

Lessons learned from use of administrative data and ethnographic observation of frail population: health related facilities

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ABSTRACT The decennial census results from a congressional mandate to count all U.S. population once every ten years and count each person once and in one place only. This study examined issues associated with the use of administrative data provided by health related facilities (HRF) and explored the costs and benefits to using these records to complete census forms. Findings are based on focus groups and unobtrusive ethnographic observations conducted during the 2010 Census in three HRF (including skilled nursing homes and hospice). Results show some potential for error, for example, pertinent demographic information required by the Census, such as ethnicity, was not always available in the administrative listings. Accuracy in other areas are provided because administrative listings maintained by the observed HRF were continually updated as a requirement for an accurate daily bill for services. Enumeration was complicated by rapid population transitions with admissions, discharges and deaths. The collection of additional information, such as admission and discharge date, and patients' last known residence could help improve the accuracy of census count such as resolving Census' duplicated records. This paper will conclude with a model summarizing the advantages and disadvantages using administrative lists in HRF for census enumeration.

Introduction and Background

Every ten years, the U.S. Census Bureau conducts a census on all U.S. population. The Census Bureau's goal was to count everyone once, only once, and in the right place. The majority of the U.S. population is enumerated at their residence, referred to as 'housing units.' A small proportion of the U.S. population live in a group living arrangement known as Group Quarters (GQ), which is "owned or managed by an entity or organization providing housing or services for the residents. This is not a typical household-type living arrangement. These services may include custodial or medical care as well as other types of assistance (U.S. Census Bureau, 2009)."

In 2010, nearly 8 million people were living in group quarters (GQ), approximately 2.7 percent of the total U.S. population (U.S. Census Bureau, 2010). 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 (ARs) as the data source for completing the census forms.

The *Census 2000 Evaluation: Group Quarters Enumeration* report encouraged the population count using ARs as the primary source for census enumeration (Jonas, 2003). Recently, the GQ Enumeration Operation is proposing to conduct research to develop procedures to collect electronic ARs files from all GQs (U.S. Census Bureau 2011). This qualitative research has two purposes: (1) to develop a better understanding on the usage and quality of information obtained from ARs to complete the census forms; and (2) to examine the issues associated with ARs provided by Health Related Facilities (HRF) and to explore the reasons why records may have errors when used to complete census forms.

The remainder of this section provides a brief overview of Administrative Records (AR) usage for completing the population census in other countries, and a review of two types of HRF – skilled nursing facilities and in-patient hospice. Administrative Records Data from administrative lists have been utilized to enumerate the population of the Nordic countries for decades (Hendriks & Amberg, 2011; Redfern, 1989; Schulte, Ossen & Daas, 2011), and more recently, from other European countries, such as Austria, where ARs were used for the 2011 Austrian Census (Berka et al, 2011).

The quality of administrative records have been noted by researchers (e.g. Lee, 2002), with several suggesting both pros and cons to the approach (Berka et al, 2011; Jabine & Scheuren, 1985; Redfern, 1989). When using ARs as compared to using surveys, the respondent burden is decreased and information collection may be less expensive (Berka et al, 2011; Jabine & Scheuren, 1985). Health related facilities are ideal for the use of administrative lists due to the increased burden involved with interviews. Specifically, it would be difficult to determine which residents would have the cognitive or physical capacity to respond accurately, due to HIPAA regulations and the need to screen for dementia or other severe functional disability (Salari, forthcoming 2012). For statistical purposes, studies have indicated that administrative data represented a significant improvement over interviews; for example, the prediction of morbidity and mortality transitions in a population of elderly residents in Canada (Roos et al., 1988). Researchers suggest that establishment survey quality can be improved using results from various investigative research techniques, such as focus groups and interviews (Phipps, Butani & Chun, 1995). However, there may be technical and legal difficulties associated with access to ARs and uses of such data (Jabine & Scheuren, 1985; Redfern, 1989).

Quality assurance is based on the accuracy of the administrative data, as well as the cooperation of the “population manager,” who collects, updates and shares the group information with census takers (Henriks & Amberg, 2011). The quality of the information provided by ARs is best evaluated on several dimensions, including the usability of the data, accuracy of information, record completeness, time-related indicators and the ability to integrate the data for other uses (Daas, et. al, 2010). Clearly, the frequency with which the information is updated is important, which will have an effect on the accuracy of administrative data (Redfern, 1989).

Health Related Facilities

Skilled nursing facilities (SNF) 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 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, 2009).” According to the U.S. Department of Health and Human Services (2009), 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%), compared to voluntary nonprofit (30.8%) or government (7.7%) and more than half were affiliated with a larger chain (54.2%) versus independently operated (45.8%).

The typical nursing home resident is female (70%), white, widowed, of advanced age (median 83.2) and suffers from multiple health problems (U.S. Census Bureau, 2007). Nursing home residents typically comprise about five percent of the population 65 and over (Hillier & Barrow, 2007), however about three percent of this population lived in skilled nursing facilities in 2010 (U.S. Census Bureau,

2011). There has been a trend toward short stay rehabilitation in recent years as the age under 65 population has increased from 11.7% in 2002 to 14.9 % in 2010 (Centers for Medicare and Medicaid Services, 2012). Short term residents eventually return to their own community-based home, so more active connections to family and friends in the outside world are necessary for these temporary institutional arrangements. The National Nursing Home Survey (NNHS) recently estimated 1.5 million residents were receiving care in 16,100 facilities (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. The need for this type of institutional care will increase dramatically with the rise in the older veteran population in the next two decades (U.S. Department of Veteran’s Affairs, 2010).

Hospice services are typically provided for those with six or fewer months of life expectancy, who wish to shift to non-curative care. Estimates suggest that 38.5% of deaths were under the care of a hospice program in 2008. More than half of hospice patients were female (56.6%) and a minority (16.8%) were under 65 (National Hospice and Palliative Care Organization, 2009). The majority of hospice services take place either in a patient’s own home, in-patient hospice centers, hospitals, long term care facilities or 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, 2009).” In 2008, there were an estimated 520 inpatient facilities in the U.S. and were the location for 21 percent of hospice deaths. These facilities offer end of life care and short term respite for caregivers (National Hospice and Palliative Care Organization, 2009). The needs of hospice patients and families are considered more acute than those in general nursing home care, due to the stress of the dying process.

Access to data and records in health related facilities has become more restrictive over time. The Omnibus Budget Reconciliation Act of 1987 (OBRA) increased patient’s rights for making decisions and planning their own care in skilled nursing facilities (Hillier & Barrow, 2007). The philosophy shifted from institutional goals to the least restrictive environments for residents. Another major change began in 1996 with the Health Insurance Portability and Accountability Act (HIPAA) required health related facilities and services to protect the privacy of patient health records (US Department of Health and Human Services, 2010). Rules and training procedures were developed to manage electronic patient data records, as well as keeping patients’ information safe from financial exploitation, identity theft and pharmaceutical mismanagement. In addition, there have been statewide background check requirements for employees in health related facilities and nursing homes. These changes may influence the ease of collecting administrative records in health related facilities. This study examined three facilities: one in-patient hospice facility and two free standing skilled nursing facilities (the Patriot Facility and the Consumer Facility) with a variety of services including short stay rehabilitative, respite and hospice care.

Research Questions

The following research questions were used to guide the current study that examines the pros and cons of administrative record use in HRF.

RQ1: What blockages were associated with access to facilities and administrative lists?

RQ2: How accurate and complete was the observed administrative record method?

RQ3: How were resident characteristics and the timing of population turnover related to the usage of Administrative Records in census enumeration for HRF?

RQ4: How do facilities’ managers influence administrative list creation and sharing?

Research Methods

Qualitative research such as ethnography is well suited for the study of the characteristics of residents and the culture within institutions (Hendricks, 1996). This work was commissioned with many specified research questions including the study of resident characteristics, population transitions, and decennial census observation. 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 used in this study allowed the investigator to (a) observe the naturalistic setting and contexts, (b) gain the perspective of the insiders (administrators, staff, and residents), (c) observe both the formal and the more implicit agenda (Ward, 1999) and d) determine the impact and effectiveness of the population count process. 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 administrative list utilization to enumerate this type of group quarters. This study was primarily inductive and used a multi-method approach including observation and focus group interviews to examine three institutional settings that housed residents with specialized health concerns.

Study Sites

Three health related group quarters were observed in this research. There was originally a fourth facility, but the researcher was ultimately denied access. In each setting issues of access, resident health and population turnover emerged as salient themes influencing the census enumeration process. All three facilities observed eventually utilized administrative lists for population enumeration. The following section describes the facilities in more detail and they can also be viewed in summary in Table 1.

Table 1: Facility Structure and Resident Characteristics

FACILITY	Type	Dementia Unit	Study Cooperation	Used Administrative List	Census AL Created by
PATRIOT	Veteran's SNF	Yes	Yes	Yes	Census Trained SNF staff
CONSUMER	SNF, Short Stay Rehab	Yes	Yes	Yes	Facility staff
OPTOUT	SNF, Rehab	Yes	No	Unknown	Unknown
HOSPICE	In-patient	No	Yes	Yes	Administrator

HOSPICE Facility was observed for 18 hours. The in-patient facility had 21 beds available, but typically housed 15-18 current residents. 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—often with few signs of life. Cognitively, some of the residents had dementia or “dysphasia” and the Administrator estimated 50% of residents would not be capable of census self report.

Population turnover was a very salient issue in HOSPICE FACILITY as there were 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 April 2. The census enumerator visited the facility ahead of the census process and again on April 8th. The Administrator submitted a list of 15 residents to the enumerator based on her records and memory of population transitions for April 1.

On the designated census date, the observing 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 DOB, 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). The population included 12 females and 3 males, with an age range from 71 to 94. Each resident was identified within the facility, and physical condition was noted. In a focus group, the Administrator expressed a strong preference for the use of resident lists for census data collection and hoped that option would be available again in the future. Given the severe physical disability and terminal decline of residents, the lists provided information without resident burden.

PATRIOT Facility 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. A resident had died on 3/31/2010 so there were 79 residents on April 1. The Administrative focus group estimated about 40 to 50% of the residents were cognitively aware, and about 41 were too demented for simple tasks. 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. These were among the four staff members who were trained and sworn to administer the census for the facility. The option was provided for trained staff members to use medical/administrative records or ask residents to report for themselves. Ultimately, 100% of resident information came from administrative data and the knowledge of the in-house enumerators, rather than resident interviews. The Administrator and Social Worker used computerized administrative record files and transferred them to paper census forms for each resident. The completed forms were collected the next day by the Census Representative.

The observing researcher created an alternate list on April 1, 2010 using a generated 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 because admissions on and around April 1 were better understood with the inclusion of admission data.

OPTOUT Facility—This 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. Some of the specific criticisms involved the elevated risk of physical restraints, and lack of adequate pain management.

Phone conversations with the reception staff yielded some information, but the facility was in a transition phase of hiring a new administrator and ultimately did not cooperate with the census ethnographic research study. 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. The theme that emerged suggested the problems with poor quality of care and institutional disorganization interfered with the ability to grant access to the institution.

CONSUMER Facility—This Alzheimer’s Care Skilled Nursing and Short Term Rehabilitation Facility had a maximum of 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. Approximately 70 – 85 residents were observed to reside 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 impaired, but had relatively good physical health. The focus group held with two administrators estimated 30 to 50% of the residents could respond to the decennial census for themselves. The respondents expressed a strong opinion that residents who were capable should be given the right to be interviewed for census information. For those who were cognitively incapable of completing a form, the preference was that family members should have been proxy respondents. According to the 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. Once the census enumerator made contact (April 2), the administrator complained that he had little advanced notice, and was caught at a busy time with “month end” business. The census worker and the administrator disagreed about the strategy of using administrative lists to count the SNF population. At first the Administrator was uncooperative, sending the census worker away without a list. The administrator wanted capable residents to answer for themselves, or use family members as proxy respondents. 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 attributed 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 list 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 and ages ranged from 47 to 96. 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 of the administrator, CONSUMER Facility did not provide the researcher open access to the resident data binders.

Study Data and Methods

The methods included: (1) passive participant observations - where the observing researcher immersed herself into the daily lives and routines of those residing and working in designated HRF, (2) interviews, (3) qualitative data analysis yielding the results and informing theory construction and (4) collection and assessment of administrative records. 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 principal investigator is the professional ethnographer trained by the Census Bureau, regarding the proper use, storage and transfer of Title 13 data. Interview schedules and consent forms were approved and human subject's approval was obtained by ORS.

Facility entrance presented challenges to the researcher. Entrance requirements involved HIPAA training, ID badge, health screening, and an orientation tour. Additional specialized training in bereavement, grief, patient care and resident rights was included. Observations began one month ahead of the census date. People in advanced ages, those with serious injuries or late stage terminal illness are much more likely to experience mortality during the process. Regular observations included a continual check of resident beds and administrative reports regarding transfers, deaths, admissions and hospitalizations that took place since the last observation.

The researcher attended all meetings and training sessions held between facility administrators and census enumerators. The observing researcher attended as a covert "researcher" in each case. 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 Census Day (April 1, 2010). Each resident's records were compared to their appearance and visual inspections were used to help verify gender, approximate age, and race. In HOSPICE Facility, the researcher sometimes had difficulty determining visual signs of life, as residents were often discolored and motionless. PATRIOT and CONSUMER Facility had 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 PATRIOT and HOSPICE facilities and were located in binders in a records room. Available information included name, birth date, age, sex, and race of the residents. HOSPICE did not typically collect resident ethnic information. In addition to the census information, the researcher collected the admission date and the last known residence (or usual home elsewhere). CONSUMER Facility did not provide the researcher with access to a records room or resident binders, but the administrative assistant created a list with the characteristics, including 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 transcribed immediately after the observation. Unobtrusive techniques of observation used the "busywork" notion—where the investigator had a pad of paper for note-taking and appeared to be looking down, engrossed in writing. Field notes were ultimately managed, content analyzed and referenced, and themes emerged from the process. Field note coding and observation categories involved the agreement of multiple researchers. Using observation data cleaned and absent of identifiers, the investigator employed two

research assistants to assist in coding categories that emerged from the data generated themes. The process was repeated for 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. 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. 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. The focus group in CONSUMER Facility 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. Consent forms were relatively simple and were signed prior to the interview and a copy was provided to the respondents. Two of the interviews systematically questioned individuals simultaneously. This process had a goal of aiding respondent's recall and establishing a group consensus. There was little evidence of controversy, and agreement was usually attained among the parties in each focus group.

These data were mined with content analysis, repetitive reading, coding, team agreement and attention to the emergence of themes. The observing researcher 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 observing researcher and two assistants, who also verified the emergence of themes.

Results

The observations, interviews, and focus groups served to inform the study about access to environments, resident characteristics, institutional culture, decennial census preparation, and the enumeration process using administrative lists.

RQ1: What blockages were associated with access to facilities and administrative lists?

All four facilities in this study had some measure of difficulty obtaining cooperation and OPTOUT Facility eventually denied entry. A series of "roadblocks," may have been intentionally designed to stall or discourage intrusions by outsiders for research or evaluation. The three 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. HIPAA legislation has influenced patient privacy concerns by encouraging staff members to be vigilant and suspicious toward outsiders. This suspicion was sometimes directed at census enumerators and the observing researcher. Entre procedures required in CONSUMER Facility included viewing several VHS tapes about HIPAA. 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."

Facilities attempted to minimize outside intrusion into the culture and setting, and were particularly protective of residents who 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. Protective behaviors of staff members and administrators may limit the access census enumerators have to resident information and records in a health related facility.

Quality of care and code of conduct were emphasized and in CONSUMER Facility where the observing researcher 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 including the right to a dignified existence, communication and access to persons and services, rights as citizen or resident of U.S., to use of a legal surrogate, to be free from coercion and discrimination, to 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, 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. CONSUMER Facility Focus Group participants felt it was “worth it” to allow resident involvement in their own census enumeration. 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.

Proprietary ownership in long term care has added a business emphasis to the provision of skilled nursing and terminal care. The existence of newer facilities and changes in funding over the years have led to increased competition for CONSUMER and HOSPICE facilities. Observations indicated these facilities were in a constant struggle to recruit new business. 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. CONSUMER Facility focus group pointed out that improper use of staff resources would come from the pockets of residents.

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, CONSUMER Facility 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, PATRIOT Facility staff members felt burdened by the 2-hour census training session which prepared them to conduct their own census. Encouraging further cooperation with the study became challenging.

RQ2: How accurate and complete was the observed AR method?

Results indicate the administrative records were considered accurate in most instances. It was explained during a focus group in CONSUMER facility that the daily census must be kept up to date to reflect the billing of individuals and government payers (Medicaid and Medicare). Any inaccuracies would be cause for great concern about fraud. The three cooperating facilities took this task seriously and were accurate in their administrative list reporting. The fourth facility OPTOUT was not willing to have their administrative lists studied by the observing researcher, and their ratings and practices were deemed vulnerable to inaccuracies.

The census enumerators (from the staff) of PATRIOT Facility were very likely to have an accurate count of the residents based on their access to the Medicare records, as well as their personal knowledge of each resident in their own facility. The observing researcher was able to verify the information using hard copy resident binders, when she made the alternative administrative list. In CONSUMER Facility, the staff members who made the administrative list would not allow the researcher to verify using hard records. In the end, the list provided to the census enumerator was similar to that provided to the observing researcher—with a difference of three residents (who had been discharged) and the ethnicity of one man (who was reportedly Hispanic by the administrators, but was investigated by the observing researcher to be Native American). Administrative list accuracy was specifically discussed during the CONSUMER Facility focus group interview:

Admin G: I could have given her bogus information. How does she verify it?...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...

HOSPICE Facility provided access to hard copy medical files of the residents, but it was not their practice to note ethnicity. The comparison of the list provided to the census enumerator was the same as the one generated as an alternate by the observing researcher.

RQ3: How were residents' characteristics and the timing of population turnover related to the use of administrative records for census enumeration in the HRF?

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

CASE STUDIES

HOSPICE Facility: There were several deaths per week in this terminal care facility; sometimes as many as three deaths took place in one day along with a steady stream of new admissions. On Census Day (April 1st), there were 15 residents. Complications arose from deaths (2) and admissions (3), and admissions that also included a death on the same day (1) and an admission with death the next day (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.

PATRIOT Facility: 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.

CONSUMER Facility staff M kept the researcher up to date on the weekly transitions by consulting a book of records. Every week several residents were lost to death or discharge. Admissions would follow, but the facility was not full and contained several empty beds. 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 residents who transitioned in and/or out of the facilities. Specialized residents such as Medicare short stay (CONSUMER Facility) or recently admitted residents would potentially be counted at home and in the facility. The researcher noted from observations that rehabilitation residents had “one foot in the outside world and one foot in the facility for recovery” and they typically did not attempt to assimilate into the institutional culture. Keeping track of HRF population transitions and recording their entry and exit was a complicated task.

RQ4: How do “population managers” and census enumerators influence administrative list creation and sharing?

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 HRF staff were prepared for the interaction and information exchange. In another case (CONSUMER), the advance work had not been successfully accomplished and the facility administrator expressed surprise at the sudden intrusion. The census enumerator approach was sometimes perceived as 1) too serious, 2) too pushy, or 3) too complicated. Enumerator culture seemed to convey a concern for finishing the task promptly and without much effort. CONSUMER Facility census worker’s perspective was perceived as pushy initially but she allowed for other options when the administrator resisted her push. Facilities eventually grew tired of cooperating with census enumerators and even the observing researcher.

CASE STUDY PATRIOT FACILITY: 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*. 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 then 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... “

This research also detected slight frustration among HRF members who generated administrative lists and those who “self enumerated,” because the AR 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 HRF environments if administrators could submit information to the Census Bureau electronically. All three facilities studied here obtained their administrative list information from computerized records. They are aware of data security measures and how to guard such electronic records from HIPAA violations.

On April 2nd, CONSUMER Facility had a meeting with the census enumerator that became argumentative. 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 (CWS) had the 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.”

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

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, 60-70 % are long term ...

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...”

CWS: “We need information...we can get it easily or take 3 to 4 days with a combination...”

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 resident 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...”

CWS: “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.”

CWS: “Everyone can be asked if that's how you want to do it.”

He emphasized several times that he is an advocate for the elderly. He was concerned 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 among the HRF in the study, but that method was not necessarily the first choice of all facilities. When residents are unable to self report census employees assumed the facility could simply supply the needed information. The focus group of CONSUMER Facility 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. Can census enumerators request administrative lists, without relative or resident knowledge? Interviewees in the CONSUMER Facility focus group described the process as breakdown of “chain of permission” 1)

resident, 2) family 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, HOSPICE Facility 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."

Discussion

The use of an ethnographic examination of the HRF in this research has provided for a level of richness that may not be detected by quantitative analysis alone. The observations lent understanding to the culture within the health related facilities studied. It was through entre and training procedures that the observing researcher was able to become familiar with the issues of resident's rights and the protection of health related data and records (HIPAA). Creation of an alternate list of residents to compare to the official census enumeration, allowed us to judge the quality of the administrative records. Focus groups provided an additional interpretation, coming from the insider's perspective. It was there that "census fatigue" could be understood as a potential influence in the HRF enumeration process. The ethnographic approach permitted the ability to shed light on the pitfalls as well as benefits of administrative record collection.

As we introduced earlier, the quality of the information provided is best evaluated on several dimensions, such as data usability, accuracy of information, record completeness, time-related indicators and the ability to integrate the data for other uses (Daas, et. al, 2010). Our ethnographic research findings indicated that observed HRF facilities worked to keep accurate daily records, which were used for billing consumers and other payers. The accuracy of lists was noted to be good, when compared to our independent creation of an administrative list. Other institutions may have had less accurate lists, such as the OPTOUT facility which denied researcher access. Record completeness was sometimes an issue because some information was not available, such as the hospice facility's lack of information about resident ethnicity.

Time-related issues were key in the collection of resident information, due to the rapid transitions in the population caused by admissions, temporary respite care, short stay rehabilitation, discharge to home or hospital and deaths. In one day the population might have an enormous change, with several losses and gains. It was our opinion that the census would wish to collect additional information from such records to better keep track of these rapid transitions. For example, it would be particularly important to note the date of admission as well as their last known residence to keep track of rapid residence changes and prevent double counting.

Population managers must be considered in the acquisition of data from administrative records. Some were cooperative and others represented more of a challenge to the method. For example, the hospice facility administrator was very cooperative with the collection of resident information from lists and she expressed hope that it would be available in the future. Her appreciation stemmed from the concern for residents and their families during the last stages of the dying process.

Another "population manager" refused access to the principal researcher—which may have been related to the poor ratings that facility had received in the publicly available nursing home rating system.

The administrators in two other facilities showed some level of resistance to the process of collecting data for the census. Even though the collection of administrative list information was less of a burden to the residents, the administrators' focus group results indicated a degree of "census fatigue" which sometimes influenced the level of cooperation and/or satisfaction with the process.

The business model of administration (CONSUMER Facility) often questioned the costs to the facility in terms of staff cooperation and coordination required for production of an accurate administrative list. HRF have a daily census, but the information needed by the census may include a bit of extra effort expended by the staff member who puts the list together and keeps it updated with the specific information needed by the Census Bureau.

The barriers to access administrative records set forth by the 1987 Omnibus Reconciliation Act and 1996 HIPAA require specialized training for staff, privacy protection and legal rights for residents. For that reason, it would make sense to use resources to hire existing staff members to collect resident information from records, rather than to have census enumerators from the outside attempt to fit regulatory requirements and construct a list him/herself.

Our model (Model 1) indicates the potential problems as well as the advantages associated with using administrative lists for HRF population enumeration. Potential challenges include 1) the rapid population transitions of admissions, respite, discharges and death, 2) legal and privacy considerations (HIPAA), 3) incomplete data availability (such as the need for ethnicity in HOSPICE Facility), and 4) the level of cooperation from facilities and administrators who are under pressure to utilize staff resources/time with the construction of a census-specific administrative list. The advantages include 1) accurate data collection from billing records, 2) low resident burden (during a vulnerable time), 3) the potential to integrate electronic data files and 4) the lack of a need to evaluate resident characteristics of interview competency.

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Model 1: Administrative List Utilization: Challenges and Advantages

