

clients. The nurses jot some notes during the encounter, then electronically enter information via

a secure connection to the server afterwards. The documentation system is comprised of a

dashboard with forms incorporating short check lists and considerable provision for narrative

notes. A dictionary defines the clinical terms used in the documentation system, and links to

standardized, clinical assessment measures and recognized clinical guidelines are embedded.

The across-communities' data provided below is derived from information entered into the

electronic clinical documentation system. This data is considered

secondary use of client information for quality monitoring and program development purposes,

thus does not require Institutional Review Board (IRB) review or client informed consent (U.S.

Department of Health & Human Services Office for Human Research Protections).

(https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/quality-improvement-activities/index.html).

Profile of Clients

The clients served are somewhat diverse from community to community, with the greatest

demographic difference being a client's financial situation (as determined by self admission or

inference). In the least affluent community 67% of persons are financially stressed, while 11%

are so in the more affluent communities. Some persons live in publicly subsidized apartments,

others in their family home of many years. In spite of these differences, in all communities the

proportion of clients who live alone is close to one third, and the median age of clients served is

close to 80. As a result of these demographic similarities, the problems they experience in daily

life are remarkably similar; although in the more affluent communities there are more often part-time personal caregivers, who are frequently in need of guidance and support themselves.

Client Problems

Impaired mobility and falls have little respect for socio-economic level and are problems for approximately 60% of the clients in all communities. Frailty, too, crosses socio-economic groups with at least a third of the clients considered *frail*. Neither is social isolation confined to a particular socio-demographic group, albeit more varied across communities: in a more affluent community, 40% of clients were identified as being adversely affected by it in "normal times." In a less affluent community, the social isolation rate was 88% during "normal times" and even higher during COVID-19 times. These "normal time" social isolation rates are higher than the national average for persons over age 65 (National Academies of Sciences, Engineering and Medicine, 2020), which may be a result of the higher average age of our client population and the rural and semi-rural nature of our communities. Overall, 31% of the clients struggle with self-care activities such as bathing, moving about in the home, toileting, and eating well. Notably, 44% of clients were assessed to have poor symptom management when first seen by the Community Nurse. Disease-related problems such as pain, shortness of breath, and high blood sugar levels, are often related to misunderstandings or lack of knowledge regarding medication management, which are amenable to nursing interventions. In some cases, it has become evident to the nurse that medication mismanagement is related to the client's inability to afford the prescription. Typical clients have 3-4 health-related problems that the nurse can address.

Nursing Interventions

The client problems just described (impaired mobility, falling, frailty, poor symptom control) are issues that are difficult to assess and address during primary care office visits. Therefore, home visits focus on assessing and understanding the client's functional abilities and difficulties in the social context and physical environment of their daily lives. This understanding enables the Community Nurse to work with the client's primary care provider and other providers to develop a plan of care that is in accord with client values, goals and resources. During or after 40% of client encounters the nurse engaged in some form of care coordination or referral to community service agencies and resources. Calls to primary care providers or their nurse care managers to clarify illness management specifics or report changes in condition are frequent. This coordinated care often helps improve client health status and wellbeing by addressing issues that have not been previously recognized or addressed in a truly person-centered manner, and by focusing on what really matters to the client.

The nurse often has the opportunity to talk with family members and personal caregivers to gain their perspectives on difficulties, and to suggest ways of dealing with what is frustrating them in caring for the client. Whereas 36% of clients have a diagnosis of cognitive illness or noticeable degrees of cognitive deficit, it is not uncommon for the nurse to spend time with caregivers to formulate ways of dealing with behaviors such as poor decision making, financial mismanagement, wandering, agitation, expressions of anger and delusions. The nurse's knowledge of the community makes it possible to tap into neighbors, churches or local volunteer organizations to address caregivers' need for respite.

For clients with chronic stable problems, a phone call every couple of weeks provides an opportunity to voice concerns or request assistance in solving a problem of daily life such as

identifying someone to pick up household trash. Alternatively, or also, the nurse might connect

the client with a volunteer group that does daily or weekly check-in calls. Living in rural and

semi-rural areas, transportation for health care appointments and obtaining groceries,

medications, and household items, can be problems that the Community Nurse can help solve,

often by connecting the client with a community volunteer program or neighbor. A goodly

proportion of clients have active contact with the Community Nurse over several years.

In short, the Community Nurse works with the client, family, primary care providers and

community agencies to improve clients' quality of life and help them maintain personal dignity

by fostering the client's and family's self efficacy for dealing with the challenges of aging.

Impact

Outcomes are difficult to evaluate as there are many influences on the client's wellbeing. In

asking clients about how their lives improved since the nurse had been involved with their care,

it became clear that this population of older adults had little tolerance for even a few structured

questions. Therefore, at the time of discharge, and at 6-month intervals, nurses record outcomes

they believe were impacted by the services they provided.

Reduced client and/or family anxiety are consistently high across-program outcomes.

Other meaningful outcomes, with potentially greater cost savings to the larger health care

system, include improved client symptom management (in 41% of clients) and ability to

continue to live at home longer (in 44% of clients). The fact that the nurses have the impression

that an ED visit, hospitalization, or first responder call was prevented in 17% of those seen is not

insignificant—for both the client experience and the cost to the mainstream health care system.

The Community Nurses' success in improving clients' daily function and wellbeing is in part because they have no limits placed on the conditions of their service--i.e., eligibility, frequency and duration of their contacts with client---unlike skilled home care providers functioning within the Medicare reimbursement guidelines. The Community Nurses' success can also be attributed to the fact that they have considerable clinical experience, many in skilled home care, care management or in geriatric settings. These attributes contribute to their overall knowledge of chronic illnesses, respect for the reality that they are a guest in someone's home, interpersonal sensitivity, and the ability to manage challenging health care situations including psycho-social problems stemming from the social risk factors of health.

Umbrella Organization

Although the 9 Community Nurse programs are independently financed and directed by the community or the parish, there is an umbrella organization, the Upper Valley Community Nursing Project (UVCNP), that provides support to both the individual community-based programs and their nurses. Nine years ago, a nurse with home care background and a geriatrician responded to the recognition by one town's volunteer organization serving older adults that they needed a nurse to better support their residents. Building on the model of 3 existing Parish Nurse programs in the area, the nurse and doctor established UVCNP by extending the model to towns. The UVCNP, a 501(c)3 organization, is governed by a 9-member board of directors (one of whom is a volunteer medical director) and led by a part-time nurse leader and a part-time executive director.   The organization's website provides further information: www.UVCNP.org

UVCNP provides the following supports to the communities, the parishes and their nurses:

- Meets with communities considering a Community Nurse program and coaches them in setting up an organizational structure, recruiting a nurse, and seeking funding.

- Makes available up to a $5000 startup grant to each new program

- Convenes monthly meetings of the Community and Parish Nurses to discuss clinical experiences and have discussions with representatives from regional health care agencies. Although the nurses work for their community program and receive direction from their board or steering committee, there is a great deal to be gained from talking with other nurses doing a similar job and facing similar clinical and service issues.

- Maintains the electronic documentation system for the communities and their nurses. From this system, semiannual reports (called *At-A-Glance*) are produced that convey service numbers, referral sources, client profiles, client problems, nursing interventions, and outcomes. These reports have proven quite useful to the communities in securing funding, providing accountability to donors, and program planning.

- Builds relationships with regional health care providers, hospitals, and skilled nursing facilities. Recently, the UVCNP facilitated the Community Nurses' access to an electronic communication system made available to providers by the region's largest health care system. This system offers secure email communication between community providers and the health system's providers.

- Markets programs to local hospital discharge staff and clinic staff to make them aware of these Community and Parish Nurse programs. This has been an ongoing activity but has

recently become more of a challenge because of staff turnover and the use of traveling

nurses.

Adaptation to COVID-19

The Community Nurses' ways of functioning changed considerably with the onset of the

Coronavirus pandemic. Initially, home visits were still being made, albeit with COVID-19

screening questions, full provider protective equipment when necessary, and the use of masks for

both the client and the nurse for all visits. When weather permitted, visits were held on porches

or outdoors. The nurses also made more phone calls to check on established clients. Phone calls

from residents about issues such as possible COVID-19 exposure, testing, visiting of

grandchildren, and travel restrictions, increased as COVID-19 rates in rural communities

increased. As COVID-19 vaccine became available, the nurses helped clients get appointments

for vaccinations (even transported them to vaccination sites) and worked with the regional VNA

and emergency service organizations to arrange vaccinations for homebound persons. Gradually,

home visits with masks and social distancing resumed for most clients.

Throughout the pandemic many clients have been anxious, even fearful. This resulted in

conversations in which the nurses work with clients to overcome their fear of contacting their

primary care provider about an exacerbation of symptoms or making a dreaded trip to the

emergency room. During late-2020 to mid-2021, in 70% of client encounters, the nurse advised

or provided information or reassurance regarding COVID-19. Breakthrough cases resulted in a

new round of questions and need for information and reassurance. As a result, many clients came

to rely on the Community Nurse as a trusted provider to guide them through uncertain times.

Assisting clients with tele-health visits increased in most communities, and continues going forward. When the clients' hearing difficulties make phone communication difficult, or when a video visit would enhance a provider's assessment but the client does not have an electronic device with video or the technical savvy to manage such an exchange, the nurse goes to the home and facilitates these visits. Of course the nurses often have valuable insight to contribute to the conversation.

The nurses have also worked with their local emergency management leaders and groups to promote residents' knowledge about safe behaviors and answer questions. Several communities host virtual meetings for residents to hear short COVID-19 updates and ask questions.

The COVID-19 situation is evolving and guidelines regarding social contact are often changing. The Community and Parish Nurses have resumed in-home visits and continue to deal with the many challenges associated with aging, many of which are more complex logistically under COVID-19. Given the demographics of Northern New England, the ever-increasing cost of health care, and the reality that more people will choose to age at home or will have to age at home, it is clear that the need and demand for in-home care support and care management from programs such as the Community Nurse Project will only increase.

Summary

The Community Nurse model of in-home support and health care coordination for older adults fills significant gaps in the health care continuum, particularly in rural communities. The fact that the programs are locally embedded enables the nurses to tap into and work with community

partners, as well as partners from the traditional health care system, to improve the quality of life

for older adults.

References

Binette, J. and Vasold, K. (2018). 2018 home and community preferences: a national survey of

adults ages 18-plus. Washington, D. C: *AARP Research*, August 2018.

https://doi.org/10.26419/res.00231.001

National Academies of Sciences, Engineering and Medicine (2020). *Social Isolation and*

Loneliness in Older Adults: Opportunities for the Health Care system. Washington, D.C:

The National Academies Press: https://doi.org/10.17226/25663.

November 2021