

Aging *Futures*

... older adults living well
as they define it.

Qualitative Interviews of 41 Older Persons January - February, 2003

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INTRODUCTION

Broome County organizations and agencies which serve older adults are interested in planning for an increasingly older cohort of service recipients. The needs of this older cohort are being transformed as they age and confront the social and medical demands of living on their own with chronic illness. The predominance of chronic illness is the hallmark of industrialized societies and the prevalence of multiple chronic illnesses is seen in older adults. The management of chronic illness is extraordinarily complex because of the varied skills and resources, both material and emotional, which are essential to successful outcomes.

This study of the lives and service needs of older adults in Broome County is a response to the call of the Aging Futures Partnership for an investigation to determine where the Broome County long term care system is succeeding and failing to meet the needs of the elder, functionally limited population. Specifically, the Partnership requested a study about the needs of older persons who face nursing home admission, the events which precipitated the admission, and the desires of the older care recipient regarding care and choice of domicile. In addition, the Partnership sought the identification of beneficial supports for those who had been discharged from the nursing home to the community. Interviews with family caregivers were to be included in the research plan in order to understand more fully the nature of supports necessary to assist the older care recipient.

This document is a report about a study designed to fulfill the research request of the Aging Futures Partnership. This investigation sought to answer the central research question: What makes it possible for a frail older person to return home after a nursing home stay and continue to reside at home? All participants in the study were asked details about the help they received or gave, depending on their role in the care partnership. Information was gathered about the events that led to the older person's nursing home admission, and the kind of help the person had been receiving at home before and after the nursing home stay. Each older individual also gave a short life history so that we might understand something of their personal history and the context for the events that unfolded regarding their health history and home life.

METHODOLOGY

Approach

This study used an ethnographic approach which included informal and semi-structured interviews, observations, and qualitative analytic techniques in order to inquire into the milieu framed by the posed questions. The central figures in this study were the older adults who were receiving some level of help, either from their friends and family members or from formal caregivers in a community agency or in a nursing home. These older adults are referred to as care receivers in this report. In addition, there was great interest in discussions with family members or friends in the community who provided care since these caregivers are inextricably integrated into the lives of frail older adults. The preponderance of data in this report comes from the verbatim accounts of care receivers and caregivers gathered in semi-structured interviews. Observations about the social and physical environment of study participants and many informal discussions inform the description of the context of the lives of participants.

Study Participants

All of the study participants were identified by Broome County nursing homes or by Broome County CASA. Almost all of the care recipients had been recently admitted to or discharged from nursing homes, or were the family caregivers of those individuals. Some individuals were participants in a Long-Term Home Health Care Program, or were the caregivers of these participants. Many of the nursing home residents were or had been participants in a nursing home rehabilitation program in Broome County. Forty-one individuals agreed to participate in a face-to-face interview in their home, an office, or in a nursing home. An interview lasted approximately one hour. All of the interviews were conducted in January and February, 2003. Each study participant was asked to sign an “informed consent” document. The consent form was reviewed carefully with each potential participant before the interview. An interview began only after a consent form was signed and a copy was given to the participant.

Analysis

Analysis consisted of (1) a demographic description of the study population; (2) content analysis of the interview transcriptions, and (3) an interpretation of field notes regarding the contextual aspects of participants lives based on observations of the researcher during the course of this project.

All of the semi-structured interviews were taped using a micro-cassette tape recorder. Each interview was personal, face-to-face and conducted by the researcher. Interviews were accomplished in a quiet setting and in a confidential manner. Three-fourths of the interviews were transcribed verbatim and completely, but without the use of names of participants or anyone else identified in the interview. The content of these transcriptions was then coded by the researcher according to a set of categories defined by the subject matter of the project.

This is a qualitative analysis of data collected from individuals who wished to participate. As is the case with many qualitative studies, the group studied is not a random sample of the larger universe of possible participants. For example, to participate in the interview, care receivers had to be able to talk about their experience as recipients of care. Among the elders who did participate, some clearly had difficulty remembering details about certain aspects of their lives. On the other hand, every one of them expressed themselves quite clearly about where they wanted to live and why, as well as about the kind of help they wished to receive. For caregivers to participate, they had to be willing to discuss details about their care giving role. A few of the potential caregivers who refused to participate told me they were ambivalent about openly discussing this part of their lives.

The value of a qualitative study is not in numbers and percentages but in the way in which data is solicited and analyzed. Through the interview used in this study, the participant informs the researcher about which variables should be paid attention to and why. In this consumer driven project, as defined by the Partnership coalition, this qualitative study asks participants to come forth and speak about their wishes and their concerns. Frankly, many of the study participants were very courageous as they spoke about their feelings and their desires.

RESULTS

Description of the Study Population

A total of forty-one individuals participated in this study. Of the total, twenty-three were elder recipients of long-term care services and eighteen individuals were community caregivers, usually a family member. The care recipients and caregivers who participated in this study were not always care partners. That is, interviews were not always conducted with *both* members of the caregiver/care receiver pair. (In addition, three of the study participants were first interviewed in the nursing home and then at home after

the care recipient had been discharged from the nursing home rehabilitation program. One care recipient was first interviewed at home. Six weeks later he was admitted to a nursing home. He agreed to a second interview, this time in the nursing home at the beginning of his stay.)

A. Care Receivers

There were 23 care receivers: 19 were female, 3 of whom were married and 16 were single, widowed or divorced. Four care receivers were male, 3 were married and 1 was widowed. The mean age of the group was 82 years, with a range from 55 to 93 years. The overwhelming majority were white. Two female care recipients were of African American descent. Both women were in their 90s, had divorced after relatively short marriages in midlife and had no offspring.

Twelve of these individuals were interviewed “at home” which was a single family home, an apartment or a trailer. Eleven individuals were interviewed in a nursing home. Six of the eleven were homebound; a few of this group were interviewed just days before their discharge. Of the five remaining, three would probably remain as residents in the nursing home and two others may or may not go home depending on the outcome of their extended rehabilitation and their discharge plan. About 60 percent or 14 of this group were urban dwellers, and 9 had lived or were living in homes in rural or semi-rural settings. About 60 percent of the care receiver group had Medicaid health insurance.

B. Caregivers

There were eighteen caregivers who participated in this study, thirteen females and five males. The mean age for the group was 60 years with a range from 47 to 85 years. Two of the caregivers were Asian female; one was a spouse and the other, a daughter. The remaining 16 caregivers were white. There were seven caregiver/care receiver pairs who participated in the study. This included three spousal pairs, one husband/wife interview also included their daughter who lived at home and was a very active caregiver. There were three mother/offspring pairs in the study. One of these groups included a son and a daughter, both of whom were active caregivers. The seventh pair was a neighbor/care receiver partnership. The neighbor was a paid caregiver but who also acted as a surrogate daughter.

FINDINGS ABOUT FRAIL ELDERS LIVING AT HOME

The major research question is: What are the factors that are important to the ability of an older, frail individual to return home after a nursing home stay or to remain living at home? In other words, the central concern of this inquiry is understanding how an older person continues to reside at home in spite of compromised physical and cognitive abilities. What assistance from others is beneficial? What personal adaptations and attitudes are essential? What *is* it that makes the difference and enables a person to return home after a nursing home stay or to continue to live at home in spite of reduced function?

The Desire to Live at Home

After talking with all of these care receivers, the most essential element in maintaining their home as residence is the individual's determination, desire or commitment to live at home in spite of what appear to be insurmountable odds. The person must want to live at home because that place affords the expression of personal identity, their idea of comfort, a positive link to the past, aesthetic riches, daily contact with nearby friends, family, or a pet, or numbers of other possible reasons for the personal need to live at home. This determination or desire was articulated very well by a number of the care receivers as they talked with me in their home or apartment, or as they told me how they could not wait to get home when their stay in the nursing home ended.

The following are statements made by care receivers about the importance of their home or apartment and their desire to continue to live there:

Mr. Johnson lives with his dog, Molly, in a modest home which he built himself almost 50 years ago on a country lane more than 12 miles from Binghamton. His wife died several years before yet he continues to live in his cozy home with Norway spruce and meadows views from its picture windows. He has problems with his legs and other chronic health problems which put him in the nursing home for rehabilitation a few months earlier. A woman comes in each weekday morning to help with cleaning, cooking, and laundry. When he is on his own for most of the day, Mr. Johnson is content to listen to his radio, talk to his dog, and reminisce by looking through the large older photograph albums he has on a nearby table. When I asked him the reason that he was able to stay at home on his own, he said cheerfully:

“Determination. Not give up. Don’t say you can’t do it. You can do it if you try. I wouldn’t think of living anyplace else. Can you blame me?”

Mr. Johnson continued to speak of his memories in this home and the region, his happy marriage, his farming boyhood, and his work as an adult in the area. As we sat at his kitchen table, looking at old photographs, he described his past life, and his current gratitude to the “special” woman who cared for him. Even her husband helped with maintenance on Mr. Johnson’s home. As I thought about him and his life, it was almost as if he were rooted in that place much like the large spruce trees standing in front of his home.

Another participant, Mrs. Ellsworth, emphasized autonomy and choice as central to her desire to continue to live at home. This 88-year old woman who lived alone in the country had a range of services through a long term home health care program. Her husband had recently been admitted again to a rehabilitation program in a nursing home and this time, she said, he was going to continue as a resident there because “he’s doing so darn good that we’re going to leave him right there.” Now, she said her nurse wanted her to join her husband in the nursing home, but Mrs. Ellsworth said she wanted “to stick right here as long as I can.” When I asked her why she liked living at home, she said:

“I got my freedom. I don’t have somebody telling me that you’ve got to come and eat now or you gotta do this, you gotta do that. They don’t boss me around. I can have what I want at home and that’s what I like. If I get thirsty and I want a drink, I ain’t gotta ask for it, I can get it. That’s what I like.”

I interviewed a man in his 70s who was very ill, but was back at home after a long nursing home stay. He was now living comfortably with the help of his wife, a number of attentive adult children, and some formal care. He spent many months in a nursing home after hospitalization for surgery and serious complications afterwards. In speaking of his feelings about his situation at that time and his determination to return home to be with his family, he said:

“I’ve been laying on my back, ya know, bouncing from one hospital to another hospital and then I wind up in a nursing home and I got to fight my way out of there. Ya know, I shouldn’t use the work ‘fight’, I mean they’re such good people, I’m telling you.... they got me kind of psyched up....so they gave me calisthenics in bed.... And I graduated to a wheel chair, from the wheel chair I went to a walker and went from a walker to a cane, so here I am, ya know.... I was frightened all the way though, but nobody was going to stop

me. I was going to go home no matter what the hell happened, ya know. That's my ultimate goal is to get out of there and get home."

The Role of a Caregiver/Advocate

Even when a care receiver is determined to live at home, this may not be enough to accomplish this goal especially if the care receiver's cognition is compromised. A caregiver/advocate must share this commitment about having the older person continue to live at home or return to home. This is dual commitment; if a care receiver has the capacity to express the desire to live at home, both caregiver and care receiver must agree in this understanding. The following cases describe three categories of relationship between caregiver and care recipient as this relationship relates to the outcome of residence at home:

A. The less than determined care recipient and the committed caregiver

I spoke with a caregiver who was totally committed to helping her husband return home after rehabilitation in the nursing home. The husband had suffered a second stroke and had been admitted into a nursing home once again for a period of rehabilitation. This time the husband was despondent about his situation, and he did not participate actively in his rehabilitation work. His wife described the unfortunate consequences of his depression and his inactivity. She related the circumstances of his short visit home at holiday time. She had expected to take care of him at home for several days but asked for him to return to the nursing home after only one day. He had become so deconditioned that he had lost the ability to transfer from his bed or wheelchair even with her assistance. Although she continued to state that she felt that their home was the best place for him to live, it seemed to the wife that her husband's prognosis for a return to their home was poor.

B. The determined care recipient and the uncommitted caregiver

I spoke with a woman who had been the primary caregiver for her 85 year old mother. The mother lived in her own in a flat above her daughter's apartment. The mother was receiving daily formal home care but the daughter felt that she had reached her limit in terms of caring for her mother at home. The daughter decided it was time for her mother to live in a nursing home. The daughter described her mother as depressed and as having very poor eyesight. The daughter also said that her mother had asserted very clearly and unambiguously that she did not wish to live in a nursing home, but the caregiver daughter

felt it was the best choice for her mother's care. The daughter had reached her limit in terms of supporting her mother's care in her own home and secured her mother's placement in a nursing home.

C. Both the care recipient and caregiver are determined to have the care recipient return to or stay at home.

The following are four cases in which a committed caregiver is central to helping an older frail individual continue to live at home. It is important to emphasize that if the care recipient has reduced cognitive capacity, a committed caregiver is essential to enable the care receiver return home after a nursing home stay:

1. Husband as caregiver of a wife with reduced capacity, but both are determined to have her return home from the nursing home

I first spoke with Mr. Donahue on the phone when I called him on a Sunday evening to make an appointment to speak with him in the nursing home where his wife of 60 years had been recently admitted. He answered his home phone with the words "Good Evening" which is a good indication of the nature of this gentleman's demeanor. This tall, straightforward, kindly and "sentimental" man, as he describes himself is the father of two children, and the husband of a woman with whom he is still in love. Mrs. Donahue has been admitted to rehabilitation programs in nursing homes twice in the past couple of months. The first time she suffered from congestive heart failure, and very recently she was admitted for a broken hip after a fall at home. She has other chronic conditions including Parkinson's Disease, diabetes, and vision loss which this couple has been living with and adapting to quite well over the past several years. In two interviews, one in the nursing home, and then another in their home a day after Mrs. Donahue had been discharged from the rehab program, I learned a great deal about their history, their close connections to their children, friends and community organizations, even as Mrs. Donahue's abilities, both physical and cognitive, have waned. As I spoke with Mr. Donahue about the ways in which he was caring for his wife and himself, I heard about a number of conditions which enabled her to return home: (a) a totally committed husband who was in "very good" health, and very adaptable and inventive regarding home and life management and who had his wife's welfare as his first priority, (2) a ranch style home which was very manageable for someone using a walker or wheelchair, (3) close, supportive relations friends and neighbors and a helpful son who lives in Broome County, and (4) assistance with personal care for his wife after her first nursing home

discharge. The Donahues expected help again after this second discharge as soon as an aide became available. In the meantime, they felt they would do fine on their own.

2. Spouse as caregiver of a husband with reduced capacity; both are determined to have him return home from the nursing home

Mr. Reymond and I met in the nursing home and proceeded with our interview about his life before and since his admission to the home. Throughout his description of his life history and his health problems, I became very aware of his memory difficulties and his inability to summarize coherently any of the important pieces of his narrative. After Mr. Reymond and I had been talking about 40 minutes, his wife arrived for a morning visit, introduced herself and said how pleased she was to have an opportunity to discuss their situation. A retired schoolteacher in her 80s, she was articulate, with an excellent memory and keen analytical skills. I quickly learned that Mr. Reymond's admission to the nursing home rehab program was related mainly to lack of strength in his legs, and his difficulty walking. He has other chronic problems including very low vision, incontinence, shoulder pain related to a serious work injury and difficulty using one of his arms which may be the result of a stroke. He had been in the nursing home for ten weeks, his ability to walk had improved greatly and both of the Reymonds were looking forward to his discharge. This was not Mr. Reymond's first stay in a nursing home and living in an institutional setting had not gotten any easier for him with practice. As I spoke with this couple in their 80s, it was apparent that they wanted to get on with their lives at home. They had adapted in many ways to the limitations of the one partner. Now they wanted to spend their time talking about things that didn't matter to anyone else, playing and listening to music, and watching movies on video that both of them liked. I talked with this couple in the nursing home and about a month later when Mr. Reymond had been home for a few weeks. Mr. Reymond is able to live at home comfortably because (1) he has a partner who is as interested in having him there as he is in being there. She is an experienced caregiver, having cared for a first husband who had Multiple Sclerosis and who was cared for at home until the end of his life. She is a cheerful and capable manager of the many aspects in life that must be attended to in a family in which there is serious chronic illness. (2) They live in a home with a single floor plan which is well suited to ambulation with a walker or in a wheelchair. The bright and airy kitchen was clean and spacious with a big central table around which all the household business flowed. (3) Mrs. Reymond is in good health, good spirits and is a confident driver. (4) The Reymonds are closely connected to their children, grandchildren and their neighbors. As Mrs. Reymond said, "I can tell you what my

daughter in Florida did yesterday.” Mrs. Reymond continues to be engaged with her community since she is still an active member of her church.

3. A Daughter as caregiver who is determined to have her mother live at home even as the mother’s function and health deteriorate.

I spoke with Mrs. Moore and her daughter, Irene, in their two bedroom apartment on a sunny winter morning. Irene, a widow in her early 50s, is a mother and grandmother who took care of an disabled husband until his death a few years ago. Her mother, Mrs. Moore, had been living alone in an apartment with daily formal care until the previous year when she began falling, and had more serious lung and back problems. At that time, Irene, made a decision about becoming more involved in her mother’s care, conferred with her mother, and mother and daughter began to live together soon afterward. Now they are a partnership, with Mrs. Moore, who was breathing oxygen throughout my visit, helping in the house as much as she is able, as well as doing her best to adjust to life with her daughter. It appears that both of them are strong and kindly women who understand that life is about mutual dependence. There are a number of conditions that support Mrs. Moore’s ability to live at home: (1) Her daughter is a cheerful and experienced caregiver who has decided it is her responsibility as a Christian and loving daughter to help her mother live at home. (2) Mrs. Moore is herself a devout Christian and an experienced caregiver having cared for her ailing husband until he died about 20 years ago. Mrs. Moore is very understanding of what it takes to make a successful care partnership. (3) Mrs. Moore receives almost two hours of formal care each day which is important to both mother and daughter with respect to the physical work of Mrs. Moore’s care.

4. Son as caregiver who is determined to help his mother continue to live in her home after a nursing home stay.

I met Mrs. Curry and her son and daughter in her rural home in the Town of Binghamton. Mrs. Curry is an alert and gregarious 90 year old who had just returned home after rehabilitation for her second hip replacement. In the past 10 weeks, Mrs. Curry had broken one hip and then the other. This resulted in two separate hip replacement surgeries and two successful rehabilitation regimens. She was in good spirits during my visit to her home with her 65 year old daughter visiting from the Midwest for a week, and her 60 year old son who lives in a newer home about 100 yards from her back door. Mrs. Curry had moved to Broome County from New York City about 25 years ago when she and her husband retired, because her son who worked in Broome County had found this home for his parents to retire to. They loved the house and the area. Mrs. Curry’s

husband died when she was 75 years old. She exclaimed. “ I learned to drive when I was 75. I had a ball going all over in my little car....I loved my car. I still love it. I don’t want to get rid of it.” She stopped driving about five years ago because her eyesight was poor and she felt she might hurt someone. Mrs. Curry has a number of chronic conditions, including non-insulin dependent diabetes. She has controlled her diabetes for decades with a strict dietary regimen. She has been a thin and active person all of her life. Mrs. Curry is able to remain at home for a number of equally important reasons: (1) She is an independent, adaptable, and socially adept individual whose cognitive abilities are still very good. She is still connected with neighbors, her three living children, and her cat of whom she is very fond. She loves her country property. She said: “I explored every tree and every flower that grew. I knew where every nice flower was growing.” (2) Mrs. Curry’s son is a very attentive advocate and caregiver. He lives nearby and visits her home a couple of times a day to see how she is doing. He drives her to appointments, gets groceries, and now helps with her financial matters only because his mother’s eyesight is so poor. (3) Even though Mrs. Curry’s home is old, it is well suited to living on one floor. She pointed out to me that she has everything she needs in her three modest sized first floor rooms including her bathroom and washer and dryer. (4) Mrs. Curry was receiving personal care and rehab at home at the time that I visited her. She appreciated these services, yet she was very aware that they would be of very limited duration and so, she would not become dependent on them.

Living Alone Without a Committed Caregiver/Advocate

If an individual does not have a committed caregiver/advocate, but has good cognition including insight about their condition, and the determination to return home after a nursing home stay, the following factors seem to improve the likelihood of returning home:

1. A home environment that is welcoming, that is, a home that has fond, rich memories and/or a pet that the individual cares for.

I talked with a number of women who had good cognition, lived on their own, did not have a committed caregiver and who looked forward to returning home after their nursing home stay. These women talked with great fondness of their home, its importance in their lives, and often they mentioned a pet or pets that they cared for. One 85 year old who had been in the nursing home for cardiac rehab, had just returned to the nursing home after a pre-discharge assessment visit with a physical therapist. She said, “When I went in the house, the kitty cat was so tickled to see me. I have memories there, plus it’s

familiar, it's mine. Ya know and I can do what I want to and I love it. I love my home. People would say after I retired, this house is too big for you, why don't you sell it and buy a condo down South or something. I said, I traveled down South in the business, I don't like Florida and I love this house and this is where I'm going to stay."

I had a long interview with another nursing home resident in the rehab program who was determined to return to her modest apartment in Johnson City. She spoke of her friendships and her daily coffee and visiting in the Red Robin Diner. At different times in the interview, Mrs. Seymour told me small bits about life in her neighborhood. I asked her to tell me about her apartment and her life there. She told me about her neighbors and how attentive they have been to her health and safety. I said, "It sounds like you have really good friends and neighbors. Mrs. Seymour replied, "I have plenty of cats, too." She took delight in explaining that she and others in her neighborhood took in stray cats in the winter, and then in the spring the cats would go back to living on the street. Mrs. Seymour was actively engaged in a social network which included neighbors, domesticated animals, and an active café life and she was eager to return to her everyday life.

2. A home which is accessible, that is, it can be negotiated by someone who uses a walker or a wheelchair.

A number of individuals who lived on their own, described to me how easy it was to get around their place with a walker because of the floor plan. When I made home visits, several women invited me to look in their bathrooms to see how well it was designed so that one could use it easily without help. The following is typical of these comments: "One good thing about the house is that it is all on one level, no stairs, except to go down cellar and that's only for service men....Easy for the wheelchair, easy for the walker and also easy to get in and out of the garage because the door goes up automatically." This ease in living in a home or apartment made a difference in attitude of the individual who lived there. In addition, it seemed that the convenient floor plan was a way for the elder to persuade therapists and nurses that she would be safe when she returned to live in her own home or apartment.

3. Feelings of connection with people in the neighborhood, with church members, or others in the community, especially if the individual is single or has little family support

Mrs. Newton lives in a senior apartment building and receives formal services twice a week. She still cooks for herself and is able to bathe herself. She is in her 90s, has lived

most of her life as a single women, and has no children. She has always been very active in her church and in a number of fraternal organizations. She has lived a life of service and piety. In spite of her mobility problems, she is quite active socially, especially in the life of her building. I asked her if she had any friends in her building, Mrs. Newton said, "Oh my Lord, do I ever. Yes. Someone's always bringing me dinner. Oh certainly, I have lots of church friends and I have a neighbor across the street there and she and I converse every day in the house over there. I have loads of friends. Even in this building. Everybody here is on a first name basis, very friendly." She went on to explain that neighbors in the building were planning their monthly potluck dinner and she was looking forward to baking chicken for the dinner. In older age Mrs. Newton and other women I spoke with who live on their own without close family support, continue to be well connected to their communities and have begun to reap some of the social benefits of having given so much help to others throughout their long lives.

4. A sense of self-confidence and courage to be able to cope with what lies ahead

A number of individuals expressed strong feelings of optimism, of personal responsibility and independence, courage and self-confidence as they faced going home alone after a nursing home stay. There was nothing maudlin about their notions about their changed physical condition and of their hope about a future that still held promise. One woman, Mrs. Wright, could not wait to leave the nursing home and get back to her small apartment and to her friends in her building. Mrs. Wright was a widow with children who were not very attentive. She accepted them on their own terms. As we spoke I was taken with this eighty year old woman's resilience, stamina, and excellent cognitive capacity. Mrs. Wright had grown up in a poor family, married, worked all of her life in low income jobs, raised three children with meager financial resources, cared for a disabled husband, and never lost her strong Christian faith. Now, she sought life satisfaction from relationships with the friends she had made in her apartment building and in the things she enjoyed doing on her own. She emphasized her independence even in the nursing home. "I even have charge of my own medications. I've got a key. I keep the medicine in the top drawer, keep it locked.... I take my own medicine. Just like as if I was home." As we were ending our discussion and I asked Mrs. Wright about her feelings about her future, she said confidently, "I know I could get along on my own."

Another woman who was ending her stay in rehab at the nursing home, discussed with me how active she was throughout her life and how she faced the future with her usual good spirits and optimism. When I asked how she felt about going home very soon, she said, "I'm not afraid." She went on to describe how she handled her discharge

assessment visit at home with a physical therapist. It was a very snowy day and how impressed the therapist was with the way she handled herself and the walker in the ice and snow. This keen 85 year old woman told me about the disparaging feelings others have about the mental abilities of older people: "Cause when people say 80, 85, that's it. You don't know anything anymore, the attitude people have sometimes. You've lost all your faculties and everything.... It annoys me when people sort of talk at me like, am I understanding what they are saying, you know what I mean? Because I haven't lost my ability to think and I don't intend to.... You have to keep up. I watch the news. I read the newspapers. I pay attention to important things in the country." This woman and others I interviewed who are on their own, displayed nerve and pluck, and at the same time, an appreciation for the ways they must modify their activities in order to continue to live alone at home.

Choosing To Live in a Nursing Home

As a contrast, it is instructive to look at the situation of an individual who wishes to remain as a permanent resident in a nursing home when given the opportunity to leave. What are the conditions that underlie the decision of a nursing home resident with good cognition and very good function who does not wish to return home after a period of successful rehabilitation? The following paragraphs describe the situation of an older woman who is in good condition after rehabilitation in a nursing home. She does not want to return to her home or to an apartment with formal services in either domicile. Life in either of these places would allow Mrs. Welk more independence and choice, yet she is not interested. Before coming to the nursing home, Mrs. Welk, a widow with two sons, lived alone in a home that is owned by a son who now lives in Florida. She described her house as "awful cold" and having "a lot of steps" and "the inside needs fixing". She has lived in this home for about fifteen years but she does not know her neighbors. The only part of her life that she described with pleasure was her garden because she likes flowers and she grew a number of them in her yard. Mrs. Welk appears to have little connection with friends and she has never been a church goer, nor has she been a member of any other organization. She did not describe a daily interaction with anybody, other than aides who gave her formal help twice a week over the years. It sounded as if she had not formed an attachment with these individuals either. She is alienated from one adult son who owns the home in which she lives. A second son lives in Broome County and gives her assistance with getting groceries and with her finances, but he is not committed to helping her return to her home. Her situation at home has been one with little warmth from relationships with people or pets, or from her inhospitable and inaccessible home environment.

On the other hand, she described her life in the nursing home as very positive experience. When I asked what she liked about living in the nursing home, her immediate response was about the food. She described the food as good and that it was different every day. Secondly, she said, “the workers are really kind,” and lastly, she said the nursing home is “so nice and clean”. The nursing home has been a refuge for this older woman who is quite physically fit, and cognitively intact, but who feels emotionally incapable of caring for herself any longer. It seemed that this nursing home stay was one of the few times in her life when she experienced any sustained nurturing, and she was very reluctant to give that up.

Additional Observations About These Care Receivers

There are a number of observations about these care receivers which are important and should be mentioned.

1. Individuals who are living at home and receiving home care are often very personable.

Many care receivers have optimistic, outgoing, and engaging personalities. I remember, in particular, a delightful woman I visited in her rural home. It seemed almost as if Mrs. Wilkinson was entertaining me with details about her life. She was practically bed bound and had great care needs. She had many visitors including formal care each day, as well as friends who visited often. I was there when a nurse and aide visited her home; she greeted each of us with enthusiasm and great personal warmth. Both men and women whom I interviewed described their personalities and demeanor as friendly, trying to get along with others, smiling a lot, and joking whenever they could. As Mrs. Wilkinson told me: “What’s the use of being crabby or being miserable? It don’t get you anywhere. God don’t want you that way. He wants you to cheer up people, make everybody happy-go-lucky, and that’s what I try to do.”

2. Surprisingly, only a few of the care receivers mentioned financial matters as a major factor in their ability to return home or stay at home.

When I asked the question, “What kind of help will you need when you leave the nursing home”? one woman responded: “I’m going to need some extra money.” This was the only time anyone specifically said that money was the major issue in terms of assistance. Other interviewees talked about having to manage their meager resources or about not having had much money throughout their lives, but these individuals did not mention

finances as central to their being able to live on their own. By and large, this is a frugal group of individuals who had lived through the Great Depression. They learned how to cope during lean times. As a group, one would call these individuals hard working and self-reliant who see it as their responsibility to take care of themselves. Most of these individuals had never received any kind of public assistance. Yet, as I spoke with them about their incomes and living conditions throughout their lives, I thought certainly some of these individuals would have qualified for assistance if they had applied.

3. Rural care receivers rarely mentioned transportation issues as a challenge to living in the country.

Individually arranged transportation is a necessity in American rural life. Of the rural care receivers I spoke with, one gentleman still drove his car for errands very near his home, and some people told me how they drove a car in the past and now missed it. Most interviewees told me about family and friends who drove them to doctors appointments or on outings. Some described formal van services that they used and appreciated. One woman told me that BC Lift was available but that she rarely used it. I expect that transportation issues for rural care receivers need to be addressed satisfactorily quite early in their adaptation to life without driving their own car, or that individual will not be able to maintain a rural residence.

4. Many care receivers had been very committed caregivers earlier in their adult lives. This is one of the most important unexpected observations from this research.

It is notable that many of the older, frail individuals whom I interviewed, talked naturally and without self-pity about their serious caregiving responsibilities in the past. Women and men described taking care of disabled spouses, parents, siblings, in-laws, and those in their neighborhood or church. This caregiving activity was described as a normal occupation in the course of living a life. It seemed to be a normalizing experience for the person who was now the recipient of care. One mother/daughter care partnership was based on the recognition that they could get along living together in their partnership because they were both experienced caregivers. The daughter said, "I think (we have adapted) because we both have situations in our lives where we've been the caregiver. She was caregiver for my Dad. I was caregiver for my husband, plus my grandson." Another woman who now received a great deal of formal and informal care each day, described how she had taken care of a disabled brother-in-law for years. Then after he passed away, she cared for her mother-in-law. These descriptions of past caring by current care receivers were a motif in many interviewees life stories.

5. Some care receivers have overcome lives of great poverty and adversity.

Some of the individuals I interviewed have had particularly difficult lives from childhood. Among the themes in a number of life stories were lives of hardship, poor educational opportunities, strong faith, and struggles to make ends meet. For example, one 86 year old woman described her childhood as one of neglect and poverty. After she finished eighth grade in an institution for children whose parents could not or would not take care of them, she immediately began work as a live-in housekeeper and servant. Throughout her life, she worked at low skill jobs, raised children and coped with and cared for an alcoholic husband. She has always been a woman of strong Christian faith, caring for others as well as her own family. She could be described as a member of the class of working poor. As an older woman, she is cheerful, independent, grateful for the care others have shown her, and eager to continue with her life after she leaves the rehabilitation program for home.

6. Care receivers had well defined ideas about the attributes of good formal caregivers.

The following are some of the ways in which good caregivers were described by different care receivers. In describing an ideal caregiver, two very different older women described the personality of an ideal caregiver as “bubbly.” One of these women elaborated about a formal caregiver she liked: “Well, she’s outgoing and you can talk to her. She’s friendly and it just seems like natural feelings go between us. Ya know. Like we’re very compatible.... The first time I had an aide, she just stood there like cold, ya know. She didn’t speak to me or do anything, ya know and I said, I don’t need that. I can do that by myself.”

Another care receiver described a good caregiver as anticipating his needs. He said, “She’s always good natured. She always speaks to me....And if I need something, she sees I have it....They keep an eye on you. They can tell when you need something and when you don’t need something. See. And they’ve got eyes in the back of their head, let’s put it that way. Now, my water glass can be down. The first thing I know, there is another water glass sitting there, not even saying ‘boo’ ”.

Compassion was the theme in a number of descriptions of good caregivers. One gentleman responded, “I think they’re concerned. I think they are there to help you and they’ll do all they can to help you.” Another male care receiver said about the kind of people he wanted helping him: “They would be people that consider what you are going

through.” This same gentleman mentioned respect as important. He elaborated, “When a person like myself (tells) them, ‘ My name is Jim. Will you please call me Jim, instead of Honey or Dearie, or something like that’ ”.

Family caregivers, on the other hand, used words like “professional” and “well-trained” to describe the ideal formal caregiver. One family caregiver described a good caregiver in the following way: “Someone who is mannerly, talks like an adult, not like a baby. See, I think that a lot of aides and other help treat older people as though they were infants and it’s a lot of baby talk. It’s a lot of ‘honey’ and ‘dear’ and ‘sweetheart’ and all that stuff that I don’t think is professional. If you go into an office, you don’t talk that way to somebody.”

In another case, a neighbor who is a formal caregiver for an older woman she likes and respects, talked about sensitivity and kindness between care partners. She explained, “Her being patient with me if I have had a bad day and me being patient with her if she’s had a bad day. And I think that’s a word that people don’t use very often today. People have to be more patient and considerate.”

POLICY AND PLANNING IMPLICATIONS OF THE STUDY RESULTS

A. The trajectory of chronic illness and long-term care

A responsive long-term care system is needed to meet the needs of older adults who suffer the burden of more chronic illnesses with increasing age, and whose social supports are in flux. The trajectory of chronic illness is not a straight line toward increasing levels of disability. Rather, as the histories of this group of care receivers demonstrate, individuals experience times of increased need because of an event like a hip fracture, and then possible stasis for a longer or shorter period depending on an individual’s personal story. A number of these care receivers had been recurrent patients in hospitals and residents in long term care facilities and had been receiving various levels of home care at different times in their long lives. As more Americans live to very old age, we will hear more stories like these. That is, an individual may suffer one on more serious chronic conditions, sometimes with a hospitalization and rehabilitation, with greater or less informal support, depending on the number and ability of friends and family who are nearby to give assistance. In addition, systems of rehabilitation have improved greatly so that individuals who are very ill and incapacitated, can become ambulatory and relatively self-reliant once again. We can be sure to see more individuals who experience these cycles of disability and regained abilities in the future. Long-term

care systems will be asked to respond to these changing needs of older individuals and their families in both institutional and community care. The closer the integration of institutional and community care systems, the better these needs will be met.

B. Building social capital

The wider and deeper the net of social support, the better an individual will endure the stresses of life. Social support can be built through the development of close social relationships with family and friends throughout an individual's lifetime. Development of these close social ties is facilitated by living in one location for many years and through helping others in one's family, neighborhood, church, and community. Almost all of the care receivers in this study have lived in the Binghamton area for at least twenty years. (Only two care receivers lived in the area for less than twenty years.) The majority of care receivers have lived in the area all of their lives; some have been living in the same residence for the past forty to fifty years. And very importantly, many of the individuals now receiving care have been committed caregivers earlier in their adult lives. This is one of the most important unexpected observations in this research. Thus, many of these care receivers have built reserves of social capital which they are now drawing upon in their time of need. Also, in that earlier caregiver role, these individuals have developed attitudes and knowledge about the care partnership which now serves in their adaptation to the recipient role. Community organizations can work to increase awareness of the importance of social capital and develop ways to improve the development of social capital for its residents. In addition, organizations and agencies might try to develop creative ways to employ social capital in the creation of innovative service systems for Broome County's older adults.

C. Education and other assistance for caregivers

An individual must have a large fund of knowledge about long term care in order to make a sound judgement about appropriate care for a loved one. This knowledge must be both general and specific. That is, caregivers must learn the general landscape of long term care options in Broome County, then for example, she must apply it to her particular case with her aunt or mother. In spite of having resources like the excellent Broome County Elder Services Guide, this is a daunting task for most individuals who face it for the first time. In my discussions with caregivers, I learned that many caregivers get discouraged, angry, and frustrated trying to find the care that matches the needs of the older person they are trying to help. Even when a caregiver has found the level of care that seems appropriate, caregivers still need help with understanding the parameters of appropriate

interactions with an agency and its personnel. For example, a caregiver asked me for advice in the course of our interview. He asked something like, “Can I discuss openly with the home care nurse which aides we like and why?” Formal care is so important to many families that they do not wish to jeopardize the continuation of that help, nor do caregivers wish to create problems for agency employees. Community caregivers could benefit from face-to-face discussions with someone in a community agency who acted as an advocate for the caregiver. This advocate would not only provide information, but would also assist the caregiver in the process of decision making about choices. Caregivers need assistance in both of these arenas.

D. Diversity

1. Ethnic differences and care of older relatives: A serious attempt was made to include individuals from different populations in this study. Two African American care receivers, both single, childless women were interviewed. Both women were older than ninety years. One woman lives in a senior apartment with services, the other in a nursing home as a permanent resident. Both women are possibly not living in a family home because they have no offspring since the norm for most African American families is to care for older parents at home. Two Asian caregivers agreed to participate in this study. One woman is the wife of a man who is enrolled in a nursing home rehabilitation program. She very much wants him to return home so that she can care for him there. The other participant is the daughter of a woman who is receiving formal services in her daughter’s home where she resides. The daughter is one of many siblings, some of whom do not live in the United States. The daughter wants to do the right thing in caring for her mother and the cultural norm dictates that the mother should live with her daughter. This caregiver was married to an Asian husband, had children and a full-time job. She seemed to be a caring person who said she felt “stuck” as she straddled the norms of her mother’s culture and those of her adopted American home. Knowledge of caregiving norms in different cultures and sensitivity to the conflicting feelings of immigrants as they care for family members are an important part of education and advocacy services for caregivers.

2. The rural-urban continuum: About forty percent of the care receivers interviewed lived in rural or semi-rural settings. Most of the individuals who lived in very rural settings were not farmers, but rural residents who had made their living in one of the Triple Cities. Because most rural Broome County residents have become so integrated into the urban economy, it was difficult for me to see significant differences between rural and urban study participants. When asked, rural residents did seem to point very quickly in the direction of a neighbor as the person they would go to for help in an

emergency. Also, rural residents often mentioned the natural beauty of their surroundings. So it seemed that rural dwellers were more in touch with their environment including the people who lived nearby. What does seem apparent is that Broome County has become more suburbanized which suggests that services for future older adults will continue to be needed in the rural areas surrounding the city of Binghamton.

3. Family size and social support: Social support from adult children is a conventional expectation of aged parents, as well as the wider society. Sometimes that social support is restrained, inconsistent, or even nonexistent. The greater the number of siblings, the greater the chance that one of the group of siblings will conform to the societal norm of filial piety. Only two of the study's care receivers who were parents appeared to receive almost no social support from their children. In a few cases, only one offspring in a family took on the responsibility of parental support. One of the interviewed caregivers pointed out the importance of shared responsibility in family caretaking. This caregiver was in her early 60s and treated her responsibilities for caregiving of her parents, and childless older aunts very seriously and competently. She had had one sibling, a brother who had died a decade earlier. She missed his help since she knew if he were alive, he would be there doing his share. The current generation of American families have gotten smaller with fewer offspring. In addition, the potential for the supportive child not living nearby will be greater for future older adults in Broome County. Other sources of informal social support of aging parents will become more important in coming years. Finding ways to develop social support beyond family systems is an important task for planners who can foresee the implications of this demographic change.

Some Personal Observations

The following are several paragraphs about my observations and interpretations that are not specific to any particular planning guideline but may be helpful to those planning services or additional research.

Care receivers as experienced informants

This is a group of experienced care receivers. Most of the care recipients had been receiving formal or informal help with one or more of their activities of daily living for many years. Some individuals had experienced multiple hospitalizations and more than one nursing home stay. They were a wealth of information about long-term care. The four individuals with whom I had a follow-up interviews showed me how valuable a longitudinal study could be to better understand the trajectories of chronic illness.

Coping with loss, especially serious loss of physical function

Many of these care receivers were old enough to have already suffered the emotional loss of death of a spouse, close friends, even their own children. Now, these survivors were having to cope with the loss of personal physical integrity, especially loss of the ability to walk and of vision. It made a difference when these individuals had insight into their situation and had the ability to adapt, sometimes with good spirits. Some personal insight and adaptability seemed to help very old and frail individuals to be hopeful about the future.

The ability to express one's feelings

A number of interviewees had noticeable and significant memory loss and decline in cognitive function. But these individuals knew how they felt about their situation, what they felt about the quality of their care, and what they wanted for themselves at this point in their lives. Their verbal communication may not have been expressed with perfect English syntax, but I understood what they meant as they spoke about their feelings.

The desire for friendly visitors

Many of these care receivers were looking for formal caregivers who would be their eyes on the world. Often it seemed they wanted friendly visitors in the form of formal caregivers. Many of these older people were hungry for lively conversation, expressions of warmth, compassion and interest. Regular visits from friendly visitors, just to stop in to see how both care receiver and caregiver were doing, was an expressed desire of several of the individuals I interviewed.

Note: All of the names used in this report are pseudonyms.