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## **What Matters to At-risk Seniors: An Interview Study and Supporting Literature Review**

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## **EXECUTIVE SUMMARY**

*What Matters to Seniors: An Interview Study and Supporting Literature Review* was conducted by Brian Costello, MD, for the Frail Elderly Project. The Frail Elderly Project is an initiative of the Vermont Medical Society Education and Research Foundation, with funding support from the Vermont Health Care Improvement Project. The purpose of the Frail Elderly Project is (1) to identify barriers to providing the best primary care for high-risk elders in two rural primary care services areas (PCSAs), and (2) to recommend changes that will result in improved outcomes. The project focuses on the Little Rivers Health Care PCSA and the Gifford Health Care PCSA.

The study was conducted in February through April of 2016. It employed structured interviews and focus groups, with a total of 18 seniors and 3 caregivers from the two participating PCSAs.

For models of care that target frail and high-risk seniors to successfully deliver high-quality, high-value care, it is critical to understand seniors' perspectives on health and wellbeing and their perspectives on the health care and social service system. Understanding these perspectives at the onset makes it possible to choose and/or design a model of care aligned with what matters to seniors.

This study identified several factors important to seniors. Of these factors, maintaining independence was the most frequently cited response. Other factors that participants identified as important for their health, wellbeing, and quality of life included physical health, functional capacity, financial security, social connection to friends and family, being treated with dignity and respect, and reducing their burden on others. The participants also identified several barriers to health care, including transportation, social isolation, caregiver burden, financial constraints, and limited availability of health care providers.

Participant opinions were divided regarding their experiences with primary care. Many recalled very positive experiences of compassionate providers delivering individualized care. Others, however, described negative experiences with providers who lacked empathy. Multiple participants commented on the difficulty of recruiting and retaining primary care physicians in rural areas. Some participants suggested that the inability to speak with the primary care provider over the phone led to increased use of the emergency department. One suggestion that came out of the focus groups was that primary care offices provide more information about local health and social services.

Amongst participants who discussed emergency services, many described a lack of alternatives to the emergency department in rural areas, which led to inappropriate use of the emergency department. In general, participants felt that care in the emergency department was costly, impersonal, and not timely. Participant opinions were divided regarding hospital and specialist care at Gifford Medical Center and Dartmouth-

Hitchcock Medical Center. Some appreciated the intimacy and personal nature of care at Gifford, whereas others preferred the more comprehensive services available at Dartmouth.

Most of the participants had utilized local social and health care services. Participants universally praised the Central Vermont Council on Aging, but had mixed experiences with other services, such as Meals on Wheels and the Visiting Nurse Association. Satisfaction with home health services correlated with financial resources. Those who could afford private home health had a positive experience, whereas those with less financial resources expressed a need for additional subsidized home health services. Most participants were either reluctant to discuss the mental health system or did not have experience with it. One participant who had a positive experience receiving mental health services cited her relationship with her primary care provider as critical to enabling her to reach out for help and receive needed care. Many participants acknowledged the role of community organizations and volunteers as an important complement to the more traditional social service delivery system.

Lastly, participants were nearly universally enthusiastic about the concept of home visits from their primary care provider or a representative of the primary care office.

The supporting literature review aligned with the viewpoints of the participants regarding factors that contribute to health, wellbeing, and quality of life, and barriers to care. The literature review also identified the following components of care as important to high-risk seniors: convenient access to providers, individualized and coordinated care, continuity of care, providers who listen well, and clear communication of a care plan.

## **INTRODUCTION**

The Frail Elderly Project seeks to identify barriers to providing the best primary care for high-risk elders in two rural primary care services areas (PCSAs) and recommend: 1) practice changes to primary care, community-based care, and supportive services that will improve outcomes that matter to patients; 2) payment innovations to support the redesign; and 3) measures to track changes in outcomes that matter to patients.

The project focuses on the Little Rivers Health Care PCSA and the Gifford Health Care PCSA. Little Rivers Health Care has health centers in Wells River, Bradford, and East Corinth. Gifford Health Care has health centers in Randolph, Bethel, Chelsea, and Rochester. Both Little Rivers and Gifford are Federally Qualified Health Centers (FQHCs).

The Frail Elderly Project is an initiative of the Vermont Medical Society Education and Research Foundation, with funding support from the Vermont Health Care Improvement Project.

The Project utilized four methodologies to accomplish its objectives:

- Literature review
- Analysis of public claims data bases
- Focus groups and interviews with seniors and their caregivers/surrogates
- Structured key informant interviews with health care providers, community-based service providers, and policy experts.

The Vermont Medical Society Education and Research Foundation convened a multi-disciplinary team of sub-contractors to carry out the four project components. This report presents the findings of the focus groups and interviews with seniors and their caregivers/surrogates as well as the portion of the literature review relevant to patient preferences. It was completed by Brian Costello, MD.

### **Disclaimer**

The findings in this report are based on information about programs and services as understood and reported by seniors. Due to the volume of information gathered in the interviews, it was not possible to fact-check or confirm the accuracy of their statements about details and availability of programs and services.

### **Acknowledgements**

This study could not have been completed without the contribution of Dr. Fay Homan, Dr. Milton Fowler and the contribution from staff from the Blueprint for Health, Central Vermont Council on Aging, and the Randolph Area Community Development Corporation. Nancy Bianchi and the University of Vermont Dana Medical library supported the literature review. Dr. Josh Plavin, Erica Garfin, Steve Kappel, and Randy Messier also provided critical feedback throughout the process. Lastly, the vision, dedication, and guidance of Dr. Cy Jordan of the Vermont Medical Society Education and Research Foundation were the driving forces behind Frail Elders Project.

## **METHODS**

The Frail Elderly Project Team, with approval from the state, developed a set of 11 research questions (i.e., areas of focus) to guide the research. This focus groups and interviews with seniors and their caregivers/surrogates, as well as the supporting literature review were designed to gather information addressing the following research questions:

1. What matters to seniors?
2. What barriers to preferred care exist?
3. What aspects of the delivery system are and are not working locally?
4. How could the local delivery system be improved?
5. What are unnecessary expenses and how could they be reduced?

An interview tool was created to elicit information relevant to each of these research questions through the use of open-ended as well as targeted follow-up questions. For interview questions *see Attachment A*.

The two physician leaders who were part of the Frail Elderly Project Team, along with staff from Blueprint for Health, Central Vermont Council on Aging, and the Randolph Area Community Development Corporation identified seniors appropriate for this study. In total, 21 people (18 seniors and 3 family members/caregivers) were interviewed individually or in focus groups. The seniors ranged in age 77 to 95, and 15 were female and 3 were male. There were 6 seniors from the Little Rivers PCSA and 12 seniors from the Gifford PCSA.

The structured interviews were conducted from February through April 2016. All participants were interviewed in person and both the individual interviews and focus groups lasted from 1.5 to 2 hours. Participants only responded to questions that they were comfortable answering.

The methods for the literature review are detailed in the accompanying report *Who are Frail and High-Risk Seniors and What Models of Care Support Them? A Literature Review*. The literature review identified several articles that investigated patient perspectives and preferences.

Both the interview study and the literature review identified what seniors value when it comes to their health and identified barriers to care for this population.

## **INTERVIEW STUDY FINDINGS**

**Note:** Any findings that are specific to the Gifford or Little Rivers PCSAs are noted in the narrative that follows. Most of the findings, however, are generalizable to both regions.

### **What matters to seniors?**

Interview and focus group participants' perspective on health and wellbeing, as well as outcomes important to them, were evaluated by asking the following questions, "What do you think of when you hear the words good health?", "What do you think of when you hear the words poor health?", and "When it comes to your health, what matters to you most?"

Major themes that arose from the participants' responses to these questions were **independence, functional capacity, and deriving satisfaction and meaning from their daily activities**. In addition to the major themes, participants also expressed **the importance of being treated with respect and dignity**. Almost every participant interviewed individually or in the focus groups reflected on one or all of these themes. **Financial security and social connection to friends and family** were also frequently cited as important to seniors; these responses are both discussed in a separate section (see '*What barriers to preferred care exist?*').

With respects to good health one participant capture the sentiment of many others saying, "To me I look at [good health] as being able to live a reasonably normal life. To be able to do some things that have to be done. To enjoy life as much as I can." Another offered, that good health is being "able to get up every morning. Thank God that you can put your feet on the ground and be able to get your own breakfast. Do whatever you have to do. Be able to go out and socialize. That I consider good health. I don't care if I have an ache or a pain now and then. I can deal with that." Regarding functional status, one participant said, "I think it's important as long as you can be mobile and be able to get out."

### *Independence*

In response to questions about good health and what matters to seniors, **independence was the most frequently given response**. One participant said, "Being able to be independent is the main thing. I don't like to rely on other people to do things for me. I want to be as independent as I can be. I've always made my own way in life and I want to do that as long as I can." Another participant stated, "If I can do the daily things that have to be done and don't need excessive help than I'm doing pretty good." One of the drivers for desiring independence was concern about **being a burden on family, spouses, friends, and other caregivers**. Participants were willing to accept support and services that could help them to maintain independence and not burden others.

A few participants identified the **importance of remaining in their own home**. Describing her home, a different participant said, "I love this house. I [find] myself saying

to people, this is a sanctuary and I feel completely safe here.” Other participants, however, looked forward to moving to senior living communities (or already lived there). Many participants mentioned that they were concerned about living in a skilled nursing facility permanently. Commenting on a poor exchange with her primary care provider, one participant said, “My doctor wanted to force me to go to a nursing home. I value my independence.”

### *Poor health and resilience*

The participants described poor health as the opposite of their definition of good health—limited independence, limited functional capacity, and inability to partake in the activities they derive meaning from. Most often, changes in physical health (such as worsening arthritis, having cancer, or surgery) were cited as precipitating experiences of poor health. One participant explained, “2014 was a terrible year for me. That’s when I had open-heart surgery. In August or July of that year, I had brain surgery. In that whole period of time, I was recuperating from cancer. I got severe radiation treatment and oncology chemo treatment, all in that one year. Plus, I was working with a kidney problem. I had a kidney that didn’t want to function for a while.” This same participant, however, was able to recover to a state of ‘good health’ after this period of time. He attributed this to the support of his family, the health care he received, and support from the Visiting Nurse Association (VNA). He also expressed that he had to change his expectations in what he could do for himself. When his health recovered, he continued to spend as much time outside as possible—something important to him—but he limited the amount of work that he did. Another participant reflected on this experience, “The last three winters, I never really knew what I had, but it was heart connected. And that is why I was so feeble. I just could not do anything. I had no energy to do anything for two winters. Last winter was the worst. I still have the condition, but I have decided to do what I want to do anyways!” The participant explained that in spite of her health condition, she succeeded at taking her life back into control. **Continuing to find meaning and purpose after a decline in health can help frail seniors overcome the psychological impact of this life change.**

### *Being treated with dignity and respect*

The majority of participants had positive exchanges with the health care system in this regard, but did sometimes encounter forms of ageism. One participant described some doctors as “treating seniors like they are all going to die at any moment.” Another reflected on the culture in the United States, as one that does not value older people as much as other cultures. For the seniors interviewed, **it was highly important to be viewed not simply as their state of health, but as individuals with unique stories and life experience, and to be treated with dignity and respect.**

### **What barriers to preferred care exist?**

To assess barriers to care participants were asked “What makes it difficult to get the health care you need?” and “What makes it difficult to get the help and supportive



services that you need to maintain your health and wellbeing?” The barriers to care that participants mentioned fell into the following categories:

- Transportation
- Social isolation
- Financial
- Care giver burden
- Limited providers/lack of quality health care

### *Transportation*

Based on past experience or on concern about the future, many participants cited transportation as a barrier to care. For example, one participant said, “I can see the time where I am not going to be able to drive and that unnerves me and that makes me want to make sure there is transportation available.”

In the Gifford PCSA, many of the participants had used the transportation service Stagecoach. Most had very positive experiences with Stagecoach. However, **one participant explained that Stagecoach does not serve certain geographic areas.** He felt as though the defined area was arbitrary. He and his wife told the following story:

“She was at rehab and she tried to make contact with Stagecoach, and she had a conversation while she was in rehab. But we were left holding the bag, if it wasn’t for the church and the other friends helping us, we would have been locked in.” His wife added, “Stagecoach comes to pick up a lady two miles, or short of two miles from us. I told them that, and I said can’t you come a mile and half miles more to pick up me and my husband? Stagecoach is there to serve the community. ... But I could not convince them to come just a little bit further.”

In the Little Rivers PCSA, there was confusion amongst participants about the availability of transportation services. One participant explained that Stagecoach started to provide transportation services in some towns in the Little Rivers PCSA in February of 2016, but no one was sure of the exact geographic area. There were other transportation services (e.g. Rural Community Transport out of St. Johnsbury) in the area that some participants had had success with. **Participants suggested that primary care offices should have available information about transportation services and the towns that each serves.**

### *Social Isolation*

**The majority of the participants interviewed in their home or in the focus groups acknowledged the importance of social connection.** Although one participant did not find it necessary stating, “I don’t want any companion. I like to be alone.” Most of the participants had sufficient social connection and support and help from their family and friends. These same participants acknowledged that many of their peers do not have this social connection and support, and that **not having this support would make it harder for them to remain healthy.** Two of the participants interviewed in their homes and one person from the focus group lived full-time with a son or daughter. Explaining his role, one participant’s son said, “She needs someone right here . . . It’s a full time

job. I go grocery shopping, clean the house, do maintenance on the house, drive her where she has to go to go.”

One participant, who had significant support from friends and family, faced limitations because of geographic and social isolation. She lives in a remote area, and stopped VNA services because of she was concerned that VNA was travelling too far to see her. She has had a stroke, seizures, and open-heart surgery and diligently engages in her physical therapy. However, she will not do her exercises when she is alone because she is afraid of falling.

### *Financial*

**Participants with adequate financial resources had a very different perception of the health care and service system than those with more resources.** Participants with more resources viewed services such as home health more positively, whereas those without resources viewed home health as too expensive and desired more affordable home health options. Likewise, those with more financial resources could more easily afford supplemental insurance in addition to Medicare. With supplemental insurance, seniors do not face as many out-of-pocket expenses, such as for prescription drugs. One participant explained, “I pay over \$200 per month for my supplemental insurance, but it is well worth it. When I had my heart valve it would have cost thousands of dollars.” A participant without supplemental insurance explained, “If you have just Medicare, it’s very expensive if you go outside of your physician’s office. Some of us just have Medicare. We don’t have a supplemental insurance.” Another participant added, “In a way, I am lucky, having the Vermont Medicare, I pay a certain amount. Pills are very expensive. Operations are very expensive. A lot of people are putting them off because they cannot afford to have them. I think that the whole medical system has to change. If you have plenty of money it doesn’t matter, but if you don’t people just don’t go.”

Another participant felt that supplemental insurance was necessary for him and his wife because of significant health needs, but felt that it was too costly. They have to fit the cost of supplemental insurance into a very limited budget. He explained:

Between all the insurances I get, it costs \$500 per month and I only get \$1300 a month of social security. That’s a good chunk of that. It has eaten up, like I said, before just about any savings that we had. We are down from one next month to the next. It’s very stressful. I can’t remember when we have gone to a movie. I can’t remember when we have eaten in a McDonald’s, no less a fancy restaurant. Simply because there was no money to pay that kind of stuff. ... Practically living from month-to-month as far as our social security check is concerning. I don’t know how much longer we can go with that. Depending on how things progress outside of it. Things keep going up [in cost] and they keep not giving us increases in social security. We are not going to be able to do it. So that is what’s right now on my mind the most.

**Financial assistance from the state, such as Three Squares for meals and fuel assistance does help some participants.** However, one participant explained that **the assistance that he and his wife received was reduced even though his social security income remained the same.**

We get Three Squares and I get fuel assistance and both of them have dropped off considerably. Three squares has probably dropped off about 150 dollars per month. We are down to 88 dollars per month and they tell me that inflation has not gone up. But tell the storekeepers that when you are going there to buy the basic groceries . . . Fuel assistance has gone down somewhat. Not that much probably 100 dollars to 150 dollars. That's not per month, but for the heating season . . . That's about the only thing that we were getting, and that helped us out considerably. Now, we are still able to get by, but I keep thinking about how long we are going to be able to do that.

#### *Caregiver burden*

Many seniors are also caregivers for spouses, and this caregiver burden can lead to considerable stress that negatively impacts their health and wellbeing. One participant told this story of her struggle with her husband with dementia:

I have a husband with dementia. He won't go anywhere, I have been trying different things . . . He swears at me and yells. . . . I can't keep the house—6 rooms and 2 baths. And I'm 86, he's 90. And he goes into fits all the time and I've had to call the state police . . . I've been down to senior help in Barre and they've told me a few things. They told me I could get guardianship over him. She said I could do that without having to pay a lawyer or anything. To do other things, they suggest I get a lawyer to take care of it. It has been a long struggle for two years. . . . That is my situation. Right now, I don't see a way out of it.

#### *Limited providers/lack of quality health care (see next section)*

#### **What aspects of the delivery system are/are not working?/How could the delivery system be improved?/What are unnecessary expenses and how could they be reduced?**

When asked about the health care and social services delivery system, there were two patterns of response. Some had stories of a poor experience and were quick to share that experience and solutions. Others had high praise for the health and services they had received, but on further questioning (or reflecting on responses from others in the focus group), they would discuss problems in the delivery system. The components of the health and social service delivery system that participants discussed are detailed below. If successes, deficits, and suggestions for improvement are specific to either the Little Rivers PCSA or the Gifford PCSA, then it is indicated in the text. Otherwise, the content is generalizable.

### *Primary Care*

**Many of the participants from both the Little Rivers PCSA and the Gifford PCSA had very positive experiences with their PCPs.** For example one participant said, “[My PCP] has made it very easy to be who I am. You just feel better when you walk in the office. He represents health. In a wonderful way, you laugh. [My PCP was helpful] especially at times when I have had about of depression. . . . He was always there, and he helped me to embrace health.” Another participant offered this anecdote that captures **the benefit of compassionate, individualized, and high-quality primary care:**

I got pretty sick. I was going to die. I gave up. My sister will tell you. I got the shingles. I had a heart attack. I decided I was going to die, so I went to bed. I lay there for 3 weeks. Any kind of pills that [my PCP] could think of that would help me but nothing was touching anything. I was so depressed. I was in a terrible depression. One of my kids came in and said something, so I called [my PCP] and said I need an appointment. She and I talked, and she talked me out of staying in bed. She talked me into going to the sewing club with Joan. I made a lot of new friends, and was in touch with friends who I had forgot about and who had forgot about me. Last week, when I went to senior meals, so many people came over and said, ‘oh you are back, how are you? Would you like to go this club or that club?’ or ‘we’re going out to lunch, would you like to go out with us?’ And it makes me feel like a new person. I’m so busy now, but I was pretty bad. . . . My family was very supportive, but [my PCP made the biggest difference]. She was always on the other end of the phone when I needed her. We became close and I could talk with her. It was really quite something.

Unfortunately this positive experience with primary care was not universal amongst the participants. **Participants’ negative experiences with PCPs were related to a lack of knowledge of the individual, a perceived lack of empathy, or lack of availability.** Contrasting her current PCP who she had praise for with her former PCP, one participant said, “The doctor ... always made me feel ‘why are you here?’ I always felt that I was not sick enough to be there. I didn’t like that, and I was very aware of that.” Another participant explained, “I didn’t think my primary doctor, when my husband was around, was very good. He kind of overlooked you. A couple of times, I had to call him and say ‘isn’t it time for a physical or something like that?’ I think that he didn’t know too much about old people.” Another participant from the Gifford PCSA expressed frustration that his PCP was rarely in the office and difficult to connect with.

Participants in both the Gifford and Little River’s PCSAs acknowledged that **rural communities face challenges recruiting and retaining primary care providers.** Participants in both focus groups mentioned that it could be **difficult to find a PCP**, but this was more frequently cited from participants in the Gifford PCSA. One participant said, “I have found it difficult to get a PCP at Gifford. I have needed to discuss things with a doctor, and I had to go down to Dartmouth.”

Amongst the Gifford participants there was concern about the impact of the upcoming retirement of one of the PCPs. Participants expressed concern about being able to find another PCP, especially one who “knows our history . . . knows our family.” In both focus groups, participants thought that physician’s assistants’ (PAs.) could provide some primary care, but expressed concern about their level of knowledge.

In the Gifford PCSA, multiple participants expressed **frustration with the phone service at Gifford Primary Care**. Participants explained that when they called Gifford Primary Care, they would frequently have to leave a message rather than speak with someone directly. Moreover, their message would frequently not be returned until the next day or not at all. One participant added, “Even if you are talking to a human being and you tell them your problem, you don’t have a call back.” The inability to contact the primary care office can lead to use of more expensive services. In the words of one participant, “When you have a lot going on with your health, it’s hard to not be able to speak with anyone. You know maybe we don’t even have to go in and see someone, but we don’t know that.” Another participant offered, “You cannot get through to the doctors as Gifford. If you call, you get an answering machine. What kind of an answer is that when what you have is vital but you do not need to use the ER services. You are forced to use those services. There is no other way.” Participants said that they understood that it might not always be possible to speak directly with their PCP, and they were open to speaking with someone else, either a nurse or front office person, as long as this individual could address their concern in a timely manner.

#### *Emergency Services*

**Participants in both the Little Rivers and Gifford PCSAs had some negative experiences with emergency services and the emergency department (ED).** One participant living in the Gifford PCSA explained that one time, the ambulance could not find her house and this delayed her care. Since that time, she has been reluctant to use the ambulance, instead relying on friends. In the Little Rivers PCSA, multiple participants cited the high costs of ambulance services as a deterrent to calling an ambulance. One participant related that she has a pending bill of over \$600 for using an ambulance to go a short distance. Other participants noted the long wait times and the inattentive care at the ED. Participants would prefer avoiding ambulance services and using the ED. They were acutely aware of the high costs of these services. As one participant put it, “I also know that if I go to the [ED], they are going to do so much, and I don’t want any part of it.” However, **some participants found that in rural areas, there are not enough alternatives to emergency medical services.**

#### *Hospital, specialists, and skilled nursing facilities*

**Opinions of hospital and specialty medical care at the Gifford Medical Center and Dartmouth-Hitchcock Medical Center differed from participant to participant.** Multiple participants appreciated the intimacy and knowledge of the individuals at the Gifford Medical Center. Others had negative experiences with Gifford, including one participant who explained that one physician at the Gifford Medical Center misdiagnosed his

cancer, which was later correctly diagnosed and treated at the Dartmouth-Hitchcock Medical Center. This participant was also impressed with the communication between providers that the electronic medical record (EMR) at Dartmouth allowed. He contrasted this with his experience at Gifford, where he felt physicians or other treatment providers had inadequate knowledge of his medical history on first meeting him. This participant also had a positive experience with the care coordination at Dartmouth explaining, "Dartmouth Hitchcock hooked me up with Visiting Nurse Service, with [CVCOA]. Any service I needed, they went out of their way. I didn't have to do a thing. They set up the original first appointments. They set up everything." Another participant did not have a positive experience at Dartmouth-Hitchcock stating, "You are pretty much a number [at Dartmouth] compared to Gifford."

One participant commented on insufficient SNF beds explaining, "I know when you are inpatient in the hospital, there are social workers within the hospital that will arrange beds... they have feelers out to the various nursing homes and rehab centers. But the problem there is there are often not any beds available."

#### *Bureaucracy*

**Participants found it difficult at times to navigate the health care and social service systems.** Reflecting on the forms for financial assistance at Gifford Medical Center, one participant explained, "I have to answer fifty questions for whether or not I have to pay a 10 dollar copay." He has a representative from CVCOA help him with these forms. He believed that it could be a much more straightforward process, saving him and CVCOA time.

#### *Social services/health care services*

Many of the participants had utilized social services and health care services such as home health, VNA, Central Vermont Council on Aging, and meals on wheels. **The experience with home health services correlated with financial resources.** Those who could afford private home health reflected a positive experience with these services. Those who could not afford private home health had a difficulty getting the care they needed in the home. One woman reflected that due to a neurological condition, it is very difficult for her to bathe and shower. She has minimal financial resources and has been unable to find an organization who can provide her the care and services she needs.

Many of the participants had received VNA services following hospitalizations or surgery, and **some of the participants praised the quality of the VNA services.** One participant said, "I had a hip replaced and a knee replaced. VNA came in, and that was an enormous help." However, **a few of the participants in both the Gifford and Little Rivers PCSA had negative experiences with VNA.** Participants explained that some of the VNA nurses were inexperienced nurses and unable to provide the needed health care. For example, one participant had a VNA nurse who was unable to administer

antibiotics through a peripherally inserted central catheter (PICC) line. VNA did respond to this situation, and the subsequent nurse knew how to administer the antibiotics. Other participants had experiences where VNA nurses did not show up when they were scheduled to. Lastly, one participant explained that VNA is unable to provide nursing services sometimes for seemingly arbitrary reasons. Reflecting on her friend's experience she said, " They told her she wasn't sick enough [to receive services from VNA], but she has rheumatoid arthritis and can't hardly move her hands." For seniors with significant health needs, participants expressed a desire for additional high-quality home-based nursing services.

**Participants had mixed experiences with meals on wheels.** Many had used it and did not have any issues with meal delivery, but some said that the food was poor quality.

**Participants in the Gifford PCSA had very positive experiences with the Central Vermont Council on Aging (CVCOA).** Participants had connected with this organization because of a significant decline in health, care giver burden, and a need for assistance navigating the health care and social service system. In these situations, CVCOA was of great help to these participants.

**Some participants thought that it would be helpful for their primary care offices to have easy access to information about area health and social services.**

Housing services were infrequently discussed, however participants acknowledged that additional housing for seniors was a need in both the Little Rivers PCSA and Gifford PCSA.

Multiple participants' spouses or participants' friends who had passed away had used **hospice services and all had high praise for these services.**

### *Mental Health*

**Most participants either did not have experience with the mental health system or were reluctant to discuss the mental health system.** One participant who had experienced depression and anxiety explained that she was very fearful "When I had my first bout of depression, I really was afraid. I didn't know what was happening to me." It was in large part because of her existing relationship with her PCP that she was able to reach out and get the treatment she needed. Since then, it has been easier for her to reach out for help when she is experiencing depression or anxiety. "Sometime in the last year, I called [a counselor]. I felt like I was going to explode, I was in a panic. I recognize the danger symptoms, having had enough of them. That is gone, and I have been quite happy since that happened." However when asked if she thought her peers would reach out if they were experiencing depression or anxiety, she said "'I would say probably not ... I think people, especially older people, do not want to open up."

### *Community*

**Many of the participants interviewed mentioned community organizations and volunteers as a complement to the more traditional social service delivery system.**

These organizations and volunteers include churches, Senior Centers, the American Legion, “senior companions,” and individuals in the community. These organizations and individuals can provide the social connection and support that some seniors with otherwise lack. In the Wells River group, a few of the participants were dismissive of the meals and social support that community resources like the Senior Center can offer, citing their own friendships as more valuable. In response, one caregiver explained that the woman she cares for found value in these resources, especially after her husband passed away. She explained, “[Mrs. X] takes advantage of things like senior meals to connect with friends.” The participant herself added, “It’s wonderful to go there and see your friends.”

In the Gifford PCSA focus group, a couple of participants discussed the role of one individual in the community who provides and repairs medical equipment for seniors. However, there was concern about what would happen when individual, a senior himself, had to stop or passed away. **Multiple people expressed that the Gifford PCSA could benefit from an organization or an individual taking over the responsibility individual providing medical equipment to seniors in need.**

He is a source for medical equipment underwritten by the VFW. He is our age. He is 84. He has been responsible for wheel chairs, walkers. He has given willingly to anyone who needs it. Not just veterans. It is for the community. He has been repairing the equipment. It is given gratis, but if they want to put something in the pot, it is graciously received. The point is his age. Nobody in the community, the senior citizens, a church or two, the American legion. Once it dies, it dies. Somebody, some organization needs to take it over. Once it’s over, it’s over.”

The Gifford PCSA focus group participants also discussed **the need for more help with at home from volunteers, such as with yard work.** They referenced a program that used to exist where high school students would come to seniors’ homes after school to provide help and companionship. This program, however, no longer exists. One participant commented, “It’s unfortunate because it gives young people a purpose and helps the community.” In the Wells River focus group, a lower income participant also discussed the need for more organizations or volunteers that provided free home-based services, care, and companionship to low-income seniors. The provision of additional home-based services would make it easier for many seniors to live independently in their homes longer.

### *Home visits*

A few of the participants had had home visits from their PCPs and spoke highly of this service. One participant explained that in the home environment, it was easier to open up about certain health and personal issues, such as depression. **When asked about**



**home visits and services from health care and social service providers directly connected to the primary care provider, nearly all participants were enthusiastic.** One exclaimed, “That would be the dream!” Participants said that they visits from their PCP would be preferred, but that they would be very open to a nurse, or community health worker, visiting them in the home instead. One participant felt that it was unrealistic to expect PCPs to be able to routinely visit patients in their home, but that anyone connected to the provider could be beneficial. LITERATURE REVIEW

## **LITERATURE REVIEW**

Seniors’ perceptions of health, wellbeing, care preferences, and barriers to healthcare are topics of several peer-reviewed studies. The details of the studies included in the literature review, including methods and population characteristics, are displayed in Table 1.

**Table 1: Frail Elders Preferences and Perspectives**

Study	Population characteristics	Methods	Key Findings
<p>Ebrahimi Z, Dahlin-Ivanoff S, Eklund K, Jakobsson A, Wilhelmson K. Self-rated health and health-strengthening factors in community-living frail older people. <i>Journal of Advanced Nursing</i> 2015; <b>71</b>(4): 825-36.<sup>1</sup></p>	<p>Age 80+ or 65-79 with 1+ chronic disease and 1+ ADL (Activity of Daily Living) dependence. Recruited at the ED.</p>	<p>This study examined and analyzed the connection between health-strengthening factors and self-rated health among community-dwelling frail seniors. This study used face-to-face interviews with 161 seniors including a comprehensive CGA. Researchers used different validated interview tools to measure <i>experiences of health, experiences of being secure/safe in everyday life, managing the unpredictable body, reinforcing a positive outlook, managing everyday life, having a sense of belonging, and connection to the whole.</i></p>	<p>Regression analysis found that <i>satisfaction with ability to care for one's self, having physical health symptoms, and not feeling lonely</i> best predicted the feeling of good health in community-dwelling frail older people. These three factors accounted for 37% of the variation in self-rated health. Those with a self-reported satisfaction with the ability to care for one's self were 8 times more likely to rate their health as good than those not satisfied in their ability to care for themselves. Those who had 10 or fewer physical health symptoms were 6 times more likely to rate their health as good than those with more than 10 symptoms. Those who did not report feeling lonely were 5 times more likely to rate their health as good than those who did report feeling lonely.</p>
<p>Ebrahimi Z, Wilhelmson K, Moore CD, Jakobsson A. Frail elders' experiences with and perceptions of health. <i>Qualitative health research</i> 2012; <b>22</b>(11): 1513-23.<sup>2</sup></p>	<p>Age 80+ or 65-79 with 1+ chronic disease and 1+ ADL dependence. Recruited at the ED. Sample selected from the "Continuum of Care for Frail Elderly Persons intervention."</p>	<p>Qualitative evaluation of lived experience of 22 frail older adults through analysis of semi-structured interviews.</p>	<p>The researchers identified 5 structures essential to a <i>balanced state of health: being able to master daily life, the experience of the body working by itself, being happy and satisfied with existence, being validated as a worthy and competent person, and being involved.</i></p>
<p>Hoogendijk EO, Muntinga ME, van Leeuwen KM, et al. Self-perceived met and unmet care needs of frail older adults in primary care. <i>Archives of Gerontology &amp; Geriatrics</i> 2014; <b>58</b>(1): 37-42.<sup>3</sup></p>	<p>Age 65+. Score of 3 or higher on PRISMA-7. (7 item questionnaire: 85 years old, male, activity limitation due to health problems, needs help on a regular basis, homebound, can count on someone in case of need.</p>	<p>Assessment of self-perceived care needs through a validated tool that evaluates environmental, physical, and psychosocial needs and identifies met and unmet care needs. 1137 seniors living in the Netherlands completed the assessment.</p>	<p>The researchers found that the highest proportion of unmet needs were in the psychosocial domain for these participants. The researchers found the highest unmet needs for company ("few social contacts, loneliness, social isolation") and daytime activities ("difficulty with regular, appropriate daytime activities"). Other unmet needs that were found to be high included caring for another, and housing, and cognitive difficulties. The participants in this study reported primary care in the Netherlands provided sufficient attention to and help with physical health but insufficient attention to and help with psychosocial needs. This study was completed in the Netherlands, and frail seniors living in other areas might have other met and unmet needs. It highlights the importance of evaluation of met and unmet needs for frail seniors.</p>

Study	Population characteristics	Methods	Key Findings
Abu-Bader SH, Rogers A, Barusch AS. Predictors of life satisfaction in frail elderly. <i>Journal of Gerontological Social Work</i> 2003; <b>38</b> (3): 3-17. <sup>4</sup>	Community-dwelling low-income, frail elderly. Frail as determined by need of assistance with ADLs. Low-income. The average participant needed assistance with 2.6 ADLs and 5.3 IADLs (Instrumental Activities of Daily Living).	With a random sample of 99 low-income, community dwelling, frail older adults, researchers completed standardized interviews that included LSI-Z instrument for life satisfaction, the Iowa Self-Assessment Inventory, the Geriatric Scale of Recent Life Events, the Multidimensional Health Locus of Control Scale, the Index of Activities of Daily Living, an evaluation of perceived health using a 5-point Likert scale, a mini-mental status exam, and a guided conversation. Data analysis consisted of stepwise and hierarchical regression.	Amongst the sample of low-income community-dwelling older adults, 40 % of participants reported high levels of life satisfaction. Regression analyses identified four significant predictors of life satisfaction: <i>physical health, social support, emotional balance, and the extent to which an individual believes he or she can control events that affect them.</i> Although perceived physical health was associated with life satisfaction, more objective measures like IADLs and ADLs did not correlate with life satisfaction. Perception of health and wellbeing had a greater impact on life satisfaction than actual functional status.
van Kempen JAL, Robben SHM, Zuidema SU, Rikkert MGMO, Melis RJF, Schers HJ. Home visits for frail older people: a qualitative study on the needs and preferences of frail older people and their informal caregivers. <i>British Journal of General Practice</i> 2012; <b>62</b> (601): 417-8. <sup>5</sup>	Age 65+, community-dwelling, and frail. Frailty was defined as having one or more of the following problems: multimorbidity, polypharmacy, cognitive disorders, disabilities, psychosocial problems, and loneliness.	Qualitative analysis of semi-structured interviews with 11 frail older adults and 11 caregivers.	Most participants said they would like to receive home visits from their general practitioner (GP/PCP). Participants desired home visits because: they were more likely to discuss non-acute, chronic health problems in the home; home visits helped to build trust with their GP; home visits would allow for more knowledge of the individual within the psychosocial context; home visits allowed for more patient-centered care. Some participants did not think home visits were necessary, except in the case of patients with substantial need. Participants preferred home visits from the GP, but were open to visits from others (nurses). Whoever visits, the participants want continuity—to see the same person on subsequent visits.
Bayliss EA, Edwards AE, Steiner JF, Main DS. Processes of care desired by elderly patients with multimorbidities. <i>Family Practice</i> 2008; <b>25</b> (4): 287-93. <sup>6</sup>	Age 65+ with condition of diabetes, depression, and osteoarthritis, and member of an HMO.	Qualitative analysis of semi-structured interviews with 26 seniors with multimorbidity.	This study identified 6 themes important to the elderly with multiple chronic conditions: convenient access to providers, continuity of care, clear communication of care plan, individualized and coordinated care, and being heard.
Goins RT, Williams KA, Carter MW, Spencer M, Solovieva T. Perceived barriers to health care access among rural older adults: a qualitative study. <i>Journal of Rural Health</i> 2005; <b>21</b> (3): 206-13. <sup>7</sup>	Age 60+, community-dwelling, and lived in rural community.	Qualitative analysis of 13, 90-minute focus groups at senior centers.	This study identified 5 categories of barriers to quality health care: transportation difficulties, limited health care supply, lack of quality health care, social isolation, and financial constraints.

### *Life satisfaction*

Perception of health and wellbeing can have a greater impact on life satisfaction than actual functional status. For example, one study that evaluated life satisfaction amongst low-income, community dwelling, frail seniors found that the following self-reported variables predicted life satisfaction:<sup>4</sup>

- *Physical health*
- *Social support*
- *Emotional balance*
- *Locus of control (the extent to which an individual believes he or she can control events that affect them)*

Notably, though the perception of physical health correlated with life satisfaction, objective measures of functioning such as assessment of Instrumental Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs) did not correlate with life satisfaction. The results of this single study may not be generalizable, but these results point out that perception of health may impact quality of life more than objective measures of health.

### *Perception of health*

A study focused on community-dwelling frail seniors identified several factors that contribute to self-rated health.<sup>1</sup> In this study, self-rated health was measured using one item from the SF-36-Item Short-Form Health Survey, "In general, you would say your health is (poor, fair, good, very good, or excellent)." The factors with the greatest contribution to self-rated health were the *ability to take care of one's self, having physical health symptoms, and not feeling lonely*. By contrast, the variable relevant to *remaining in familiar surroundings* was not associated with self-rated health, but the authors acknowledge that the measure of this predictor may have had limited validity. Taken together, these results indicated that self-rated health was related to social, functional, and emotional concerns, as well as to direct physical symptoms. For example, maintenance of the ability to care for one's self was multifactorial, determined both by physical ability to do so and from the support received. Loneliness was impacted by social contacts, and while physical health status might impact one's ability to socialize, the authors noted that declines in physical health may not necessarily lead to social isolation with the proper supports in place. The authors concluded that the focus of health care for the frail elderly needs to be multidisciplinary and encompass both medical care and social services to address their physical and mental health needs, social needs, and other areas of support.

In a qualitative evaluation of contributions to a sense of a balanced state of health for frail seniors, researchers identified the following contributors:<sup>2</sup>

- *Being able to master daily life*
- *The experience of the body working by itself*
- *Being happy and satisfied with existence*
- *Being involved*
- *Being validated as a worthy and competent person*

For these frail seniors, mastery of daily life entailed doing whatever they could independently, given their concurrent health-related limitations.<sup>2</sup> Study participants noted that balancing health-related limitations and independence was a moving target, and the authors concluded that the ability to accept health and functional changes while maintaining control over certain aspects of one's life was important for the perception of a balanced state of health. Functional imitations stemming from poor health (e.g., vision impairment, hearing impairment, balance and/or mobility impairment, cognitive impairment) contributed negatively to the perception of a balanced state of health. However, seniors could maintain the sense of a balanced state of health when they learned to adapt to the functional limitations and cope with the accompanying emotions. For many, this coping entailed acceptance of their current state of health and drawing meaning from the world around them. Maintaining social connection, being involved with the community, and spending time outdoors all positively impacted perception of a balanced state of health. Lastly, being respected and acknowledged as an individual with value was important for a sense of wellbeing. This study identified physical, functional, and psychosocial contributions to the perception of a balanced state of health for frail seniors. Models of care for frail seniors should be equipped to assess and address the everyday needs of this population across these domains.

#### *Unmet needs*

For frail seniors, perception of health and life satisfaction are impacted by both psychosocial factors and physical health. It is important to assess how health care and social service systems address these needs. One study evaluated met and unmet needs of community-dwelling frail seniors living in the Netherlands.<sup>3</sup> For these seniors, the study found that there were greater needs in the psychosocial domain compared to the physical health domain. The highest needs endorsed were for increased social connection and daytime activities. Help with caring for another, housing concerns, and cognitive difficulties were also identified as unmet needs. Though physical health needs (e.g., treatment of chronic illness) were identified as well, these needs were mostly met. Overall, the participants reported that primary care addressed their physical health needs but did not sufficiently address psychosocial needs. This study was completed in the Netherlands, and cannot be generalized to other health care and social service systems. However, this research highlights the importance of evaluating of met and unmet needs for frail seniors.

#### *Processes of care*

Frail and high-risk seniors often have multiple chronic conditions, which present unique care needs. A qualitative study in which researchers interviewed seniors with multiple chronic conditions identified the following themes as important to seniors:<sup>6</sup>

- *Convenient access to providers*
- *Continuity of care*
- *Clear communication of care plan*
- *Individualized and coordinated care*
- *Being heard*

The study found that the complex nature of managing multiple chronic conditions necessitated convenient access to providers.<sup>6</sup> Further, this study found that this population of seniors sought telephone numbers with a direct connection to a care manager or nurse, as well as prompt appointments in many situations. Most of the study participants frequently interacted with the health care system, and desired continuity of care in the form of continued care by the same providers. They also expressed appreciation for reminders about next steps in the care plan. Study participants had intricate multi-step care plans that needed to be clearly communicated, and as such desired written as well as verbal instructions. Also due to their unique care needs, participants sought individualized and coordinated care. One participant recommended one point-of-contact or care coordinator based out of the primary care office. Of high importance to this population (and all patient populations) was being heard and understood. Overall, this study demonstrated that patients with complex needs desire well-coordinated, individualized, patient-centered, and compassionate care.

#### *Barriers to care*

Seniors living in rural areas face unique health care and social service needs. One qualitative study evaluated the complex needs by interviewing rural community-dwelling seniors. The research identified the following categories of barriers to quality health care:<sup>7</sup>

- *Transportation difficulties*
- *Limited health care supply*
- *Lack of quality health care*
- *Social isolation*
- *Financial constraints*

For these rural seniors, there were multiple barriers to transportation, including having to travel long distances for specialty care, limited public and medical transportation programs for seniors, and weather-related issues.<sup>7</sup> Participants in this study noted that health care supply was limited by difficulty with both recruitment and retention of physicians. Participants also commented on the limited choice of provider that living in rural area afforded. Participants remarked on multiple issues related to the quality of health care, including providers who were unable to accurately diagnose their health conditions, difficulty scheduling appointments, and a perceived disinterest by providers in them because they were older. Many of the participants reflected on the increased social isolation that comes with living in a rural area. Additionally, financial constraints presented difficulties for these rural seniors. Participants remarked on the cost of health care services, the expense of prescription medications, ineligibility for Medicaid, and inadequate insurance coverage. The results of this study illustrate that models of care for in place in rural areas must consider the unique barriers to care that can come with rural living.

### *Home visits*

Home-visits are component of many models of care that address the needs of the frail elderly population.<sup>8-10</sup> In home-based primary care models (HBPC)<sup>8-10</sup>, these visits are from primary care providers (PCPs), but other models use social workers, nurses, or others to complete assessments and provide support and care in the home.<sup>10</sup> One qualitative study in the United Kingdom evaluated the perspectives of frail elders on home visits.<sup>5</sup> Most participants said they would like to receive home visits from their PCP. Participants preferred the visits to be from their PCP, but were open to visits instead from other professionals, such as nurses. Participants wanted continuity of care—for example, for the same professional to visit them in their home each time. Of note, participants felt that home visits were only necessary for patients with substantial need. The results also suggested an advantage of home-visits in that participants might be more likely to discuss health problems earlier in the home environment, rather than wait until the symptoms are more serious. Additionally, participants expressed that home-visits would allow for the provider to better understand them in the psychosocial context and allow for more patient-centered care. The results of this study highlighted frail elders in the United Kingdom's desire for home-visits. Though the research was conducted in the United Kingdom and thus may or may not generalize to the United States, it points to the need to evaluate the perspective of frail elders when implementing a model of care for this population that includes home visits.

## **CONCLUSION**

The interview and focus group study and the literature review both identify several common themes regarding what matters to seniors. Seniors—in particular those who are frail and high-risk—value independence, maintaining physical health and functional capacity, social connection, financial security, being treated with dignity and respect, and reducing burden on family members or other caregivers. Although a decline health can bring significant life changes, many seniors are resilient and can find new meaning and purpose to overcome the psychological impact of health-related changes.

Rural seniors—including those in the Little Rivers and Gifford PCSAs—face several barriers to care including transportation difficulties, social isolation, financial constraints, limited health care supply, and in some instances a lack of quality health care. Many, but not all, seniors interviewed had very positive experiences with primary care. Those who had a negative experience cited lack of empathy from providers and lack of provider availability. The seniors interviewed had a generally negative perception of care in the emergency department. They suggested that alternatives, such as after-hours phone contact with representatives from the primary care office, would curb unnecessary use of emergency services.

Interviewees' experience with social and home health services varied, often along financial lines. Those with more resources had a more positive experience with services, whereas those with lower income suggested that there should be additional high-quality home-based health and social services for seniors in the two PCSAs. Community and volunteer organizations play a crucial role in supporting seniors in the two PCSAs. Lastly, nearly all seniors interviewed would be open to home visits from representatives of the primary care team.

Overall, the seniors and caregivers from the two PCSAs felt that the quality of health care and social services varied, and expressed that there was room for improvement. The results from this study indicate that this need for improvement could be addressed best through a model of care in line with what matters to frail and high-risk seniors. This model of care needs to promote independence and to address physical and emotional health, by providing financially-subsidized and integrated health and social services delivered in the home when possible. In addition, frail and high-risk seniors desire personal and individualized care from providers who respect their autonomy and treat them with dignity.



## **ATTACHMENTS**

### **Attachment A: Interview Questions**

#### **General Questions:**

1. What doctors or other healthcare providers do you see?
  - a. How often do you see these providers?
2. Do any family members, neighbors, or friends help you out?
  - a. How so?
3. What other services help you in your daily life?
4. How often do you use these services?
5. When was the last time that you were hospitalized? [If less than one year ago, ask how many times in the last 12 months]
6. When was the last time that you had to go to the emergency room? [If less than one year ago, ask how many times in the last 12 months]

#### **What matters to seniors?**

1. What do you think of when you hear the word good health?
2. What gives you the feeling of good health?
3. What gives you the feeling of poor health?
4. When it comes to health, what matters to you most?
  - a. When it comes to your health, are there things that you'd like to have now that you once had?
5. When it comes to your wellbeing, what matters to you most? When it comes to your wellbeing, are there things that you'd like to have now that you once had?
6. When it comes to your health and wellbeing, what kind of support or assistance could prevent you from losing what matters to you most?
7. When it comes to your health and wellbeing, do you believe that your primary care provider thinks the same things are important that you do?
  - a. Do you believe that other healthcare and service providers believe that the same things are important?
8. When it comes to what you find important for your health and wellbeing, how do you think your primary care provider could get on the same page as you?
  - a. How do you think other health care and service providers could get on the same page as you?

#### **What barriers to preferred care exist?**

1. What make it difficult to get the health care you need?
  - a. What gets in the way of getting the health care that you need?
2. What makes it difficult to get the help and supportive services you need to maintain your health and wellbeing?
  - a. What gets in the way of getting the services that you need?

**What aspects of the delivery system are and are not working locally?**

1. What services and resources are available to seniors locally?
2. What local resources help you to get the services that you need?
3. When it comes to what works well?
4. When it comes to what does not work well? How so? How could this be improved?
5. Are there services or resources that are not available that would help you? How so?

**How could the local delivery system be improved?**

1. If you were in charge what changes would you make to help seniors get better health care?
  - a. In your opinion, what would improve the health care system?
2. If you were in charge, what changes would you make to help seniors get better services?
  - a. In your opinion, what would improve the social service system?

**What are unnecessary expenses and how could they be reduced?**

1. Some people find that some of the health care they receive is unnecessary or financially wasteful. If you believe that this is the case, how is the health care that you (or other senior) receive unnecessary or financially wasteful?
2. Some people find that some of the services they receive are unnecessary or financially wasteful. If you believe that this is the case, how are the services that you (or other seniors) unnecessary or financially wasteful?
3. If you could take any money that's being wasted on things that are unnecessary, how do you think it could be better spent to help you and other seniors get what matters most for your health and wellbeing?

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