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**Ethnographic Study of the Group Quarters
Population in the 2010 Census: Healthcare Facilities
(Long Term and Hospice Care)**

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1 Executive Summary

This ethnographic research study examined three Health-Related Group Quarters (HRGQ) facilities. Health-Related Group Quarters (HRGQ) populations include but are not limited to those residents who live in skilled nursing facilities, long term and in-patient end-of-life care. Residents typically have serious disabilities due to poor health status, dementia, mental illness, injuries or a history of developmental delay. Population turnover is rapid in these facilities, due to high rates of death, discharge, admission and re-admission, rehabilitation and short term respite care services.

The multi-method approach taken included resident and facility observations, an analysis of the 2010 decennial census enumeration, alternative resident list creation, and post-enumeration interviews of selected informants. The research questions were the following: 1) what resistance or blockage to access was experienced by outsiders gaining access?; 2) what were the resident characteristics and limitations?; 3) how often did transitions and turnover occur in the population?; 4) how was the census enumeration conducted, and what problems arose?; and 5) what is the potential for an accurate post-enumeration survey to determine Census Coverage Measurement (CCM) in HRGQ facilities?

Observations indicated a diverse resident population. There were serious disabilities noted for at least half of the residents in the facilities studied, including dementia, stroke and the physical effects of terminal decline. Those with severe limitations were sometimes segregated within the institution (e.g., the behavioral dementia unit), and were not considered viable candidates for census self-report. However, cognitive disability was not universal in the facilities observed and it was determined that some residents could have meaningfully participated in the decennial census enumeration. Options for resident self-enumeration may be considered in the future, and family representatives should also be considered for provision of resident information. The use of facility administrative lists would be the last resort for the provision of resident information.

Census enumerators assumed administrative lists were the best method for counting the HRGQ population. Controversy was observed as one facility administrator expressed strong opposition to the exclusive use of lists. Two main points emerged: 1) who has the right to access resident information?; and 2) what is the perceived burden on the facility to help compose lists?

Resident rights specify a hierarchy for decision-making and information-gathering, beginning with the resident, the family members and lastly, the facility. Census enumerators in this study primarily sought administrative lists, without consideration of other information-gathering methods. There was a perceived burden on the business goals in long term care facilities when resources were taxed by staff assistance with administrative lists.

Long term care facility staff and management were not always hospitable to the census enumerators. Personnel commonly showed signs of “census fatigue” where they became exhausted by census procedures and personnel. The result of this process sometimes led to a lack of cooperation among key personnel, and would potentially harm chances of successful CCM. The hospice facility was different, because their goals were to minimize burden on dying patients and their families. The administrator appreciated the exclusive use of administrative lists, and hoped it remains an option in the future.

Based on the study findings it was determined the most realistic plan for CCM would involve the use of administrative lists created and maintained from the official census date. Careful planning and implementation for list creation would be required, along with staff member assistance. This research revealed a need for resident or family notification, advanced planning with the facility and staff compensation for CCM administrative list creation. The timing of CCM is crucial, as very little time should elapse between the decennial census and the secondary count. Rapid population transitions from death, discharge, respite care arrangements, hospitalizations and new admissions require an immediate second count. Beyond that critical time frame, the risk of inaccuracy increases. Encouraging staff cooperation will require creative solutions because CCM does not have the level of recognition or legitimacy the decennial census typically receives.

1.1 Census Enumeration and Census Coverage Measurement Recommendations: Decennial Census Enumeration

- The Census Bureau Group Quarters definitions need to accurately reflect the realities of competition in modern skilled nursing facilities. As an adaptation to competitive markets, many facilities actively recruit and create new categories of residents to fill beds. Assisted living, respite, short term rehabilitative services, and hospice care are often housed together influencing enumeration and requiring a mix of methods.
- Census enumerators should prepare for a diverse Skilled Nursing Facility (SNF) population. Those with severe cognitive disability or behavioral problems require information obtained through family proxies or the use of administrative lists. Terminal decline may mark a time when respondents and/or family members are under stress and not interested in reporting information to the census. In contrast, residents who are interested and cognitively aware can self-report or have information verbally obtained by an enumerator. Census workers should provide administrators at least one month's advanced notice to anticipate a selection process to determine candidates for self-report, family contact for proxy-reporting or the use of administrative data.
- Family contact permission for administrative record use could be obtained on an opt-in basis communicated through mail or electronic format. If administrators are aware of the need for this input, they can ask for it ahead of time, during admission procedures.
- Even when administrative records are collected by the census enumerator, residents should be visited personally in the institution for verification of accuracy of the lists. Disparities may arise if lists are disorganized or out of date, due to the rapid pace of death, transfer and admission.
- Short term rehabilitative SNF stays funded by Medicare are now commonplace. Duplicate counting is likely to occur in these populations when community-based family members include them on the household census form. Information about the "usual home elsewhere" is of particular salience to these temporarily institutionalized persons, and should be collected to prevent a double count.

- It is important in long term care and hospice facilities to report resident admission dates. This research noted cases where residents were admitted and died on the census date. Poor health and patterns associated with transfers, admissions and discharges can complicate the census enumeration in health-related group quarters.
- Computerized data storage is the norm in the health-related group quarters facilities studied. Compliance with census requirements often involved transferring information from computer to paper. HRGQ facilities are capable of securing data in computerized format. Future enumeration will be considered particularly burdensome for facilities if they cannot utilize computer records and send data to the census electronically. It is recommended that the Census Bureau devise a way to receive data in secured electronic format. This will significantly cut down the census fatigue and burden experienced by HRGQ administrators.

1.2 Census Enumeration and Census Coverage Measurement Recommendations: Census Coverage Measurement

- The rapid pace of transfers, admissions and deaths in HRGQ facilities require the population to be counted immediately after the decennial census. A CCM second enumeration would suffer from inaccuracy if time is permitted to elapse. This is particularly true of hospice inpatient residents, who are admitted and die with regularity. Skilled Nursing Facilities also contain residents enrolled in hospice, so the rate of mortality can be substantial.
- It is recommended that CCM be measured exclusively through the use of administrative record lists. The decennial census may be conducted with self- or family-reports, but the CCM would need family permissions to be conducted through facility record lists.
- Plans for CCM must be well publicized with the facility administrators. The decennial census has publicized legitimacy that a CCM does not have, and the facility must be treated respectfully to ensure cooperation.
- CCM schedules should be sensitive to facility administrative business pressures. In this research, “month end” was a stressful time for administrators, and they were more resistant and less likely to cooperate with census operations. Each facility needs a pre-established plan for the second enumeration, which would be sensitive to the pressures of the SNF business schedule.
- “Census fatigue” was common in facilities with recently completed decennial census enumeration. Once this perception exists, the likelihood of cooperation with CCM is diminished. Incentives will be required for further participation. Monetary rewards were suggested for staff who help create the administrative list. In this study, an administrator estimated the staff cost to be about \$300 per employee. Without outside compensation, the facility is considered to be burdened in terms of time and money.

- Facility quality varies and some struggle with disorganization, negative public reputation or poor quality. Records in these facilities may be poorly maintained or difficult to access. Strategies should be devised to assist the CCM process under negative institutional conditions.

2 Background

The ethnographic study of health-related group quarters was commissioned to study resident characteristics, Census 2010 enumeration, and to determine the feasibility of Census Coverage Measurement (CCM). This report is one of six that outline ethnographic research on group quarters populations. The research and writing of the report were carried out by the first author (Salari), and the description of the methods and findings are written from her sole perspective. The study design was conceived by the second author (Chan) who also guided the writing of the report.

Several aspects of institutional life are relevant to enumeration, including methods of data collection, trends in long term care and characteristics and limitations of the residents. Recommendations for practices to conduct a second enumeration aim to avoid problems associated with resident population transitions and the decline over time in institutional memory.

In 2006, 8.1 million people were living in group quarters (GQ), approximately 2.7 percent of the U.S. population (U.S. Census Bureau, 2007). Special challenges exist for census enumeration in these GQ facilities compared to distinct housing units. Group quarters with special health compromised populations, such as nursing homes and hospitals typically utilize administrative records as the typical mode of data collection. The *Census 2000 Evaluation: Group Quarters Enumeration* report encouraged the population count using that primary method of enumeration (Jonas, 2003).

Nursing homes provide beds and living environments to those with needs for nursing care, help with ambulation, supervision of activities or personal care. Activities of Daily Living (ADL) include; bathing, dressing, toileting, transfer and eating. Persons in skilled nursing facilities (SNF) need help with ADLs because of various mental and/or physical impairments caused by developmental disability, accidents, injuries, stroke, chronic illness and/or dementia. Residents in these facilities represent just under one quarter of the total GQ population (22 percent). “SNF are licensed to provide medical care with seven day, twenty-four hour coverage for persons requiring long-term non-acute care. People in these facilities require nursing care, regardless of age (U.S. Census Bureau Census Coding, 2010 type 301).” There were 1.7 million nursing home beds in 2004, with an occupancy rate of approximately 86.3 percent. The majority of nursing homes were proprietary (61.5 percent), compared to voluntary nonprofit (30.8 percent) or government (7.7 percent) and more than half were affiliated with a larger chain (54.2 percent) versus independently operated (45.8 percent) (U.S. Department of Health and Human Services, 2009).

The typical nursing home resident is female (70 percent), white, widowed, advanced age (median 83.2) and suffers from multiple health problems (U.S. Census Bureau, 2007). In any given year, nursing home residents comprise about 5 percent of the population 65 and over (Hillier & Barrow, 2007) and figures show a decline in the percent of old-old (75+) from 10.2 percent in 1990 to 7.4 percent in 2006 (U.S. Census Bureau, 2007). In 2004, the results of the National Nursing Home Survey (NNHS) estimated 1.5 million residents were receiving care in 16,100 facilities. The number of nursing home beds declined from 1999 to 2004, while the

average size of available facilities grew slightly (U.S. Department of Health and Human Services, 2009).

Skilled Nursing Facilities with specialized populations, such as veteran's homes, may be disproportionately male and include residents with service-related injuries. On any given day, 35,000 veterans receive institutional long term care for disabilities. Veteran's nursing homes have contractual arrangements with the VA to provide long term care to eligible persons. The need for this type of institutional care will increase dramatically with the rise in the older veteran population in the next two decades. In a market that is increasingly competitive, veteran's nursing homes still have waiting lists because per diem payments assist in affordability for residents with a military eligibility (U.S. Department of Veteran's Affairs, 2010).

Trends in skilled nursing care have recently included an emphasis on rehabilitation, which may allow residents to eventually return to their own community-based home. Connections to the outside world and family relationships may be maintained in these temporary institutional arrangements.

The Omnibus Budget Reconciliation Act of 1987 (OBRA) made nursing homes among the most highly regulated environments for health care in the U.S. The act increased patients' rights for making decisions and planning their own care (Hillier & Barrow, 2007). Several philosophies have sprung from these changes, including the emerging emphasis on "person centered care" with greater autonomy and decision-making. In addition, family members have become more involved in resident care, as studies have shown it reduces anxiety and increases life satisfaction.

A nursing home may be either free-standing or a distinct unit in a larger facility (U.S. Department of Health and Human Services; 2009). Nursing home environments are often couched within a larger Continuing Care Retirement Community (CCRC) also termed Life Care Communities (LCC) where the needs of residents can be accommodated within the same complex but in different specialized buildings to cope with varying needs for independence or specialized care. This study examined two free standing skilled nursing facilities with a variety of services including short stay rehabilitative, respite and hospice care.

Nursing homes have historically been restrictive, which negatively influences the identity of the resident. Previously, it was not uncommon for residents to have been chemically restrained with drugs, physically prevented from wandering and limited in many other ways from experiencing good quality of life in the institution. Goffman's (1967) work suggested that the social influences of a "total institution" might result in adaptation strategies, such as withdrawal or aggression. Salari supported this finding in aging services where inappropriate treatment and environments were associated with aggressive outbursts toward staff or severe introversion among clients (Salari, 2006). The 1990s saw a philosophical reform movement in the long term care industry, which is still in progress today. The Eden Alternative was founded by a physician, who argued that residents in nursing homes should be spared of boredom, helplessness and loneliness (Thomas, 1996). Scholars have encouraged care facilities to treat residents as "consumers" who are worthy of meaningful activities and high quality of life, even if they suffer from dementia (Kane, 2001; Salari, 2006). Collins (2010), Koren (2010) and others have pointed to the culture shift in long term care toward the "Person Centered Approach," which provides a home-like environment where residents have choices about meals, entertainment, health care, self-governance, and socialization opportunities. Modern long term care facilities now have legal mandates supporting the need for patient privacy (e.g., HIPAA) and residents' rights.

High regard is placed on provision of autonomy “being one’s own person, without constraint by another’s action or by psychological or physical limitations (Beauchamp & Childress, 1983).” For example, guardianship, is only undertaken when an adult is determined to be incapable of managing his or her own affairs. There is an ethical duty to use the **least restrictive** options and practitioners are urged to create individualized solutions that allow for personal freedom. Disabled persons have capacities in some areas and lack capacity in others. “Begin with the client handling their own affairs and then move up the ladder to more restrictive options (Heisler and Quinn, 1998; p. 178).” Similarly, all adults are thought to be legally competent until a court of law rules otherwise. “This means they can execute legal documents, make medical decisions, decide where to live, and...have full control of their lives (p. 179).” The focus should not be what a person is *incapable* of, but rather the tasks they are *capable* of doing (Heisler and Quinn, 1998).

Access to health-related GQ facilities have become more difficult over time, due to regulations associated with patient privacy (HIPAA), and safety. Beginning in 1996 Health Insurance Portability and Accountability Act (HIPAA) health-related facilities and services have had increased concern over the privacy of patient health records (US Department of Health and Human Services, 2010). Some of the concerns were related to patient files in electronic form. Another type of concern arose as a response to financial exploitation, identity theft and pharmaceutical mismanagement abuse that had taken place in institutional facilities. A variety of states have passed legislation mandating the requirement of background checks for employees in nursing homes. These issues have created a culture that becomes less accessible to criminals but also to outsiders in general, which may influence the census enumeration process if it is perceived to be at odds with institutional goals.

Hospice services are for those with six or fewer months of life expectancy, who wish to shift to non-curative care. With the help of Medicare, Medicaid and private insurance funding, hospice care has been increasing. Estimates suggest that 38.5 percent of deaths were under the care of a hospice program in 2008. In that year, an estimated 1.45 million patients received hospice services, and approximately 963,000 died. More than half of hospice patients were female (56.6 percent) and a minority (16.8 percent) were under 65. In the 1970s, the primary hospice admission had terminal cancer. By 2008 cancer comprised less than 25 percent of U.S. deaths, and other terminal conditions (such as dementia, heart and lung disease) featured more prominently (National Hospice and Palliative Care Organization, 2009). The majority of hospice services take place in a patient’s own home, but they may also be located in in-patient hospice centers, hospitals, long term care facilities and nursing homes. “In-patient Hospice Facilities could be free-standing or units in hospitals that provide palliative comfort, and supportive care to terminally ill patients and their families. Only those with no usual home elsewhere are tabulated into this category (U.S. Census Bureau Codes, 2010 type 403).” In 2008, there were an estimated 520 inpatient facilities in the U.S. and 21 percent of hospice deaths took place in such a location. In addition to end-of-life phases, these facilities offer an additional service of short term respite care when relatives need a break from caregiving (National Hospice and Palliative Care Organization, 2009).

Staff members in hospice facilities are trained in standard HIPAA regulations and resident rights, but there is further orientation related to coping with terminal illness and death. The needs of hospice patients and families are more acute than those in general nursing home care. Elevated stress levels and emotional exhaustion play a role in the need for services to help support those coping with impending death. This research included observations in a privately

owned in-patient hospice facility that was committed to easing pressures for individuals and families served.

2.1 Specific Goals and Objectives

This ethnographic study of selected Health-related Group Quarters (HRGQ) was undertaken to evaluate the potential for a CCM Census Coverage Measurement in the form of a second enumeration, and to evaluate the 2010 decennial census to help recommend whether a CCM should be attempted. Observations of the process and potential problems of 2010 GQ Census enumeration were utilized to provide recommendations for future population counts in similar institutional settings. Conducting census enumeration in the traditional fashion has been challenging in these HRGQ facilities because many residents suffer from cognitive impairment, severe health and functional disabilities. Some have end stage terminal illness, so mortality is a salient factor with regard to the population count and the ability to replicate the count at a later date.

2.2 Research Questions

The following research questions were used to guide the ethnographic study of health-related group quarters.

RQ1: What blockages were encountered to obtain facility entry and access?

RQ2: What were the resident characteristics and limitations?

RQ3: How did population turnover affect the potential to accurately count residents?

RQ4: How was the census conducted, and were there any problems encountered?

RQ5: Can Census Coverage Measurement (CCM) be conducted in similar HRGQ facilities?
What are the limitations to accuracy and recommendations for success?

Themes emerged from the research observations and interviews, which related to each of these general research guidelines.

2.3 Ethnographic Research

Three health-related group quarters were observed in this research. In each setting issues of access, resident health and population turnover emerged as salient themes influencing the census enumeration process and potential for CCM. The researcher noticed high standards related to facility access including HIPAA standards and residents' rights. Training sessions and security screenings were universal. The second major theme involved observations of resident health and cognitive characteristics. Finally, the rate of population turnover in the group quarters was relevant and the HRGQ resident population was continually shaped by transitions, including admissions, death, transfers (mostly to hospital), and in some cases release of short term rehabilitative stays at home. The following section describes the facilities in more detail.

Facility A – This was a Private Veteran’s skilled nursing facility with 81 beds, associated within a larger hospital campus. The residents were mostly men, and requirements included injury or age-related disability. General long term care was located on the main level and housed 60 residents. The behavioral Dementia Unit was downstairs and had 21 residents. Unlike the other facilities in the study, there was a wait list, which was approximately 80 for the main floor and 70 for the Dementia Unit. The Administrative focus group estimated about 40-50 percent of the residents were cognitively aware, and about 41 persons were considered too demented to participate in a simple task, such as answering questions about census information.

The researcher obtained entry after rigorous training and security checks performed by the volunteer office. The nursing home was observed for approximately 30 hours. In addition, data was collected from a post census formal focus group interview which was conducted with the Administrator and the Social Worker.

The campus was associated with a larger hospital, so the Census Bureau determined the census enumeration would take place following a training session where a representative would visit the facility, swear in select employees and train them to count the population on April 1, 2010. The 2-hour training session took place approximately 3 weeks before the enumeration date. Four staff members were selected to attend the session that carefully covered the information contained in the Self-Enumerating Group Quarters: 2010 Census Facility Contact Manual D-578. The option was provided for staff members to use medical/administrative records or ask residents to report for themselves. Family proxies were not considered in the decision. Ultimately, all residents were proxy coded with information from administrative data. A resident had died on 3/31/2010 so there were 79 residents on April 1. Rather than using all four trained employees, the Administrator and Social Worker used computerized administrative records files and transferred them to paper census forms for each resident. The completed forms were collected the next day by the Census Representative. Originally, there was talk of allowing certain residents to self-report, but that plan was abandoned. The researcher did not observe anyone asking the residents whether they wished to participate. The census enumeration work was split between two employees and done 100 percent using administrative records.

The researcher created an alternate list on April 1, 2010 using a list of residents and their room locations. Each resident was physically observed by the researcher. Additional information such as date of birth (DOB), gender and race/ethnic information were accessed through hard record binders for each resident located at the nurse’s stations. The researcher also took note of admissions date, which is not officially obtained in the census. Admissions on and around April 1 were better understood with the inclusion of admissions data.

Facility B – The second institution was a large skilled nursing facility with 143 beds located in a suburban area. Residents had typical age-related chronic conditions including dementia. The facility was considered to be under-enrolled, compared to past years. Nursing home quality ratings available on the internet evaluated this facility very poorly and Medicare rated it one star out of five (worse than the vast majority of the state Medicare scores). Some of the specific criticisms involved the elevated risk of physical restraints, and lack of adequate pain management.

There was initial verbal cooperation with Facility B interim director for research participation. An appointment for a meeting and orientation was scheduled. Later the meeting was cancelled, and permission to participate was declined. Once the new administrator was hired, the research investigator attempted several times to meet personally with her. Phone conversations with the reception staff yielded some information, but the facility ultimately did

not cooperate with participation in the ethnographic research study. The total facility observation time was 2.75 hours. During initial contact, the researcher conducted observations in the lobby while she waited for a meeting with the new Director. Indicators of quality were evident. For example, a representative from the state health department entered the lobby and announced his intention to conduct an investigation of alleged elder abuse. This event ended the researcher's observation, as she was ushered out of the building without meeting the director.

When the researcher consulted the administrator by phone post-census, she stated she thought medical records were used to enumerate the resident population, but she was unsure. It was estimated there were approximately 104 residents on April 1. She told the researcher she would call back with the information, but there was no follow-up.

Facility B staff and administration were not interested in participating in the observational research project. The theme that emerged suggested the problems with poor quality of care and institutional disorganization interfered with the ability to accept research intrusions from outsiders. These issues are relevant to the Census Bureau, because similar barriers to enumeration and CCM may be experienced in other group quarters with institutional disorganization.

Facility C – This was the third group quarters setting, and was observed for 18 hours. The in-patient hospice care facility had 21 beds available, but typically 15-18 current residents. The facility served dying persons with a life expectancy of six months or less, who have committed to receive only non-curative health care and support. Previous years had waiting lists for admission, but there is a recent increase in competition from curative medicine approaches and environments such as assisted living facilities with hospice services.

The facility administrators and staff were committed to providing a stress-free environment, for dying persons and their families. The residents were often bedridden with advanced stages of disease. Physically, they sometimes appeared discolored with very little body fat and a shallow breathing pattern. Cognitively, some of the residents had dementia or "dysphasia" which would require assistance with the provision of census information. The Administrator estimated 50 percent of residents would not be capable of self-report on the census.

Population turnover was a very salient issue in Facility C. The population was influenced by rapid changes, sometimes including several deaths and/or admissions in one day. On the census date April 1, there was a death at 9 a.m. Throughout the day, three new admissions were added to the population. One of those admissions died that day and another died on April 2. Preparation for the decennial census included an advanced visit from an enumerator in March. The Administrator was provided a folder with a census form, and was given notice that the census would be taken via administrative list at some point in the beginning of April. The date of the visit was April 8th, and the Administrator submitted a list of 15 residents based on her records and her memory of population transitions for April 1.

On the designated census date, the Researcher was escorted to the records room where she created an alternate list of residents. Binders contained admission records which were used for birth date, gender, race, admission date, and previous address. Ethnicity information was not available. Inconsistencies existed between hard files and the daily census record (provided by the front desk). Admission dates were complicated by the fact that a resident might have been a patient in homecare first (through the same company). Population characteristics included 12 females and 3 males. Two residents were 94 years old, which represented the oldest age. The youngest was 71. There was one African American and one Asian American, the rest were

Caucasian, non-Hispanic. Each resident was identified within the facility, and the physical condition was noted.

The administrator expressed a preference for the use of resident lists for census data collection and hoped that option would be available again in the future. Family members of hospice residents have several responsibilities, and may be under increased emotional pressure. Given the severe physical disability and terminal decline of residents, the lists provided information without asking residents and their families to perform the tasks.

Facility D – The Alzheimer’s Care Skilled Nursing and Short Term Rehabilitation Facility had 85-115 beds and was observed for over 22 hours. The facility had 4 sections which included a Behavioral Dementia Unit, two long term care units (with hospice) and a short term (Medicare funded) rehabilitation Unit. Previous years had wait lists, but at the time of this study the beds were underutilized. Approximately 70 – 85 residents were observed in the facility. About half were men and half women and the vast majority were white non-Hispanic. Some of the residents suffered from physical decline, but were not cognitively disabled. Others were cognitively unaware, but had relatively good physical health. The administrator focus group estimated 30 to 50 percent of the residents could respond to the decennial census for themselves. It was important to the administrative staff focus group that residents who were capable should be given the right to participate in the census. For those who were incapable, the preference was that family members should have been given the option to provide the information. According to the administrative focus group, the exclusive use of administrative lists was a preference of last resort.

On the census date April 1, the researcher’s alternative list recorded 69 residents and each was accounted for physically in the institution. Initial contact by the official census enumerator to the facility was unsuccessful and there was no follow up until April 2. The administrator perceived they had been missed by the census. Once the enumerator made contact, the administrator complained that he had little advanced notice, and was caught at a busy time with “month end” business. The census worker assumed it would be better to do it the “easy way” and expected the facility would immediately produce a written list of resident information. An argument ensued, and the Administrator was uncooperative, sending the census worker away without a list. The administrator wanted capable residents to answer for themselves, or use family proxies. Staff resources would need to be used to produce the administrative list. The census enumerator returned the following week. She received a list with 66 residents, 3 short of the alternative list created on April 1 by the researcher. The discrepancy was related to residents who were discharged on April 1.

Additional information about birth date, admission date and last known residence were requested and a hand written listing was provided. The community based residence of record was relevant to short-stay rehabilitation residents, due to their eminent return. There were 37 women and 29 men. The oldest was 96 and youngest age 47. The vast majority of residents were Caucasian, non-Hispanic. It was later determined the ethnicity of one resident was inconsistently coded between census enumerator and researcher’s alternative list. Due to HIPAA concerns, Facility D did not provide the researcher open access to the resident binders.

3 Methods

Qualitative research is well suited for the study of the characteristics of residents and the culture within institutions (Gubrium, 1992; Hendricks, 1996). This work was commissioned

with specified research questions related to the study of resident characteristics, population transitions, decennial census observation and the potential for Census Coverage Measurement (CCM). In addition, a grounded theory approach (Glaser & Strauss, 1967), allowed the researcher to observe aspects of the residents' social lives and to discover patterns or themes in an inductive fashion, without predicting results. Theory generation and relevant concepts were data guided and emerged during and after data collection and analysis. A constant reiterative process of data examination and coding led to interpretations from observations. The ethnographic approach allowed the investigator to: 1) observe the naturalistic setting and contexts; 2) gain the perspective of the insiders (administrators, staff, and residents); 3) observe both the formal and the more implicit agenda (Ward, 1999); and 4) determine the impact and effectiveness of the population count process.

This study utilized a multi-method approach to examine three institutional settings that housed residents with specialized health concerns. Qualitative data collection allowed the investigator to develop a deeper and richer understanding of the phenomenon under study by including both observations of the natural settings and seeking insiders' perspectives through interviews and focus groups. The results of this study are not intended to generalize to other residents or institutions, but recognize that similar facilities may have similar subcultures (Ward, 1999) and therefore these results can inform the process of counting in this type of group quarters and the potential for CCM.

The study design involved passive **participant observation** techniques—where the researcher immersed herself into the daily lives and routines of those residing and working in designated HRGQ facilities. This study was primarily inductive, with observations, interviews and data analysis yielding the results and informing theory construction. The investigator attempted to be as unobtrusive as possible, without getting involved in the activities in the natural environment. Multiple sites of observation varied in meaningful ways and were ideal for comparison purposes. The investigator's previous qualitative work used comparative ethnographic approach to compare quality of life in 10 aging services and residential facilities, similar techniques for comparison are used for the three HRGQ facilities in this study.

The principal investigator attended a conference at the Census Bureau, where she was trained in the proper use and storage of Title 13 data. Interview schedules and consent forms were approved and human subjects approval was obtained by ORS. The investigator supplemented her own fieldwork with an observation of 10 **American Community Survey** interviews in a HRGQ for developmentally disabled adults. The ACS interviewees were unavailable, so information was obtained through the use of administrative proxy materials obtained in resident records binders.

Facility entre presented challenges to the researcher and may be relevant to the experiences of census enumerators. Approval from each facility was initially obtained, but Facility B personnel did not follow through with necessary permissions and access. In the approved institutions, entre requirements involved HIPAA training, ID badge, health screening, presentation and an orientation tour. Additional specialized training regarding bereavement, grief, patient care and resident rights was also administered.

Observations were underway approximately a month ahead of the officially scheduled census enumeration date so that residents and staff members became accustomed to the presence of the researcher. The researcher could be perceived by residents and staff as a legitimate presence, yet separate from census enumerators.

Recording Population Transitions involved special attention to transfers, hospital visits, deaths, admissions and discharges back into the community. These characteristics complicate the ability to enumerate the population, and provide CCM. People in advanced ages, those with serious injuries or late stage terminal illness are much more likely to experience mortality during the process—which has serious potential to complicate the count. The researcher continually checked resident beds and double checked the administrative reports regarding transfers, deaths, admissions and hospitalizations that took place since the last observation.

Pre Census Day Preparations and Training Programs – The researcher attended all meetings and training sessions held between facility administrators and census enumerators. The principal investigator attended as a covert “university researcher” in each case. Facility A had a March 12 training and swearing-in of 4 employees, which was directed by Census Worker C. The session lasted 2 hours and strictly followed the D-578 Self Enumerating Group Quarters Facility Contact Manual. The in-patient hospice facility (C) was given prior notice during the month of March, of the imminent census enumeration, but the exact timing was not specified. The researcher kept in contact with the administrator for updates with regard to timing. On April 8th, she was present and observing as a list was exchanged between the administrator and the census enumerator in the lobby of the building. Facility D had no successful communication with the census enumerator in the month of March. Finally, on April 2nd, the researcher observed an impromptu meeting between the administrator and the census enumerator. She was permitted to take notes as a “university researcher.”

Census Day Observations and Alternative List Creation--The investigator spent several hours observing each facility on the specific census date. Observations of the census enumeration process were ongoing as administrative lists were used to count residents. In each case, the census enumerators were unaware of the social researcher’s role as covert evaluator. There were several opportunities for the researcher to observe interactions between the enumerators/census workers, staff and administrative personnel. The researcher obtained administrative lists of the facility populations and she visited the residents where they were located in the facility on April 1, 2010. Some were in their rooms in recliner chairs or in bed or in common areas. Each resident’s records were compared to their appearance and visual inspections were used to help verify gender, approximate age, and race. In Facility C (hospice), the researcher sometimes had difficulty determining visual signs of life, as residents were often discolored and motionless. In Facility A and D there were resident names and pictures on the door to their rooms—which allowed the investigator to verify the appearance of the proper resident.

Resident records were accessed by the researcher in Facilities A and C and were located in binders in a records room. Available information included name, birth date, age, sex, and race of the residents. Ethnicity was available on hospital records, but Facility C did not typically collect that information. In addition to the census information, the researcher collected the admission date and the last known residence (or usual home elsewhere). Facility D did not provide the researcher with access to a records room or resident binders, but the administrative assistant created a list with the characteristics, admission dates and addresses of each resident. The researcher’s alternate lists of residents were all hand written, without the use of electronic devices or recordings. Procedures complied with Title 13 standards for protecting privacy and were sent to the physical address of the Project Manager at the Census Bureau.

Observations noted staff preparation for the census count, the process of census enumeration, staff reaction to enumeration, enumerator interactions, and the impact of the enumeration process on the facility. There were no interactions observed to happen between regular census enumerators and residents in any facility studied.

Field notes were taken by hand on scene during the observation process, and detailed notes were filled in immediately after the observation session closed. Unobtrusive techniques of observation used the “busywork” notion—developed and utilized in previous research projects by the investigator and colleagues (Salari & Rich, 2001; Salari, 2002; Eaton & Salari, 2005; Salari, Brown and Eaton, 2006; Uriona & Salari, 2002). In these observations, the investigator had a pad of paper for note-taking and appeared to be looking down, engrossed in writing. This activity kept the researcher from social alliances or being recruited by staff or residents for assistance with tasks or other aspects of life in HRGQ. During the recording of field notes, there were often Theoretical Notes (TN) or Observational Notes (ON) inserted into the text that allowed the recorder to indicate patterns or themes as they began to emerge in the data. Field notes were ultimately managed, content analyzed and referenced.

Field note coding and observation categories involved the agreement of multiple researchers. Using observation data cleaned and absent of identifiers, the investigator and two research assistants read the field notes, and determined coding categories that emerged from the themes of the data sources. The process was repeated for coding and interpretation of interview and focus group transcripts.

Post Enumeration Interviews/Focus Groups were conducted in each facility. The insider perspective provided insight to long term care culture, along with the strengths and weaknesses of what appeared to be observed in the setting. “In-vivo coding” procedures involve learning the view of the insider or informant (Ryan & Bernard, 2000). Informal and formal interview techniques were employed. The Census Bureau is charged with obtaining information without causing burden on GQ residents. Formal sit down interviews with vulnerable adults were not appropriate in this research, but voluntary discussions over the course of observations shed light on the resident’s cognitive capacity and frame of mind. Interviews of residents were informal and stemmed from the natural observation process. Residents were the initiators of the conversation with the researcher. In-depth formal interviews in populations with cognitive limitations or end stage terminal conditions would have required a more complicated consent process, with family consent and resident assent.

Formal in-depth interviews of staff members and administrators were conducted in the three facilities. These interviews were structured and open-ended. Respondents were asked for consent to record the interview so that transcription could be accurate. Members of the focus group in Facility D declined permission for recording, so notes were written by hand. In this research, interviews with staff members and administrators aided the understanding of the institutional experience of the census enumeration. Questions on the interview schedule asked about access to residents, language barriers, health/cognitive difficulties, refusal rates, accuracy, errors and updates of administrative lists, staff adequacy, back-up plan, suggestions for improvement, and potential feedback (Appendix A). Consent forms were relatively simple (Appendix B) and were signed prior to the interview and a copy was provided to the respondents. Two of the interviews systematically questioned individuals simultaneously. The focus group systematically questioned individuals simultaneously with the goal of aiding respondents’ recall and establishing a group consensus. There was little evidence of controversy, and agreement was usually attained among the parties in each focus group.

Data Analysis These data were mined with content analysis, repetitive reading, coding, team agreement and attention to the emergence of themes. The principal investigator entered data in the computer only after it had been completely stripped of any identifying characteristics of individuals. Facility locations or names were not specified. Pseudonym nicknames were entered from the onset in raw field notes. Interview transcripts were prepared in a similar manner, without identifiers. All other data sources used pseudonyms and were disguised to prevent identification. The initial coding process was done by the principal investigator, with the assistance of two (2) Research Assistants who helped determine non overlapping coding schemes and emerging themes. This practice provided for increased validity of codes related to census enumeration and the potential for CCM.

4 Limitations

The following limitations are noted and described below.

- The three facilities studied cannot be generalized to the larger HRGQ universe.
- The researcher was **blocked from access** to Facility B through indirect and direct methods of resistance. Obvious problems and internal disorganization within the facility were evident. The facility would have been a prime location for study, partly because of their internal problems. It is likely they experienced disorganized or blocked census enumeration access as well. A post-enumeration phone interview attempted to determine how the census was conducted in the facility, but the administrator seemed to be unsure.
- Each facility required several research hours for the creation of an alternative list and observation of how the process transpired. Research Assistance would have been ideal, but the principal investigator was the only person with security clearance, sworn status and Title 13 training. The alternate list creation was successful, in part because facility administrators cooperated with a schedule that provided the investigator with adequate time for each location. Census enumeration took place between April 1 and 8, so ultimately, the observations were successfully completed by one person.
- Formal interviews of cognitively competent residents would benefit the research. In an ideal situation, the researcher would have determined how the residents felt about the census process, and their desires for participation.
- Access to formal interviews of the census workers would have been helpful. Those enumerators in this study were unaware of the researcher's covert status as a census evaluator. Instead, the researcher sat in on training sessions and meetings with between administrative staff and census enumerators to observe varying perspectives.
- There is little information available about how to determine the cognitive competence of residents, who might wish to self-report. One administrator mentioned a quick test of 3 questions might facilitate judgment about capabilities to answer census information.

- The study lacked the successful self-report by a resident. **None of the residents participated in census enumeration.** Observations did not support the notion that residents had a choice, as residents were never contacted about the census. Even the ACS interviews used administrative records as proxies for self-reporting.
- The facilities studied here had a **great deal of population turnover.** Due to the admissions, deaths, hospitalizations, temporary respite placements and discharges—the population would not be the same from day to day. Observations illustrated the careful record keeping of the three facilities, but long term maintenance of these data are less likely. Relying on institutional memory in group quarters would be more difficult than household memory in regular housing units.
- **Short term stays make enumeration and CCM more difficult.** Previous community based residence addresses are salient for census takers and should be collected. The potential for double count is there. Death may lead to a short term stay. As an example, Facility C terminal illness patients were observed to occasionally be admitted and die on the same day.
- Health-related group quarters that utilize both home and in-patient care (such as hospice) have confusing rules about “new admissions” and how they were counted by the larger company. Enrollment in the program could be from home or the hospital to facility inpatient care. If a patient was already enrolled in home care and then transferred to in-patient facility it is not counted as a new enrollee. Therefore admission dates may reflect the beginning of home care, and not group quarters care.
- GQ Definitions seem narrow for the scope of this study. **Rarely is a modern nursing home a stand-alone facility.** The enumeration and CCM accuracy will be related to the understanding of this diversity. Enumerators who expect a regular long term care facility may be surprised to find a diversity of classifications such as hospice, rehabilitation, respite care and dementia units.

5 Results

The observations, interviews, and focus groups served to inform the study about access to environments, resident characteristics, institutional culture, decennial census preparation, the enumeration process and the ability to perform CCM to check for data accuracy.

5.1 RQ1: What barriers were encountered to obtain facility entry and access?

All four facilities in this study had some measure of difficulty obtaining entry or cooperation and Facility B eventually denied entry. A common theme was related to institutional suspicion of outsiders. Nursing homes have recently been placed under increased scrutiny by government regulations and consumer groups who are concerned about quality of life in facilities. A series of “roadblocks,” which may have been intentionally designed to stall or discourage outside research or evaluation, were commonly encountered.

The facilities studied required HIPAA training, knowledge of resident's rights, ID badge, security and health screenings, and an orientation. The process took weeks to complete prior to observations. There was some evidence of anti-government bias related to the researcher's Census Bureau affiliation in two facilities (Facility A and D). Covert affiliation was required in many instances, and the researcher often described herself as a "university researcher" to inquisitive nurses and volunteers. Occasionally the researcher detected some suspicion of the project, especially from health care providers who seemed on edge that the researcher might be scrutinizing their work for HIPAA or health code violations. HIPAA legislation has revolutionized the way long term care is delivered. Patient privacy concerns make staff members vigilant and suspicious toward outsiders. This suspicion was sometimes directed at census enumerators and the principal investigator. Entre procedures required in Facility D included viewing several VHS tapes about HIPAA. The messages included "Embrace HIPAA—it is not optional." There were definitions of key terms such as "Patient Health Information" PHI and instructions for privacy safeguards, reporting a breach, destroying waste, communications, electronic handling, and groups with access to PHI. HIPAA was observed to be a key part of the culture of long term and hospice care. As observations were conducted, the researcher was repeatedly asked by nurses and other staff members "Can I help you?" The translation: "State your identity and purpose here." Sometimes the questioning had a confrontational tone, such as this line of dialog aimed at the researcher in Facility D:

Nurse: "When I see someone writing down names, I need to come over and figure out what you are doing."

Facilities attempted to minimize outside intrusion into the culture and setting, and were particularly protective if residents were terminally ill or when the facility was in crisis. Many facilities have requirements for escorts, because prescription drugs and valuables are in resident rooms, without their ability to defend from theft or abuse. The Administrator in Facility C (hospice) made a point of describing these needs in her post-enumeration interview. Protective behaviors of staff members and administrators may limit the access census enumerators have to resident information and records in a health-related group quarters environment. One method to ease these concerns would involve a HIPAA training session or two for any enumerators who may be headed into a facility for the count.

Quality of care and code of conduct were emphasized and in Facility D the investigator signed a receipt stating she had received the bill of "Resident's Rights." The typewritten handout had 34 points describing how residents could expect to be treated. Some of the items included the right to: a dignified existence, communication and access to persons and services inside and outside the facility; to exercise rights as citizen or resident of U.S.; use of a legal surrogate; be free from coercion and discrimination; be informed in a language he/she can understand; right to give consent or refuse treatment; manage financial affairs; personal privacy and confidentiality of personal or clinical records; view records pertaining him/her; the right to send and receive unopened mail promptly, etc. The resident also has the right to reasonable accommodation of individual needs and preferences and to participate in social, religious, and community activities that do not interfere with the rights of others.

Modern long term care culture attempts to make institutional living more home-like with choices, responsibilities, meaningful activities and attention to resident empowerment in decision-making. These philosophies were evident in the two long term care facilities. The

Resident is envisioned as a **consumer**, whose needs include comfort and satisfaction. In the past, residents were required to conform to institutional goals and lose their independent identities. Consistent with these philosophies, residents were permitted to decide to have some level of risk in their lives. In Facility A, Mr. Plaid's smoking habit served as an example. He was clearly a chain smoker, and made regular trips outside to smoke. In addition, alcoholic beverages were permitted and served at party functions.

Facility D Focus Group participants felt it was "worth it" to allow resident involvement in their own enumeration. The census count would be intrusive, but worth all the risks to train census employees to deal appropriately and directly with residents. The focus group perspective was aimed at empowerment for capable residents who could respond to the census themselves, and in the opinion they should be given the right to try.

Admin G: Yes we still prefer to have them answer for themselves. Worth the dignity...They built this nation and I guess I would pay more taxes if they would allow them the opportunity to answer for themselves.. We are trying to make sure government acknowledges them...

Staff M: We can't risk chipping away at resident rights.

Occasionally the researcher encountered an undercurrent of **Anti-government bias** which limited entre or cooperation. Government entities such as the Census Bureau may be perceived as interfering with individual rights and freedoms. One staff person on the larger campus of Facility A became agitated when the topic of the census came up. He said

"The census has no right to ask more than a certain number of questions... Very basic... and you do not have to answer anything else. A politician up north (name) has a whole webpage about it. You should look her up! Me, I will not answer anything more than the basics (listed them) and I don't care if they try to fine me. You see...that is what they are doing with the new President...they are going to collect revenue that way... Try to get more information out of people, and when they refuse, charge them \$5000. I don't care! I won't answer! Let 'em try to get that money from me."

Additional experience with that sentiment was related to conversations with Administrator G in Facility D. It was clear he had investigated his requirements to cooperate with the census enumeration. He mentioned that since his facility receives federal funding, he would have to allow access for decennial enumeration.

Proprietary ownership in long term care has added a business emphasis to the provision of skilled nursing and terminal care. Changes in funding led to decline in the need for wait lists at Facility D and C, due to increased competition pressures with other facilities and services. Observations indicated these facilities were in a constant struggle for business, with strategies employed to recruit new enrollment. The Consumers benefit from the competition because they are recruited and valued. This long term care business emphasis was often at odds with census data collection. Census procedures were perceived as an expensive use of resources which required too much facility staff involvement. Facility D administrator and staff M pointed out that improper use of staff resources is ultimately paid for by money from residents' pockets.

Staff M: "Residents would have loved to fill this out..."

Admin G: “Payroll expenses would have been needed. Who would volunteer to do it for free? How long would resident response take on staff time? \$200-300 to pay our staff to help residents do it...who pays the bill? I don’t, my company doesn’tOUR RESIDENTS DO....

Another barrier to emerge from these data involved the great degree of “census fatigue” experienced by staff members in the facilities studied. The facilities varied in their openness to census enumerators’ assumptions and techniques. The hospice facility was happy to comply with providing an administrative list of residents who resided in the facility on April 1. In contrast, Facility D provided more resistance to cooperation, in part because the enumerator did not plan ahead and “surprised” them with demands for an administrative list. The administrator felt his values of service provision, business competition, resident choice and autonomy were undermined by these tactics. Along a similar vein, Facility A staff members felt burdened by the 2-hour census training session.

After census fatigue became obvious in the facilities, the principal investigator felt like a saleswoman. Encouraging further cooperation with the study became challenging. Experiences included reluctance and mild annoyance among key players, hoop jumping, and barriers of compliance thresholds. The Administrator in Facility D admitted he was initially planning to refuse participation in the post-enumeration interview. She would be given “5 minutes on the phone.” After some convincing, he allowed an in-person interview (but would not allow audio tape recording). He eventually described his realization that it was worth it if the scholarly investigation could make a difference to suggest census reform. A description of more of the study seemed to ease his cooperation, and he offered to come to Washington D.C. to help inform the process. It seemed helpful for the researcher to align herself with university scholarship, rather than her work with the Census Bureau.

The observation of anti-government sentiment, business concerns and “census fatigue” were important because they influence the probability of cooperation with either the decennial census or CCM in group quarters. It was clear as the process moved on that facilities would require extra incentive to continue their cooperation. Those who wished to discontinue cooperation would be much less likely to comply with a non-mandatory activity, such as CCM second enumerations.

5.2 RQ2: What were the resident characteristics and limitations?

Administrators are anticipating a greater need for long term care in the future and there will need to be an adequate way to count these individuals in HRGQ settings. In the focus group of Facility D they pointed out future trends, where Baby Boomers will be 80 in 20 years and many more people will need nursing home settings. There is an important need for a greater understanding of the strengths and limitations of this population. Severe physical and/or cognitive disabilities exist for skilled nursing and hospice care residents. Cognitive dysfunction is most severe in the “Dementia Units” where residents were diagnosed with behavioral difficulties. The modern design of these long term care facilities involved free movement within locked units for behavioral dementia residents, so that there is no need to physically or chemically restrain persons who typically wander. Segregated behavioral units allowed non-demented residents to interact with persons who have similar cognitive abilities. In the past, it would have been common for all long term care residents to be mixed together. The staff

members would keep an eye on the doors to make sure behavioral dementia residents did not escape. In Facility D, Staff M stated units are now “integrated according to mental capacity” and they had discontinued their previous practice of segregating hospice residents.

Both Facility A and D have Dementia Units where residents are segregated, monitored and secured into their own environment. These residents were observed to have severe cognitive difficulties, with symptoms such as aggression, paranoia, hallucinations (Lewy Body Disease) and some were a flight risk, with a strong desire to wander. Staff, Administration and the principal investigator are in agreement, self-report is not possible and the residents of such units require census information to be transferred from family members or administrative records.

Cognitive Competence varies in the general SNF residence wings. Informal interviews with residents indicated that some have the mental capacity to report the census for themselves. The high level of functioning of some indicated they need nursing care for physical reasons, but cognitive functioning was still intact. According to focus group interviews up to half of residents in all three facilities were considered competent to self-report or respond to interviews.

CASE STUDY Facility A: Some residents exhibited dementia, potential Post Traumatic Stress Disorder (PTSD), and occasional paranoia. The focus group interview estimated 40-50 percent could complete the census accurately, and 41 other residents were considered incapable.

Communication issues were described by Staff R (Social Worker):

“We don’t have any who don’t speak English...but we have some who speak Dementia English (laughs)...If someone were actively dying, they would not be able to fill out the form or be interviewed.”

Disability was related to eligibility in Facility A and many residents had a high level of severe bodily injury or functional limitations from illness, and the vast majority used wheelchairs. Persons with high cognitive abilities were often severely disabled physically. An informal interview with Mr. D took place during the researcher’s observations in the residence wing of Facility A. He was clearly cognitively aware, but described his frustration associated with his physical condition:

Mr. D “I’m a prisoner... I’m 84..you wake up one morning and there you are...I can’t walk. I was WWII injured ...I couldn’t walk...I’ve been trying to learn to walk again. Not currently scheduled for more therapy...”I like to nap now but I can’t sleep at night if I do. My wheelchair feels hard about this time...I got a boil...I used to golf and ski...My stuff is with friends here and there...I lived in FH, a condo, I had to sell it. I’m like a baby now...”

Researcher: Babies don’t have the same knowledge, or memories or skills..

Mr. D. “ Yes but I can’t get myself on the toilet and I can’t wipe myself....I can’t bathe myself...they’ve got young girls who help me with that....Sometimes men, but mostly girls...Its what you’ve got to do I guess.”

Another resident of Facility A, Mr. B was a founding member of the nursing home and serves on the Board of Directors. He initiated a conversation where he described his experiences and his influence in the nursing home.

Mr. B: "Hello and who are you?"...You are a volunteer? Come and have a seat...(indicates chair... reads ID badge)... "How are you (researcher's name)? I've been to other nursing homes and this is the best. I was on the Board...and now I'm back on the Board... Did you see they are opening one in O city? I visited the legislature to lobby for that one. There are going to be resident units, 4 of them. I helped design it...it's more modern than this one...I also helped design the front room of this building... We got to take \$200,000 from CDs...The building here is designed with a lot of windows...Eating here you can feel like you are outside....Better than a dungeon! "Now [I'm] 78..I'm younger than most of the other guys in here."... I've seen 500 leave here on a gurney... I've been here since the 13th resident in this building when they first opened 11 years ago." ... (conversed for awhile) Mr. B: "Alright (name)..I hope to see you again soon. Come back and see us."

The informal interview with Mr. B pointed to his impressive cognitive abilities. He had political and social connections, and served as an "eye in the sky" about the facility and the other residents. He described his traumatic military history (potential PTSD) and how he had survived seeing 500 of his nursing home colleagues depart from the institution on a gurney (dead). He would be a prime candidate for self-report on the census enumeration task, and the researcher strongly believes he would have valued the chance for civic participation.

For the men in the behavioral dementia unit interviews would not be possible. Staff P indicated described the transition to the new way of life.

"Usually there is a 30-day transition before they get used to it [here]. They want their old lifestyle but they don't understand. One man (Mr. LJ) fell and died... Some of them were outdoorsmen, there is a store manager, a politician, Mayor, PhD, book writer, ..."

Coherent conversations were almost never observed in dementia units and one of the residents in Facility D had a shrill loud demanding yell tone to her verbalizations. "MA'AM! MA'AM! ... COME HERE!" repeatedly to the point of annoyance to everyone.

Physical barriers were related to conditions such as severe arthritis, Parkinson's Disease, ALS, MS, end stages of dying and other conditions that may have cut down the ability of residents to participate in their own enumeration process. Some residents in the large recliner wheelchairs in Facility A had trouble communicating, due to physical condition. Those in Facility C who were dying were often unable to speak loud enough to be heard, and the process was stressful. Sometimes those with physical disabilities were completely cognitively capable of participating in their enumeration and/or CCM exercises.

Terminal decline barriers often involved an inability to communicate, but can also hinder the ability of census workers to identify resident characteristics. The dying process may cause a decline in cognitive functioning and residents may be unconscious, asleep or sedated with pain medications. Voices become so weak they can barely be understood. All of the residents of Facility C had the worst possible health because of late stages of terminal illness, with a life expectancy of less than six months. Most of them were in bed and were often discolored, or had features that made their gender and race identification more challenging. The Administrator (Facility C) introduced the term "*dysphasia*" during her interview. This process is related to disease state and may limit the communication potential of residents in the end stage of dying.

CASE STUDY Ms. Puzzle actively participated as she put puzzles together and had quiet conversations with visitors in the common area of her residence wing. As she interacted with frequent guests, the researcher could hear the guest talking, but Ms. Puzzle's voice was faint. She reportedly had lived in the facility for 4-6 months. By the end of the study, Ms. Puzzle had died but her cognitive status remained intact until the end of life.

In contrast another person observed was a female respite patient who was highly confused and demented. She was vocal and clearly distressed about being in a new environment. She had physical strength, but her cognitive status was impaired.

Occasionally a resident from Facility C looked to be in fairly good physical condition. A visitor came to take Ms. Res out of the facility for lunch. The following exchange took place between the women as they joked with the male CNA.

Visitor: "We are going to a luncheon."

Ms. Res: "I might not come back!"

Male Nurse: "Well give us a call if you don't!"

Ms. Res: "The heck with that! I'm not gonna call ya." (All 3 laughed)

5.3 RQ3: How did population turnover affect the resident enumeration?

Deaths, transfers and admissions created an ever-changing population in these HRGQ facilities and represented a major barrier to accurate enumeration and CCM. This section of the results will illustrate the typical patterns observed in the facilities.

CASE STUDIES: Facility C: There were several deaths per week in the terminal care facility, sometimes as many as 3 in one day and a steady stream of new admissions. On the census date April 1 there were 15 residents. The count was complicated by deaths (2) and admissions (3), and admissions with death on the same day (1) and an admission with death the next day April 2 (1). Of the three admissions on April 1, only one survived to April 3. The two deaths on April 1 were counted as residents of the facility.

Facility A: Discharges (mostly deaths) were a part of the culture and population transitions occurred regularly. When someone died, there would be an immediate admission from the waiting list. The population hovered around a constant 79 to 81 range. The other facilities did not have waiting lists to turn to for guaranteed admissions to replace losses. Male Staff P described his perceptions of recent deaths and the reactions.

"In the past week, we have seen the 4th person... Spirits "pass on." Sometimes we have 6 people who went in one month...usually during the holiday season...."(on another day he discusses the loss of 2 men)...they were in hospice... they went quietly."

Facility D Staff M kept the researcher up to date on the weekly transitions by consulting a book which had recent changes recorded. The daily census required 100 percent accuracy for billing purposes. Every week several residents were lost to death or discharge. Admissions would follow, but the facility was still operating at a deficit. This was evident as the empty beds were observed in the various units and a male nurse described a big change in competition and enrollment over the 4 years he had worked there. Admissions can take place 24 hours per day, seven days per week. When people leave they might go to the ER, or expire. Fridays were described as big admission days from hospitals. New residents might also come from assisted living if health conditions worsened. Some admissions are short term respite residents (a few days) and some regular residents are released back home, especially after a rehabilitative stay. Staff M noted:

“Wednesday we had 3 admissions and 3 left (ER, home and “expired”). Thursday 2 admits and 2 left...Friday, 2 admits and 2 short term stays left. One or two admits today, three total coming today...Two people went Saturday and there was an admission.”

Shortly thereafter, there had been 2 deaths and a VA patient entered for a 14-day stay. The man who had broken his hip, was hospitalized and returned had died. The next day there were 2 admits and 3 discharges (2 went home and one to a specialized hospital). Next day, two admits to the rehabilitation unit and there were 2 discharges to home. Friday there were 3 admits to rehabilitation and 1 discharge home. Saturday had a discharge to home, and one status change from Medicare to private pay, but with no room change. Sunday there was a discharge to home. Monday there was an admission for Medicare stay, 3 discharges (2 home and 1 to specialized hospital). This pattern of complexity was typical for this medium large facility.

“Census double count” concerns were related to several of the residents who transitioned in and/or out of the facilities. Specialized residents such as Medicare short stay (Facility D) or recently admitted residents would potentially be counted at home and in the facility. Short stay residents were less assimilated into the long term care culture and tended to be less interested in activities or leaving their rooms. Occasionally they shut their doors completely, for privacy. A good number of these residents would have been able and willing to complete the census forms themselves. The researcher noted from observations that rehabilitation residents had “one foot in the outside world and one foot in the facility for recovery.”

Keeping track of population transitions and recording their entry and exit was a complicated task in health-related group quarters. The following section will focus on how these resident demographics influenced the census enumeration and potential for CCM.

5.4 RQ4: How was the census conducted, and were there any problems encountered?

The census was observed in three facilities and the process varied according to the style and philosophy of the census enumerators as well as the administrators. In some cases, advanced planning had taken place and the HRGQ staff were prepared for the interaction and information

exchange. In another case, the advance work had not been successfully accomplished and the facility administrator expressed surprise at the sudden intrusion.

Census enumerator approach was sometimes perceived as 1) too serious, 2) too pushy, 3) too complicated for how it turned out, and/or 4) too overbearing. Enumerator culture seemed to convey a concern for finishing the task promptly and without much effort so they could be on to the next assignment. The process appeared to resemble a “hit and run” type of philosophy. Most enumerators were professionally dressed and pleasant people. Facility D census worker’s perspective was perceived as “my way or the highway” initially but she allowed for other options when the administrator resisted her push.

As described previously, census fatigue was a theme that was pervasive throughout all three facilities. Even when the process ran smoothly, the census study, the enumeration process, trainings, conflicts with census workers and processes drained on facility resources and were perceived as drawn out and exhausting. Facilities eventually grew tired of cooperating with census enumerators and even the researcher.

One facility had intense pre-census interaction with the census worker, and resources were devoted to training staff members to conduct the enumeration themselves. The result was a perception of “census overkill” where too much had been focused on a task that was relatively easily accomplished.

CASE STUDY FACILITY A: The researcher was present for a census training program. The census worker conducted the session over 2 hours, word-for-word from a *D-578 Self-Enumerating Group Quarters 2010 Census Facility Contact Manual*. Title 13 was described, along with consequences for not adhering to proper procedures. Personal Identifiable Information was described and confidentiality safeguards were conveyed. Instructions were given for cases where residents might want to participate. Two of these staff participants were interviewed later in a focus group and they both agreed the training session was long, a poor use of staff time and could have been significantly reduced.

Administrator M: “I think a sample training would have been better time spent than reading through and actually having to read specific words and taking...our time. He could have pulled in a John Doe sample and had us fill it out and we could have....walked away with the ability to understand what was needed...It just seemed like a waste of everybody’s time...it seemed [from the training] like it was going to be a lot harder than it was.... I think they probably could have reduced their effort here...I don’t know why you wouldn’t just explain to us...and I wouldn’t have dedicated 4 staff members time if I had known...With just the right amount of people being trained and trained the right way...there could have been some time saved on all sides.

This research also detected slight frustration among GQ facility members who generated administrative lists and those who “self-enumerated,” because the administrative records often needed to be transferred from computer to paper forms. This was perceived as doing things the hard way. The process would be more easily accomplished in GQ environments if administrators could submit information to the Census Bureau electronically. Paper records are becoming obsolete and are perceived as being more burdensome for staff to prepare. All three

facilities studied here obtained their administrative list information from computerized records. They are aware of how to guard such records from HIPAA violations.

On the other end of the continuum of experiences was “census neglect.” The serious lack of communication between census workers and the administration was most notable in Facility D. The administrator had initially perceived the census wasn’t going to attempt to count the residents. As of April 1, 2010, the administrator was certain he had not heard from the Census Bureau. He said:

“19 years in the business...no census people have ever come by, or brought forms...This could be part of your audit...the fact that no one has ever come!”

When the enumerator did eventually contact the facility, she requested an administrative list. She didn’t adequately perceive that damage had been done with the administrator. He was irritated with the last minute contact, but also with the major neglect of the resident’s rights to conduct their own affairs. By neglecting to provide notice and proper timing, the contact with the census was suddenly rushed—which forced several decisions upon the facility management.

On April 2nd, Facility D had a meeting with the census employee that became contentious. The Administrator was under stress from the business model of the facility, with “month end” pressures and deadlines. It was considered unreasonable for the census to land in the middle of it, with a rather large and controversial task. The census worker had the following opening statements:

“I understand you have between 85-115 residents, correct?...I’m assuming you are not gonna want me to go around asking each resident. We can do it the easy way or the hard way.”

From the beginning, she assumed he would submit an administrative list of residents and census information. The administrator made it clear that he wasn’t going to use any staff hours to do the work she is being paid for:

Administrator: “You are being paid to do this job?” (She said yes). ..“then we will let you do it.”

In addition, he raised concerns about her assumption that residents could not answer personal information for themselves.

Administrator: Are the residents able to do their own [census form]? I’m an advocate for residents. Why didn’t they get the form? Thirty percent are short stay, 60 to 70 percent are long term (tone was argumentative)...

Census worker S: I’ve done 1990 Census work...We can do it each way. If people could do their own...fill out their own...I can make packets up...

Admin: “If we do it with records, then I’m doing work that is not mine to do...I’d love for you to go to each resident...”

Census worker S: “We need information...we can get it easily or take 3 to 4 days with a combination of both. “

Admin: "I'll try to do it your way...20 years and no one comes...then when you do come in you're not giving the residents the time of day. These people are already disengaged in the community...if they can do their own census, it can get them back into it...There is gonna be a battle every 10 years....I advocate for them...Elderly are held in great esteem here..."

Census worker S: "Well if you want to play hardball...I can have 3 to 4 people come in and question people..."

Admin: "It's not hardball...You approached me this way already...There are a handful who are alert and oriented, who could do it themselves... I guess we will have to do it the way you assumed we would...But it's a shame...I like to advocate for the elderly. About 25 could do it themselves."

Census worker S: "Everyone can be asked if that's how you want to do it."

The two of them had an argument. He emphasized several times that he is an advocate for the elderly. He was bitter about the use of staff time, the assumptions the census worker had about using a list and the lack of resident involvement.

So, the use of administrative lists was universal, but not necessarily the first choice of all facilities. Census enumerators seemed to assume use of resident records would assist data collection, and would be easier. The conditions of the lowest functioning resident were used to form opinions about the abilities of all residents. There was a belief that facility residents would be unwilling or incapable of answering census forms themselves. Ultimately, the administrator in Facility D agreed to "do it the easy way" but it was not without "cognitive dissonance." He was conflicted and felt he was doing a disservice to residents in his facility by cooperating with the census enumerator. The administrator conformed to the census worker's assumption because he didn't really have time or staff resources to tackle the workload associated with the option to let residents do their own form. The issue had been pushed out to the "point of no return;" it was impossible to get resident input on the task.

Once administrative list utilization was determined, there were no census enumerators who came to each resident in the facilities to verify the count. **Administrative list accuracy** was discussed during the Facility D focus group interview:

Researcher: What is the potential that proxy reports (administrative lists) contain errors?

Administrator G: Probably 100% for her (census enumerator) to do it...I could have given her bogus information. How does she verify it?

Staff M: The info we gathered and gave her is not in error, well maybe 10 percent, birthdate, proper names...

Admin G: If she takes the info she has a small chance of error...but how does she verify our accuracy? ...she never came to verify by visiting each room...You did...I thank you personally for taking some time...Hope your study makes a difference to them.

Despite the resistance of the administrator, all of the facilities agreed there were some residents who required proxy reports. This research project illustrated that administrative records are sometimes necessary, especially when the respondent is severely demented, physically unable to communicate or in the final phases of the dying process. Under these circumstances, the information obtained by administrative records may be more accurate than individual reporting.

When residents are unable to self-report, census employees assumed the facility could simply supply the needed information. The focus group of Facility D brought up controversies regarding the proper source for proxy coded information. “Kin proxies” are relatives with rights of decision-making, especially when they hold Power of Attorney (POA) status. Permissions should be given consideration in the process of using proxies on census forms. Observational research found family members were not given an option to be involved in any of the studied facilities. What is the legal status of this question? Can census enumerators request administrative lists, without relative or resident knowledge? Interviewees in the Facility D focus group described the process as breakdown of “chain of permission:” 1) resident, 2) family, and 3) facility administration. Their company desired to follow this chain due to their own philosophy, and many legislative and policy regulations for resident rights that support that position.

Researcher: What advice do you have that would improve the counting process in this facility? Admin G: ...Comes down to ...should it cost my facility anything? And can we afford to take out our residents from the process?

Staff M: Also a legal component. We are not Power of Attorney to do census. We can't vote or fill out taxes for them...so why census?

In contrast, Facility C administrators actually preferred the exclusive use of administrative lists so that dying residents and their families could be spared the participation in a potentially stressful task. In the case of the end of life care the researcher found concerns for “comfort trumped resident autonomy.”

5.5 RQ5: Can CCM be conducted in similar HRGQ facilities?

Hospice population turnover may be too rapid for successful CCM. The problem may not be limited to terminal care units, because the long term care facilities in this study also housed hospice residents. Bell and Cohen (2007) identified four errors in coverage measurement: omissions, erroneous enumerations, duplications and location errors. In one of the units of Facility D, the Medicare residents stayed for short term spells. *Omissions* were noted in the form of discharged persons. On April 1, Facility D provided the investigator with a daily census list of 69 residents, who were confirmed to be in the building. One week later, when the list was given to the census enumerator, there were 66 residents. The same employee made both lists. It is clear he believed he should delete the “discharges” from the official list. Perhaps he had contacted family members to determine whether the person was counted elsewhere. Clear instructions for counting admissions and discharges must be made to those in charge of administrative list creation. *Erroneous* enumerations may exist if records are poorly maintained regarding admissions, deaths, and discharges. Census rules for counting in nursing homes request a list of people staying in the facility as of 12:01 a.m. census day April 1 with clear rules for births and deaths (U.S. Census Bureau Self-Enumerating Group Quarters 2010 Census: Facility Contact Manual D-578).

Results of this research also found errors in coding race and ethnic categories. The hospice admission records had no designation for ethnicity. There were sometimes hospital records in the same binder with the designation. In Facility D the investigator was told a resident

was “Native American” but later that person was coded as “Hispanic” on the administrative list which had been given to the census enumerator.

This ethnographic examination found the potential for duplication was most salient 1) at the time of admission or 2) at the time of discharge. Discharges are a regular occurrence for short stay Medicare patients in skilled nursing facilities. If family members were made aware of the census enumeration they could coordinate and not count the person in two locations on the date of the census. Population shifts may cause an enumeration error where the resident is counted in the wrong location. Changes in location may include a hospital stay, or a move to a more specific care unit. In addition, there are services within long term care that are more transitory, such as hospice, short term rehabilitation and respite care.

Bell and Cohen (2007) point out that an emphasis and new practice associated with Census 2010 involves the improvements of questions associated with whether or not there are “alternative households in which someone may have been enumerated and whether there were any other people who sometimes live in the household.” Family members who live in the community may identify these transitory residents of long term care in those questions. There is also an effort to reduce the potential for some of these errors by deleting from households persons identified as duplicates or counted in the wrong place. It is not clear whether these practices are used for hospitals as well as households.

Post enumeration surveys to determine CCM have potential in HRGQ environments, but there are special limitations to their use.

- 1) Unlike a regular housing unit, the potential for recollection is hampered by a population that is transient and potentially large. Personal recollection would be impossible to rely on due to the inability to recall the shifts and the residents from census date.
- 2) Administrative lists are useful if they are maintained over time and kept accurate. The facilities observed here were fairly proficient at keeping administrative lists. Facility D administrator stated “billing requires 100 percent accuracy.” The problem for CCM is related to the maintenance of these records over time.
- 3) It is also likely that some facilities are not as diligent with their administrative records, as the 3 studied here. Facility B did not allow observation, and the disorganized culture seemed to indicate a greater likelihood that the administrative lists would have errors, and would not be well maintained over time.

In addition to a second enumeration, demographic comparisons are suggested as another method for CCM (Bell & Cohen, 2007), where previous counts could be compared to modern day enumerations (such as comparing census counts 10 years apart). This would provide an idea about whether the numbers looked realistic. However, there are potential problems with this method as populations change structurally over time. Facility C (terminal care) admissions director discussed the decline in resident population in recent years, due to greater competition from options available in the community.

Facility D is a long-standing skilled nursing facility, but it has had various structural transformations over time that would make for diverse populations from year to year. In 2000 there was an adult day center attached to the facility, but today the same large room is used for

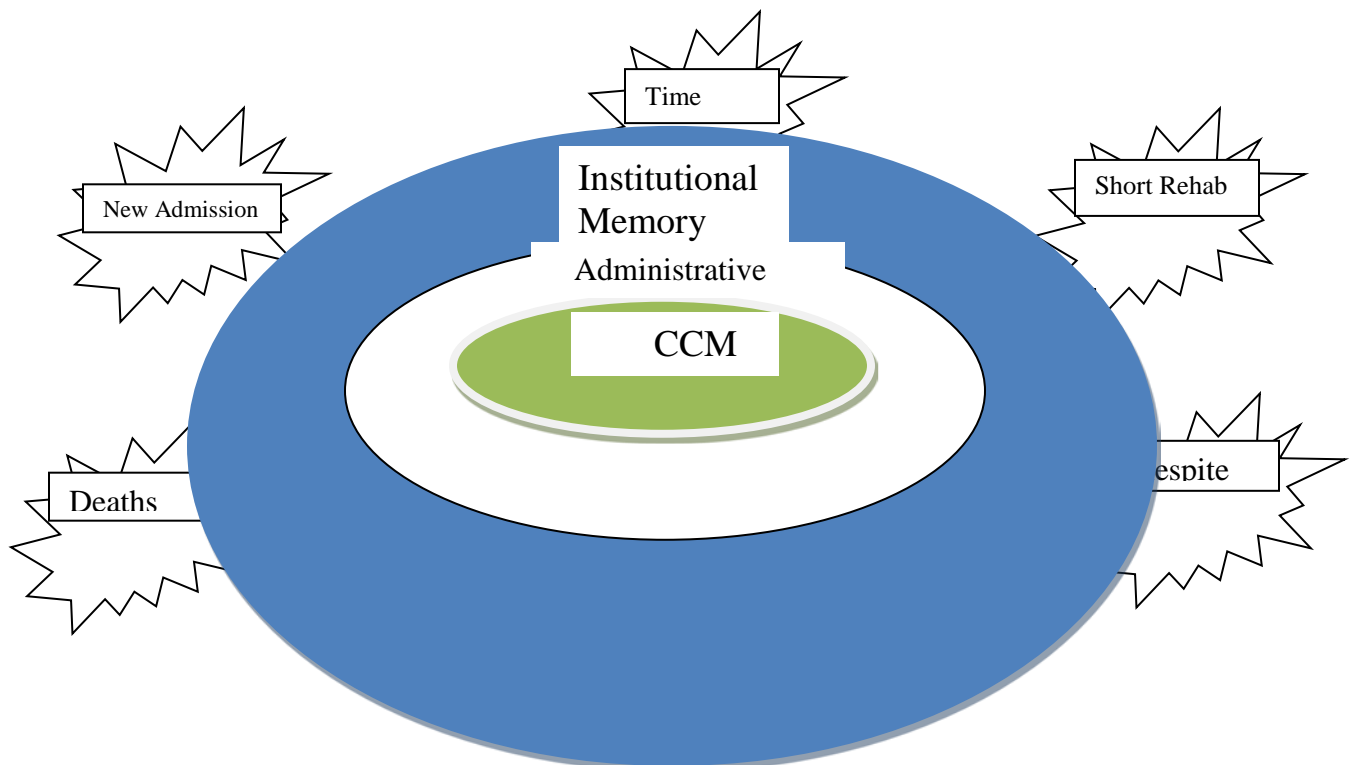
rehabilitative therapy. This shift re-affirms the trend described by Hillier & Barrow (2007) where nursing homes are taking on a more rehabilitative function—which may help to decrease overall reliance on nursing homes by allowing for a recovery and discharge.

On the last day of observation in Facility D, a male nurse described how the population had shifted from very long waiting lists 4 years ago, to much smaller populations. Competition from other nursing homes and assisted living centers were influenced by new financing schemes which allowed for greater admission and funding for assisted living admission. When a new skilled nursing facility is added to the market, the population may shift over to that facility with its more modern design. This makes CCM from demographic data less accurate as an estimation technique for HRGQ facilities.

6 Conceptual Models

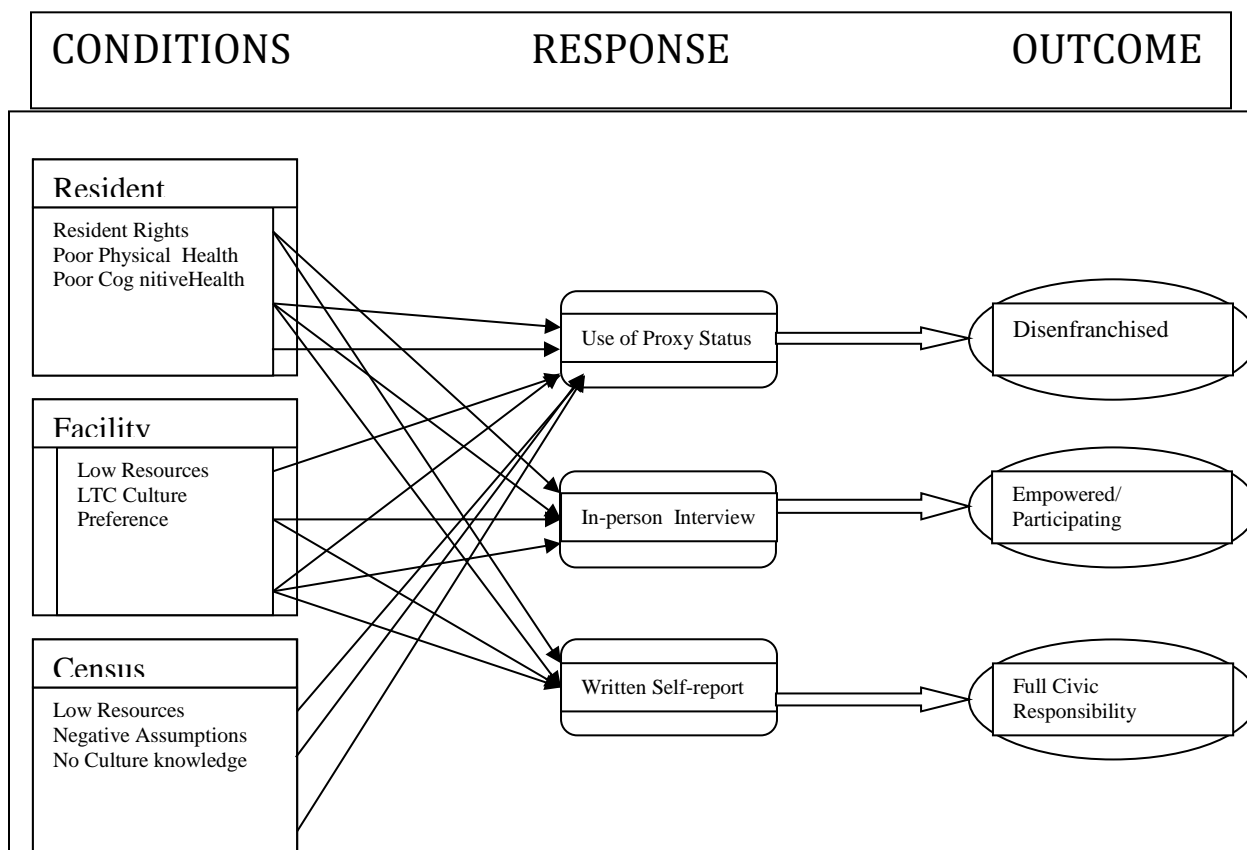
Theory construction took place as part of a reiterative process where data collected from multiple methods was coded and analyzed, allowing themes to emerge, and these were agreed upon by the research team. Conceptual models help to frame the research team’s interpretation of the data presented in this report. Model 6.1 utilized themes that emerged from the data analysis to illustrate barriers to accurate CCM in a second enumeration. In HRGQ facilities there are forces affecting accuracy of CCM, especially as time elapsed beyond the original enumeration. Resident population transitions were observed to create a fluid population through new admissions, deaths, discharges, temporary respite care and short term rehabilitative stays. Institutional memory and the ability for administrators to recall the population on the census date are negatively influenced by these factors in CCM.

Model 6.1: Requirements for Accurate CCM Second Enumeration



For accurate CCM, the facility would need to buffer the effects of negative influences and employ high-quality record-keeping skills to promote accurate institutional memory. Administrative lists would be used in a timely fashion after the primary enumeration. The CCM can only be successful if the administrative lists are accurate over time. The Census Bureau is advised to find ways of notifying, encouraging and compensating HRGQ environments for careful maintenance of accurate administrative lists that would reflect the population on the enumeration dates of interest.

Model 6.2: Barriers to Decennial Census Self-report Among Residents of HRGQ



Model 6.2 points to the **resident**, **facility** and **census** characteristics that may limit or empower the GQ resident to provide their own census information. Modern emphasis on “residents’ rights” strives to permit the maintenance of adult status and responsibilities—similar to those they had in the outside world. These rights include the right to civic engagement, self-determination, choice and autonomy. Poor physical health may limit a potential self-response. The most extreme physical limitations are associated with the final stages of dying; it may be plausible they are too impaired to contribute in a meaningful way. Census enumerators may want to specifically screen for physical impairment with the absence of cognitive disability; and these residents should have options to provide information via written or verbal feedback. Severe cognitive impairment would limit the census response to proxy status.

Facility lack of resources (time, money, staff manpower) to assist with decennial census enumeration may pressure them to seek a quick resolution to the task resulting in the use of proxies. To encourage in-person enumeration requires greater devotion of facility staff time to assisting in the determination of accurate vs. inaccurate responses to inquiry, etc. The business model might define help to government tasks as a “waste” of resident funds. Modern long term care culture encourages person centered choices and responsibilities—and gives residents “consumer” status. These provisions would encourage the productivity involved in answering one’s own census form, either verbally or physically. To answer one’s own surveys, and have the responsibility to respond, would be an example of the choices involved in adult life. In years past, the institutional “inmate” had none of the rights and responsibilities of the outside world. The facility served as a barrier and residents lost their identity through a process of “self mortification (Goffman, 1961).” Facility D fought strongly against the use of administrative lists for decennial census enumeration on the grounds of resident rights. However, the administrator eventually acquiesced to using the lists, due to a lack of time provided by the census enumerator. To allow for choice would have taken more time. Facility C wished to spare dying residents from the potentially stressful hassle of having to respond to mail or questioning. The perspectives of the administrators must be factored into the equation, since it seems inevitable that facility resources are involved.

The **census enumerators’** resources may be a factor as well—especially time and manpower. If they assume that all residents are cognitively unable to respond to their own enumeration, then the census worker will seek to obtain administrative lists, exclusively. The perceptions of resident capabilities may be based on stereotype—with a lack of recognition of the varying cognitive functioning. Future census workers should be educated to inquire about those who have cognitive abilities intact—and those residents may be able to self-report. Their knowledge of the long term care culture will determine whether they bypass the rights of residents and work to obtain administrative lists. Ultimately the residents and facilities had options that could have included other methods of counting (being interviewed or filling out forms), but these were not offered. Thus, the only outcome possible in this model disenfranchised the residents—since none of them were able to self-report.

This process may itself impact a facility, as it limits the ability for them to provide autonomy and civic responsibility to capable residents. The “all or nothing” mentality required facilities to dip to the abilities of the lowest cognitive functioning—to quickly dispose of this task. It is recommended that the census anticipate a MIXTURE of methods for counting—all based on the diversity of the cognitive and health status found in health-related group quarters.

7 Recommendations

7.1 Recommendations for Enumerators

- Despite the best efforts of enumerators, some disorganized facilities may not grant access or cooperate with procedures. The group quarters may focus efforts internally and employees may feel evaluated by outsiders.
- The best approach to enter into a facility would be to allow for sufficient notice and adequate time for the facility to make decisions about the course of action.

- HIPAA training of census employees would give the administration peace of mind regarding the security of private records and identifying information. Residents' rights training could also be of help, since etiquette involves respecting the privacy of those who live in the facilities.
- If residents can be interviewed, a determination may be needed concerning the resident's capacity to respond to enumerators. In this research, facility staff were able to identify the potential respondents. Excluded from that group were those who reside in the dementia unit (behavioral problems), those in the active stages of dying and those some others with communication or cognitive problems.
- Census employee training could include diversity in options for enumeration beyond just obtaining the administrative lists from GQs. For those who cannot self-report, family members may need to provide information or opt out.
- If administrative lists are employed, accuracy can be verified with face-to-face visits of each resident within the facility. Focus group members pointed out it would be "worth the risks" to involve the residents in the process. This interaction may require advanced planning and a staff escort.
- The Researcher observed an ACS interview and the Bureau Chief had given instructions for enumerators to visit residents personally instead of relying exclusively on administrative records. This indicates an openness to recognizing the autonomy of GQ residents. Despite that new philosophy, the developmentally disabled residents were unavailable (working) at the time of the scheduled ACS Interview, and information was gleaned from administrative records.
- Enumerators should be trained to recognize "census fatigue" and cope with the problem before it results in a decline in facility cooperation. The requests for any task that is not part of the recognized decennial census (such as CCM), may encounter resistance and would need added incentives.

7.2 Recommendations for Decennial Census

- The Census Bureau Group Quarters definitions need to accurately reflect the realities of competition in modern skilled nursing facilities. A need for new housing categories was demonstrated. Nursing homes may include assisted living, respite, short term rehabilitative services, and hospice care are often housed together influencing enumeration and requiring a mix of definitions and methods.
- The facility should be notified in early to mid-March, and given diverse options for enumeration. Advanced planning is necessary to follow through with choices. Facility D in this study was resistant to the surprise visit and the lack of options that might best fit the institution and clientele.

- The Census Bureau should obtain copies of HIPAA training materials on tape/dvd, to train enumerators. HIPAA knowledge could be used to reassure facilities who might be cautious about risks to enumerator interaction with residents.
- One reason to keep “outsiders” away from residents was related to facility protection of patient resources and pain medications. The administrator in Facility C pointed out that dying people do not have the defenses, and cannot refuse a visit, nor could they defend their meds from someone with substance abuse issues. The Census Bureau needs to be aware of these issues, and employee drug problems may not be detected by traditional background checks.
- Ideally, after safeguards are in place, all residents should be visited personally for verification of the accuracy of lists provided. An enumerator could attempt to obtain self-report information during these visits. Administrative records could be used to fill in additional information.
- Experimentation with self-reporting of residents should be conducted to determine a mechanism for judging cognitive competence and resident interest in participating.
- If the Census Bureau complies with standards of resident rights, information gathering should follow a chain of decision-making command 1) resident, 2) relatives and those with Power of Attorney, and 3) Facility Administrators would be last for provision of census information. To give full autonomy to “capable residents” is to allow them the option of filling it out themselves—or responding to interview prompts by enumerators or specially trained staff members. For legal purposes, family members should be notified ahead of the census enumeration and CCM procedures. The letter or electronic message should allow them to waive their participation in the process, or contact the census representative for further participation.
- Census enumeration should require the collection of the addresses for short term Medicare rehabilitation stays to ensure the population is not double counted. Information about the date of admission is helpful for discerning the presence or absence of the resident on census day, and to determine how salient the former residence is to the potential for double counting persons in the facility and the community (or hospital, etc.).
- The Census training program for hospital-related facilities is too long. Based on focus group responses, the investigator recommends deleting the explanations of the history of data collection, and the procedures for release of data to the public in the *D-578 Self Enumerating Group Quarters: Facility Contact Manual*. Only direct instructions for census enumeration should be included and the swearing in and training should not be longer than 30 minutes. The streamlining of this process could help decrease “census fatigue” and increase cooperation among relevant personnel.
- Health records in HRGQ environments are computerized. The facilities have standard mechanisms for ensuring the security of patient data. The Census Bureau is encouraged to follow their lead by determining a way to allow for data reporting via computer file.

The census fatigue experienced by facilities studied here was partially influenced by the need to transfer data from computer files to paper. It is predicted that in 2020 the use of paper will be rare.

7.3 Recommendation for Census Coverage Measurement

- Census Coverage Measurement timing is crucial due to the rapidly changing population in long term and hospice institutional settings. If CCM is to be successfully accomplished, the second enumeration would need to be immediate, to preserve institutional memory and buffer against the population transitions that serve as barriers to accurate recall. If CCM is carried out a couple days from the official decennial enumeration, the population in the facility will already be changed.
- In order for CCM to measure the same population of the original enumeration, the facility would need advanced warning and information about techniques to preserve data from “daily census” rosters and adjust for deaths, discharges, admissions and transfers on that date. A specific process of recollection will allow for accurate reporting in the second enumeration.
- CCM should be conducted only with the use of administrative lists, even if the original enumeration allowed for self-reports or interviews of residents. This will allow for: 1) a quicker CCM process; 2) a potentially more accurate representation of resident characteristics according to records; and 3) minimal involvement of the staff members of the facility.
- If CCM is to be conducted, the Census Bureau must have an accurate understanding of institutional “census fatigue,” which will have a negative impact on the cooperation by key personnel—such as administrators. Incentives and benefits may decrease census fatigue and improve cooperation with this extra task.
- The business model of the nursing home and hospice facility see time spent away from facility business as an opportunity cost. Staff assistance with preparation, maintenance and storage of administrative lists is often equated to money spent on something other than the direct care of residents and recruitment of new business. The Census Bureau should investigate providing compensation to facilities for their efforts related to CCM – perhaps \$300 to keep them interested in participating. A streamlined tactic would hire someone internal to the facility to conduct CCM, and pay them for their work. This provides needed expertise and familiarity with residents, along with financial benefits for cooperating.
- CCM should be scheduled and conducted at a time that doesn’t conflict with “month end” pressures of long term care industry business. Administrators are already busy with meetings, records, billing and strategies for recruitment—timing of CCM could determine greater cooperation.

- Administrators in the long term care and hospice facilities are likely to postpone the CCM on their calendars. Census fatigue may exist, and administrators would consider it non-essential census business. There are sanctions for non-compliance with decennial enumeration, but there may be a lesser perceived threat when CCM is neglected. In this research, post-enumeration interviews with facility administrators and support staff were difficult to schedule because administrators were “too busy” to devote time to a non-essential census related tasks.
- CCM may be hindered by potential anti-government philosophies. These perspectives may be more acute in the month of April, due to the pressures and discomfort related to tax season. There were instances observed of “anti-government” sentiment that questioned the census techniques and tested the limits of potential non-compliance with the decennial census. Refusal to participate in CCM could result from that sort of anti-government philosophy, with the complaint that it is excessive or
- CCM may be difficult in facilities with a large degree of internal disorganization and poor quality. Record keeping in such facilities may be erroneous, or not properly maintained or updated. Obtaining current or past administrative records may be nearly impossible. Receiving initial cooperation may be particularly difficult. Facility B in this research is a good example of a facility that would not cooperate using indirect tactics. CCM census workers would need to be aware of this potential for non-cooperation and devise strategies for encouraging participation.

Recommendations for the CCM study are designed to maximize coverage, provide participation rights to residents, and maintain the standards of the methodological framework used by the Census Bureau. Based on the findings, the researcher created conceptual models to frame the processes and assist future HRGQ facility population counts. Census 2020 should take into account access, cooperation, timing, location, data quality, population transitions and resident turnover as salient topics related to enumeration in facilities that house residents who are health compromised and vulnerable.

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9 Appendix A

Interview Schedule for Staff and Administrative Personnel

Thank you for assisting the process of better understanding the most effective and accurate way of counting residents in _____ facility. Your participation in this interview is completely voluntary. You can decline to answer particular questions or stop the interview at any time. I have provided you with a copy of the consent form. I will be tape-recording the interview so that I can go back and listen for accuracy. I could take notes instead. Do you AGREE or DISAGREE to have this interview recorded on tape? If it is recorded, it is important not to share specific names or identify the facility. Our session is completely confidential. Any names will never be used in reports, and the information is completely confidential. (RECORD START TIME)

1. Was it possible for enumerators to talk specifically to any residents/patients?
2. Are there some residents in your facility who were not accessible by census enumerators? Why or why not?
3. Do some residents have language or health difficulties that create problems communicating?
4. Are there cases where residents refused to participate?
5. Those where patient self responses were inaccurate?
6. How does mental health factor into resident response?
7. In cases where respondents were unable or unwilling to respond, were proxies used instead? Describe.
8. What is the potential that proxy reports contain errors?
9. Discuss the use of administrative lists with census enumerators.
10. How often are they administrative lists updated?
11. In your opinion, what problems hindered the accurate count of the residents on the census date?
12. Where key staff members absent? If no, what would be done if they had been?
13. Can enumerators escort themselves, or must they have special access or an escort?
14. What persons in the administration represent the key contact person for access to the facility?
15. Does this facility have difficulty with staff or administrative turnover that might hinder the enumeration process?
16. What advice do you have that would improve the counting process in this facility?
17. Do you have any questions or comments you would like to add to this interview?

(RECORD END TIME)

10 Appendix B

INTERVIEW CONSENT FORM (Staff or Administration)

Study title: Health-related Group Quarters Ethnography

Background: This research takes place in health-related group quarters residential facilities and focuses on the effective counting of residents during the decennial Census. The purpose of the interview is to determine insider perspectives on the culture, activities, environment and health conditions that influence data collection in this facility.

Study Procedure: Dr. Sonia Salari, a consultant with the U.S. Census Bureau and professor at the University of XXXX is conducting research at _____ and is involved with observing and interviewing a few of the staff and administrative personnel at the facility. We are selecting a small number of respondents for a short 20-30 minute interview. We have selected you to be one of our participants if you agree to be interviewed. If you give your permission to be interviewed, please read and sign at the bottom of this form. In the interview, you can expect the interviewer to ask you questions about the social culture, access, policies and health experiences of residents at _____. There will be no sensitive or disturbing questions asked in this interview.

Risks: The risks of this study are minimal if any. Questions are not sensitive or personal, but some may experience discomfort about discussing a particular topic. If questions asked cause discomfort, it is the right of the respondent to not answer or stop the interview.

Benefits: This study will allow you to discuss your opinions and perceptions of the social and environmental aspects of the facility with a person who is not employed or associated with the facility. It will provide you with the ability to talk about issues that concern you as well as those that are positive experiences for residents at the facility. Your responses will be confidential and not shared with other staff or administrators of the facility. The information obtained by these interviews and the other parts of the study are aimed to improve understanding of counting vulnerable or health compromised populations in group quarters.

Alternative Procedures: There are no alternative procedures available, but a respondent can choose not to participate in this interview.

Confidentiality: Your name and other identifying information will not be used in the written results, in order to protect your privacy. With your permission, we will audiotape the interview, but will not include your name on the tape. Instead, a number will be assigned for purposes of identification. Dr. Salari will protect identification numbers and a key linking the names in a secure locked location.

Person to Contact: If you have questions or concerns about participation in this interview study, please don't hesitate to contact me:

Dr. Sonia Salari at (801)867-6652

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Voluntary participation: Participation in this interview is voluntary. If at any time, you decide you no longer wish to participate in the interview, please tell the interviewer and we will stop, with absolutely no penalty to you. You can also refuse to answer any specific questions in the interview.

Costs to Subjects: There are no costs to subjects in this interview.

Number of subjects: The approximate number of interview subjects for this study in all facilities in this study is 5.

If you agree to be interviewed, please sign below:

Name (print)

Consent: I the signer have read, understood, agreed to participate and received a copy of this consent form.

_____ I agree to participate in this interview.

Signature

Date

Witness Signature

Date

COPIES: Copy 1 to interviewee, second copy for research records.

11 Appendix C

Facility Data Collection—fliers, newsletters

Facility A—Private Military Nursing Home

Letter of Permission to participate in study

Volunteer Packet—safety, prevention of back injuries, hazardous material management,
Privacy policy (HIPAA) , security awareness, Cyber security awareness, dress code,
Map of Campus, etc.

Newsletter

Facility B—Large Skilled Nursing Facility

Newsletter

Facility C—Terminal Care

Volunteer Training and Resource Manual

Includes history of terminal care, caregiver bill of rights and the dying person's bill of rights, stories, stress relievers, information about grief, etc.

Facility D—SNF and Short Stay Rehab

List of 34 Resident Rights (Examples below)

Right to exercise his or her rights as a citizen of the United States

Right to be fully informed in a language he/she can understand

Right to send and receive mail promptly and unopened

Right to access to outside world—to participate or refuse participation in social, religious, community activities

Right to choose activities, schedules and health care consistent with his/her interests, assessments and plans of care.

Right to reasonable accommodation of individual needs and preferences, except where health or safety of self or other would be endangered...

Pamphlet regarding code of conduct

Perform jobs based on ethical standards, laws, regulations, policy and directives

Meet the needs of the individuals and populations served

Recognize when someone else's behavior might be in conflict with the code

Maintenance of highest possible ethical standards and compliant behavior must be second nature

We will always seek to compete fairly and ethically and will not attempt to obtain an improper

competitive advantage.

Provide education for the maintenance of the highest level of independence achieved.

Map of Facility