LIVING WITH THE DEMENTED: EXPERIENCES AND RECOMMENDATIONS OF ELDERLY NON-DEMENTED NURSING HOME RESIDENTS

by

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ABSTRACT

This study was designed to investigate the experiences and recommendations of elderly non-demented nursing home residents regarding living with the demented, or integration. It was designed to provide descriptive information about the nature and amount of residents' awareness of the demented within their nursing homes, the lifestyle impacts of integration, residents' affective/attitudinal responses to integration, and their integration policy recommendations.

A purposive sample of 102 non-demented residents of five Vancouver nursing homes completed a newly-devised client-centered questionnaire. Uni-variate and bi-variate data analysis was done.

The results of this study indicate that almost all residents (93%) had some contact with the demented, two thirds (63%) on a daily basis. A lesser number (81%) thought about the demented, half of those (41%) daily. A roughly even split occurred between those with no demented friends (47%) and those with at least one (53%). Most residents (72%) reported that integration had minimal negative impact upon their lifestyle. One in four residents (28%), however, experienced disruption to their daily routines and/or made a conscious effort to modify their lifestyle within the nursing home on a regular basis. Just over half of the residents (54%) had a neutral affective/attitudinal response to
integration, and among those who were not neutral (46%), a pattern emerged of residents feeling unhappiness, dislike, unease, and pessimism, but also not ashamed. Four out of five residents (81%) recommended an integration policy that incorporated some degree of separation. Increased contact was directly related to increased thought about the demented, pessimism, and feeling unsafe. Those with at least one demented friend tended to feel slightly more at ease, to like integration, and to recommend it. Those who recommended separation also tended to avoid the demented and social/recreational activities with them, to feel uneasy, unsafe, ashamed, pessimistic, and unhappy about integration, and to dislike living with the demented.

These findings raise question about the suitability of integration for the non-demented. Further client-centered research is recommended to investigate more fully the multi-dimensional effects of integration upon the non-demented and the preferences of this population regarding this crucial determinant of their social environment.
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CHAPTER ONE

Introduction

Background to the Problem

Four percent of the British Columbian population aged 65 and older reside in nursing homes (Stats. Can., 1991). In these nursing homes the case mix is determined by an arrangement of care levels that reflects the amount and type of daily professional and paraprofessional care needed by residents, rather than the etiology of their disability. Nursing homes are inhabited by residents with any type of non-acute physical and/or cognitive impairment, grouped together according to equivalencies of self-care deficit. Only the “mentally retarded” those with a significant psychiatric condition, and those with grossly disruptive behavior are excluded (BCMOH, n.d.). Demented and non-demented residents live together in nursing homes, sharing the physical space and operating as peers within the social environment of home. Studies of the prevalence of dementia in American and Canadian nursing home populations are inconsistent, reporting that anywhere from 40% to 85% of residents are demented (Brice, 1986; Burnside, 1982; Mace, 1987; Peppard, 1986; US DHHS, 1980; US Congress OTA, 1987). Most agree, however, that non-demented residents are in the minority within nursing homes.
The shortcomings of this integrated model of care in meeting the needs of the demented have been recognized in recent years, and Special Care Units have been introduced to provide the specific environments and services they need (Ohta & Ohta, 1988). The challenges integration creates for the non-demented, however, have not been acknowledged to the same extent. While much anecdotal evidence exists about the increased loneliness, fear of physical and social contamination, sense of vulnerability to personal assault and theft of belongings, shame with visitors, pessimism about the future, and decreased self-esteem non-demented residents experience as a result of cohabitation with the demented, little systematic study has been done to document and measure these effects and almost no research has been done to document non-demented residents' views of integration.

The traditional health care paradigm in which specialist experts take active charge of all aspects of service design, implementation, and evaluation and patients are passive service consumers has been challenged in recent years. Consumers are becoming more active partners whose opinions are at least considered valid input into decisions made about services. The views and concerns of nursing home residents, who literally live with the decisions that are made about their care, are increasingly being sought by nursing home administrators in an effort
to provide care that meets residents' needs, that residents are satisfied
with, and that respects residents' rights.

Statement of the Problem

Despite a commitment to providing client-centered care for non-demented residents of nursing homes, their views regarding integration, a crucial social environmental determinant, are not known. We do not know how they experience integration and what they perceive its impact upon them to be. We do not know if they like integration and want it to remain the case mix arrangement in nursing homes, or if they dislike it and want it replaced by an admission case mix and/or housing arrangement that would separate the demented and non-demented.

Purpose

The purpose of this study was to provide some descriptive information about the perceptions and recommendations of elderly non-demented nursing home residents regarding integration.

Theoretical Framework

This study was based on the assumption that residents themselves are the most knowledgeable experts about facility living, and should have at least some, if not the most, input into case mix policy. It was predicated on the notion that resident advocacy starts with an understanding of the challenges and desires of residents. It was founded
on client-centered practice theory, which constructs the health and social service client's perspective as the basis for service organization and operation (Matheis-Kraft, 1990). Unlike the traditional health service model, which dictates that clients are sorted into pre-existing diagnostic and functional groupings defined by the provider, the client-centered model requires that services be configured to meet the expressed needs and wants of the service consumer (Gerteis et al., 1993).

**Research Question**

This study was designed to answer the question, "How do elderly non-demented nursing home residents experience integration, and how integrated do they want nursing homes to be?".

**Definition of Terms**

Demented - Having multiple cognitive deficits manifested by both memory impairment and one or more of aphasia, apraxia, agnosia, or disturbance in executive functioning, that represents a significant decline from previous functioning and is characterized by gradual onset and continuing decline (APA, 1994).

Integration - The case mix and living arrangement whereby demented and non-demented residents live together in nursing homes,
sharing the same physical spaces (bedrooms, lounges, common areas, etc.) and operating as peers within the social environment.

Extended Care - Twenty-four hour nursing and allied professional health care with continuing medical supervision for people with a major self-care deficit due to severe chronic disability. Residents are unable to walk 15 feet and/or transfer independently (BCMOH, n.d.).

Intermediate Care - Daily nursing and allied professional as well as non-professional health care for people with a self-care deficit due to chronic disability. Includes three sub-levels - I, II, & III - denoting increasing self-care deficit (BCMOH, n.d.).

Importance of the Inquiry

Non-demented residents are a vulnerable population. Triply marginalized by old age, disability, and their minority status within nursing homes, their concerns are easily overlooked. Social Workers, by virtue of their professional mandate, are well-positioned to encourage them to voice their concerns so that they are heard by those who decide the policies that directly effect them. Social Workers have knowledge of the complex system of interrelating public, private, and professional groups involved in policy formation and review, and have expertise in working with that system of stakeholders to ensure win-win
outcomes for all concerned. Social Workers are committed to the principles of resident empowerment and resident advocacy for those unable to act for themselves. To fulfill our professional mandate, however, we need to know what non-demented residents’ concerns and desires are. As we work in partnership with levels of governments, public health administrators, health care providers, communities, and residents to enhance nursing home care we need to be guided by those who ultimately live with our decisions. It is crucial, therefore, that we ask non-demented residents for their opinions about integration.

**Organization of Thesis Content**

This thesis is comprised of five chapters. In Chapter One the background to the problem, problem statement, purpose, theoretical framework, research question, definition of terms, and importance of the inquiry are introduced. In Chapter Two a review of the literature related to the integration issue is presented. Chapter Three describes the research methods and procedures that were used. In Chapter Four the findings are presented and a discussion of those findings occurs in Chapter Five. Finally, conclusions, implications, and recommendations are discussed in Chapter Six.
CHAPTER TWO

Review of Related Literature

Introduction

In this chapter a review of the literature is presented in relation to the integration issue with an emphasis upon direct reports of the views of the non-demented. It is divided into four sections. In the first section integration as it is documented within the general nursing home and nursing home psycho-sociological literature is outlined. The second section reviews the editorial or position papers on integration that have been published. The third section presents the clinical studies that have been done of integration. The single client-centered study that was the direct precedent for this study is examined in the fourth section. Finally, a summary of the related literature concludes this chapter.

General & Psycho-Sociological Nursing Home Literature on Integration

Sociological studies of nursing home life have consistently documented the strained dynamics that occur between demented and non-demented residents within the context of studies directed toward broader issues of institutionalization. Gubrium (1975), in his study of a nursing home in New York state 20 years ago, was one of the first to acknowledge that non-demented residents feared association with the
demented because of the stigma that was attached to their mental disorder. For non-demented residents to have associated with the demented, Gubrium reasoned, would have risked social contamination, a risk most residents were unprepared to take. He included a small number of quotations from non-demented residents as anecdotal evidence to illustrate his findings. His observations and analysis were confirmed and elaborated by Smithers the following year. Smithers (1977), in her writing about the institutional reinforcers of mental and physical deterioration in a 150 bed nursing home in California, exemplifies the behavioral documentation and psychological analysis that sociologists have provided about non-demented residents’ responses to integration. She noted that:

Oriented patients utilize a variety of protective responses to distance themselves from the senile label and the assault on self that the application of this label implies. They experience a sense of contamination from exposure to chronically senile patients. Surrounded on all sides by living examples of the horrors of advanced senescence and faced with the possibility that this might happen to them, many work hard to establish a sense of separation and distance. Some choose to remain in their rooms rather than intermingle with senile patients.
Smithers illustrated her analysis with occasional quotes of non-demented residents’ comments about integration. Gubrium (1978) affirmed that integration resulted in problematic dynamics between demented and non-demented residents in a response to Smithers’ study the year after, this time without directly reporting any resident comments.

At the same time Tobin & Leiberman (1976), based on first-hand statements obtained from prospective nursing home residents, identified integration as one of the discrete factors that compounded prospective residents’ reluctance to proceed with admission despite clear need for care and inadequacy of alternative care arrangements.

In 1979 an entirely incidental finding in a study that otherwise did not focus on inter-resident dynamics provided a strong statement of the views of the non-demented toward integration. Gutman et al. (1979), in a geography/gerontology study of the locational suitability of 15 intermediate and personal care nursing homes in Vancouver, asked residents in an open-ended question at the end of their questionnaire to identify the one thing they disliked the most about institutional living. The answer most frequently given (by 18% of respondents) was “the mixing of those who are alert with those who are senile”.

Over the next decade sociologists and other analysts of nursing home life continued to report on the strains between demented and
non-demented residents. Bowker, (1982), in his qualitative study conducted in a Wisconsin nursing home, identified dissatisfaction with integration on the part of the non-demented as a major theme in resident comments about institutional care. Retsinas (1986) echoed this finding in her sociological study of a Winnipeg nursing home, although her conclusion was not supported by residents’ statements. The findings of physical avoidance and its analysis in terms of psychological self-protection that Gubrium had reported was again made by Powers (1988), Shield (1988), and O’Brien (1989) in their sociological studies of interaction patterns in American nursing homes, often in the words of residents themselves who had been interviewed. Bohuslawsky (1989), in her critique of Canadian nursing homes, pointed out the feelings of vulnerability to physical assault and disturbance/theft of personal property by the demented that non-demented residents often feel, and cited examples of protective behaviors she had seen residents of another Winnipeg nursing home engage in. Intensive psycho-sociological studies of individual American nursing homes by Fisher (1991), Savishinsky (1991), and Lidz et al. (1992) that have explored the behavioral and intrapsychic dimensions of facility living have confirmed in recent years that avoidance of demented residents and of the demented label remains a major pre-occupying effort on the part of non-demented residents.
These studies often quoted the statements, comments, and language of individual residents.

Hochschild (1973), Howsden (1981), and Novick (1982) have explored the psycho-dynamics of "cross-cognitive" resident relations within institutions. These authors have argued that a complex combination of feelings may exist within non-demented residents toward the demented, a combination comprised of guilt, pity, sympathy, and superiority. Hochschild (1973) provided an explanatory model for the combination of resentment and sympathy/pity feelings that non-demented residents may feel toward the demented. He argued that this combination of feelings is at the heart of a defensive ego mechanism within many non-demented residents, in which they regard the demented as poor, unfortunate creatures so that they can dis-identify with them as equal peers and instead assume a superior position. By pitying the demented, a stance they tell themselves and are likely to have others tell them is appropriate and even generous, the non-demented residents can score ego points both for themselves as individuals and as a social group in two ways at once - by placing themselves above the demented in a hierarchy of competence, and by presenting themselves as morally virtuous. The latter effectively disguises the former, so that the denigration of the demented is masked.
This denial, argued Hochschild, tends to produce subsidiary feelings of guilt within non-demented residents, which may exacerbate and perpetuate the dynamic by provoking increased attestations of charitable sympathy.

This dynamic between different competency classes of residents was confirmed by Howsden (1981), who extended Hochschild's model to include other types of residents within nursing homes. Howsden argued that a social stratification occurs within nursing homes based upon health, ability, and competency, and that residents at each of the many levels in the hierarchy use the defensive pity mechanism to secure their status above those residents they see as beneath them. Novick (1982) suggested another dimension to this dynamic. She argued that the attestations of sympathy and concern that the non-demented make toward the demented are a way of modeling and setting up a normative practice of the way the demented are regarded within the nursing home so that if and when they themselves become demented, they too will be treated kindly.

In terms of the psycho-dynamics postulated by Hochschild, Howsden, and Novick, residents are triply motivated to express charitable pity. Three reinforcing rewards are available to them for doing so: immediate social superiority as pity dispensers, immediate
moral superiority as pity dispensers, and future benefit as pity receivers.

Integration Editorial Literature

While sociologists and others were finding that integration was something non-demented residents did not respond positively to, nursing home staff (Administrators, Nurses, Physicians, and Social Workers) were admitting that integration was problematic and struggling with the question of whether or not they should stick with integration and aggressively problem-solve to make it work, or discard integration altogether in favor of separation of the demented and non-demented. This policy dilemma emerged as a debate in the professional literature during the mid-1980's.

Wolfson (1983) first opened up the issue for discussion within the professional literature with a letter in the Journal of the American Geriatrics Society that appealed to the membership for advice about integration. Wolfson, noting the objections many non-demented residents had to living with the demented in the New York City nursing home he worked in, asked if integration should be abandoned in favor of a separation policy that respected the expressed wishes of many of the non-demented. In reply, Ablowitz (1983) noted the same problems with integration and the feeling among many non-demented residents that
some separation should occur in the Vancouver nursing home she worked in. Gang & Ackerman (1983) also replied to Wolfson's appeal with a description of the separate dementia care unit that had been developed within the New York nursing home they worked in. They also noted the negative impact integration tended to have upon the non-demented, and advocated development of other separate care units for the demented. In the same year Salisbury & Goehner (1983) debated the issue. Goehner constructed an argument based on her professional experience of the ways integration had benefited, or had been made to benefit, residents and staff, and based upon her projections about possible problems that separation might cause for residents and staff. Salisbury, arguing for separation, referred to the difficulties inherent in integration for staff and residents that she had seen manifest in the nursing home she worked in, and concluded that the debate was unresolved.

Two years later the debate was furthered by Mace (1985) and Novick (1985). Both referred to the general views of the non-demented without directly reporting their statements, analysis, or policy recommendations. Both assumed that it was up to the experts to determine what was best for residents and to work to ensure that residents cooperated with that policy. Acknowledging that, "a lively
debate continues over the pros and cons of (separate dementia care) units”, Mace asserted that separation was not needed but that enhanced resident management techniques for the demented needed to be implemented so that they did not bother non-demented residents. This, she argued, would solve the problem and preclude the need for separate living arrangements. Novick, on the other hand, argued that her experience in a Montreal nursing home had demonstrated to her that integration was a failure. She recounted how residents had been effected as the nursing home, which initially housed only the non-demented, had integrated the demented into the home with disastrous results for the non-demented, and had subsequently been obliged to separate the demented and non-demented through the relocation of the demented to separate areas of the home. Novick concluded that integration was the problem and that separation was the solution.

Rabins (1986), reprising Salisbury & Goehner (1983), debated the issue with himself. After reviewing the pros and cons of separation exclusively from the perspective of researchers, clinical staff and families, with no mention of the views or wishes of the non-demented, he concluded that more research was needed before expert opinion could be definitively decided and integration policy determined.

Getzlaff (1987) had the final say in the editorial debate over integration
in the mid-1980's. Getzlaff reviewed and dismissed previous arguments in favor of separation, including the fact that separation is the expressed wish of the non-demented. Echoing Mace (1985), she argued that more stringent application of resident management techniques with both the demented and non-demented was the answer. She questioned the right of the non-demented to separate living arrangements and suggested that non-demented residents who resist integration needed to be "educated" out of their "intolerance and ignorance".

Clinical Studies of Integration

Many clinical studies have demonstrated that separate dementia care units are beneficial from the perspective of the demented. Ohta & Ohta (1988), Gutman (1989), and Holmes et al. (1990), after reviewing numbers of studies of individual Special Care Units, have agreed that this general conclusion is warranted. Only two clinical studies to date have addressed the question of whether integration is harmful to the non-demented. Although both studies were concerned with the impact of integration upon the non-demented, neither investigated the perceptions or recommendations of residents. They relied instead upon quasi-experimental methodology whereby a cluster of quality of life and level of functioning indicators were measured and compared for groups of
residents with and without close daily contact with the demented. Both studies showed that integration had harmful effects upon the non-demented.

Wiltzius et al. (1981) measured the mental, intellectual, social, perceptual, emotional, and physical functioning of 20 non-demented residents of a Wisconsin nursing home before and after they were assigned a demented room-mate. They found that 85% of the non-demented residents became depressed and lonely, 60% became anxious and insecure, 25% became less friendly and more irritable, and conversely that 10% experienced enhanced mental and emotional status after two weeks of integrated living. They concluded that integration could lead to mental and emotional impairment among the non-demented. Teresi et al. (1993) measured the morale and life and environmental satisfaction of 77 non-demented residents of a New York nursing home, one third of whom lived near and/or shared a bathroom with a demented resident. They found that integration was significantly correlated with decreased life and environmental satisfaction, and concluded that integration was associated with increased demoralization among the non-demented.
Client-Centered Study of Integration

Only one study to date has taken the client-centered approach and directly investigated non-demented residents’ perceptions and wishes regarding integration. Brauner (1989) conducted a cross-sectional descriptive study that combined quantitative and qualitative methodologies. She interviewed 18 residents of a newly-integrated Montreal nursing home to obtain their answers to a questionnaire she devised that incorporated open and closed questions. She investigated residents’ feelings, attitudes, and recommendations about integration. Her results were divided, with exactly 50% reporting that integration had not affected their quality of life and 50% reporting that integration had degraded the quality of life in the nursing home. Specifically, residents noted that integration “lowers morale, elicits depression and/or a miserable feeling, produces disruptive and/or nervous tension, creates unhappiness and withdrawal, and shame when visitors come”. Forty-five percent requested that no changes be made in the facility to mitigate the impact of integration, while 33% requested a return to separation. Fifty-six percent expressed the wish to have some control over the kind of residents admitted to the facility, and 78% opposed integrated activity programs in general and a “buddy system” of demented and non-demented residents in particular.
Summary

That non-demented residents are significantly negatively impacted by living with the demented has been documented in the general and sociological nursing home literature, sparked an integration vs. separation debate in the professional literature, and been demonstrated in clinical studies. Lacking in this diverse body of literature, however, is a focus upon integration from the perspective of non-demented residents. Other nursing home stakeholders have tended to dominate discussion of the issue with reports of their inductive analyses of residents' perceptions. Only one client-centered study by Brauner has investigated how non-demented residents analyze integration, and whether or not they recommend its continuation. This study attempted to extend that investigation of the perceptions of non-demented residents and to test the findings of that study.
CHAPTER THREE
Methodology

Introduction

In this chapter the research design, sampling procedures, data collection instrument and procedures, demographics, validity and reliability, assumptions, limitations, ethical considerations, and the statistical procedures for data analysis that were used are presented and described.

Research Design

A cross-sectional descriptive quantitative survey design utilizing a questionnaire was chosen for this study. Since the goal of the study was to investigate how non-demented residents in general experienced integration, it was considered important to sample a large number of residents from a number and variety of nursing home settings. In this way an important limitation of Brauner’s (1989) study, its small sample from a single setting with a unique history of recent conversion to integration, could be avoided. Although a qualitative approach might have more readily facilitated the client-centered premise of this study, whereby the voices of non-demented residents would be directly heard, this would not have been possible to do with a large sample size at different data collection sites given the author’s time constraints. The
degree of consistency required to establish a reasonable degree of internal reliability and validity was best provided by using a standard questionnaire with all residents at all sites. Also, a closed question instrument accommodated residents’ physical disabilities. The majority of residents (approximately 75%) were unable to use a writing instrument with sufficient dexterity and/or were unable to see well enough to be able to write words or sentences. Most could, however, make indicator marks. These limitations made it necessary to provide closed questions with a range of possible answers so that respondents had only to place an indicator mark next to their chosen response.

**Sampling Procedure**

A purposive multi-stage sampling procedure was used. The first sampling screen was designed to provide a representative sample of nursing homes sites at which to conduct the study, and the second was designed to provide a representative sample of resident study participants.

The four variables considered in selecting the study sites included care level, degree of separation of demented and non-demented residents, provision of private accommodation, and size. Two extended care, two intermediate care, and one combined extended/intermediate care nursing home were selected to provide a representative range
(see Definition of Terms.). Two nursing homes which provided some separation of the demented and non-demented, one with a formal Special Care unit and one with an informal arrangement, and three which fully integrated the two populations, were chosen to represent the range of separation typically provided. Two nursing homes which provided predominately shared-room accommodation and three which provided private room accommodation were included to reflect the range of accommodation that is available. Nursing homes which ranged in size from 115 to 216 beds were included to provide a sample of medium to large sized nursing homes.

Five sites in Vancouver were selected for the study to comprise the representative nursing home sample described above. They included Purdy Pavilion, Banfield Pavilion, Yaletown House, Broadway Pentacostal Lodge, and Louis Brier Home & Hospital. Purdy and Banfield Pavilions, provided extended level care to 216 and 198 residents respectively in mostly four-bed rooms, were fully integrated units of British Columbia’s largest teaching hospital, Vancouver Hospital & Health Sciences Center. Yaletown House, a semi-integrated nursing home, provided intermediate level care in single rooms to 95 residents and special care for 20 profoundly demented residents on a separate dedicated floor within the home. Broadway Pentacostal Lodge,
also a semi-integrated integrated nursing home, provided intermediate level care in single rooms to 115 residents. The Lodge informally separated the demented and non-demented by grouping residents on each of the five floors according to their level of cognitive impairment and self-care deficit, with residents mixing together for their meals and activities. Louis Brier Home & Hospital was fully integrated and provided intermediate level care to 122 residents and extended level care to 95 residents in single rooms.

The study was open to any non-demented person who had resided for two weeks or more at one of these nursing homes. The two week minimum residency requirement was based on the assumption that the views and experiences of new residents would be distorted by the unique and powerful dynamics of the initial adjustment-to-facility-living phase. At each nursing home the Social Worker, in consultation with Nursing staff, drew up preliminary lists of residents who, in their assessment, met the two eligibility requirements and would be appropriate to invite to participate. Diagnoses of dementia in resident charts was not used as the primary screen for eligibility since the documented level of cognitive status often did not match the actual level of cognitive functioning at the time of the study. It was not unusual for a diagnosis of dementia to have been entered into a resident’s medical record years
or months before the study at a time when s/he was functioning very poorly and for the resident to have subsequently experienced substantial recovery of cognitive ability. It was also not uncommon that no diagnosis of dementia was made in the charts of residents who had consistently exhibited classical signs of dementia for quite some time. Since the reliability of charted cognitive status was questionable, current informal assessment by experienced staff intimately aware of residents’ day-to-day functioning was used instead as the primary screen for study eligibility. All of the 122 potential participants identified by nursing home staff were approached by the researcher or a research assistant and offered the opportunity of study participation (see Data Collection Procedures and Ethical Considerations for further description of the briefing process). Residents then self-selected for the study by indicating their willingness or unwillingness to participate. Approximately one in ten who were initially invited declined at each site (see Assumptions and Limitations for further discussion of possible inhibitors to participation). One hundred and ten elected to participate. The questionnaires of eight residents who later proved to have insufficient cognitive or English language ability to complete the questionnaire were deleted from the sample, yielding a net sample size of 102.
A newly-devised large print questionnaire consisting of 15 closed questions divided into four sections was used (Appendix A). Although the words dementia and demented are commonly used by clinicians and researchers, residents who first pre-tested the questionnaire were not comfortable with those terms. They reported that they customarily used the euphemistic term “confused” to refer to the demented. It was substituted in the questionnaire and was well accepted by the second group of pre-test residents. The following plain language definition of confused people was provided at the beginning of the questionnaire:

Confused people may not be sure who they and other people are, what time of day and time of year it is, and where they are. They may have difficulty learning new things and understanding what is going on around them. They may say and do inappropriate things. All of us can be forgetful and can have some of these thinking difficulties some of the time. Confused people have most of these thinking difficulties most of the time.

Section A established the nature and degree of residents’ contact with and awareness of the demented. They were asked how many times per week they saw, heard, or came in contact with the demented, how many times per week they thought about them, and how many demented
friends they had. Although it might be argued that all residents may not experience aural, visual, and interactional reinforcements of the presence of the demented equally, it was beyond the scope of this study to explore the subtleties of those differences. It was assumed that all types of sensory contact would provide comparable reinforcement of the presence of the demented. Although studies have been done to determine the percentage of demented residents within nursing homes (US DHHS, 1980; Burnside, 1982; Peppard, 1986; Brice, 1986; Mace, 1987; US Congress OTA, 1987) no measurement has been done from the perspective of non-demented residents of the amount of contact they have with the demented. This question was included to provide that information. Residents were asked about the frequency of their thought about the demented to measure the degree of impact of the demented upon their consciousness that was independent of sensory reinforcement, i.e. to determine the extent to which the impact of integration was dependent upon actual contact with the demented as opposed to awareness that the nursing home was an integrated facility. The number of demented friends residents had was investigated to refine the global contact measurement by differentiating between contact with demented people known and liked by the resident and contact with others. All questions in Section A were accompanied by an eight point answer
range of 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 or more. The maximum sensitivity of measurement of sensory contact and thought was daily, and the maximum sensitivity of measurement of number of demented friends was 7 or more.

In Section B residents were asked how often they avoided recreational or social activities because the demented were involved, how often they avoided areas or common rooms because the demented were there, how often they found that mealtimes or other daily activities were disturbed by the demented, how often they found that their sleep was disturbed by the demented, and how often they made an effort to avoid the demented. All questions were accompanied by a five point answer range of never (0% of the time) - rarely (<50% of the time) - regularly (50% of the time) - usually (50% of the time) - always (100% of the time). Questions about physical avoidance patterns, which had been repeatedly identified in the sociological literature as a common responses to integration (Gubrium, 1975 & 1978; Smithers, 1977; Powers, 1988; Shields, 1988; O’Brien, 1989; Fisher, 1991; Savishinsky, 1991; Lidz et al., 1992) were asked to measure lifestyle impacts. Differentiation was made between passive (meal and sleep disturbance) and active (people, place, and performance avoidance) lifestyle impacts to determine which predominated. Differentiation was also made
between locations/situations of impact to test Brauner’s (1989) findings that residents experienced the level of impact differently in different locations/situations.

In Section C residents were presented with opposing affective pairs (unhappy/happy, ashamed/unashamed, at ease/uneasy, pessimistic/optimistic, unsafe/safe) and were asked which feelings were elicited by living with the demented. Each question was accompanied by a five point answer range of very (the positive affect) - somewhat (the positive affect) - neutral - somewhat (the negative affect) - very (the negative affect). These questions were asked to determine the nature and degree of residents’ affective response to integration and to test Brauner’s (1989) findings about the affective impacts of integration and Bohuslawsky’s (1989) finding about the effect of integration upon residents’ perceptions of safety and security.

An attitudinal question about the degree to which residents liked or disliked integration was included in this section because the format of the question and accompanying answer range of the affective questions was well suited to the attitudinal question about liking. This question was asked to provide information about the extent to which residents liked integration and to test the findings of other researchers
(Gutman, 1979; Bowker, 1982; Retsinas, 1986; Brauner, 1989) about residents' dislike of integration.

Section D gave residents four integration policy options ranging from total separation to complete integration. They were asked to indicate their first-ranked, second-ranked, etc. recommendations. This question was asked to provide information about residents' integration policy preferences and to test Brauner's (1989) finding.

**Demographics**

Demographic information was not sought from participants since the primary eligibility criterion, being a non-demented resident of a nursing home, sufficiently identified them for the purposes of this study. Other demographic information was not collected since it was predicted that it might have been perceived as invasive by participants, and would have been inconsistent with the goal of the study to determine the collective views of non-dementing residents regarding integration. As residents of publicly funded nursing homes it could reasonably be assumed that participants would fit the demographic profile of the typical resident, which is female, over the age of 65, Anglo-Canadian, and lower to middle class. An informal survey of respondents confirmed that they conformed to this general demographic profile.
Validity and Reliability

Pretesting (n = 8) suggested that the measure had a reasonable degree of face and content validity. Four residents at an extended care nursing home and four residents at an intermediate care nursing home completed the questionnaire and were interviewed afterward. They were retested two weeks later with the same instrument. In addition to the terminology issue outlined above, residents identified the redundancy of two affective questions about feelings of unease and anxiousness. At their suggestion the question about anxiousness was deleted. Overall, they felt the questionnaire had a reasonable degree of face and content validity, and found they were able to use the questionnaire despite their marked physical disabilities if given some assistance with reading and marking their answer choices on it.

Questionnaire results were largely confirmed in post-test open-ended interviews with the same eight residents described above. Questions and discussion about the amount and nature of their contact with the demented, the impact integration had upon their lifestyle and affect, how much they liked living with the demented, and what integration policy they thought should be adopted revealed that their voiced opinions closely matched the written responses they had given on the questionnaires. Although the wording
used by residents in their interviews tended to differ from that used on
the questionnaire, no direct contradictions emerged for seven out of
eight residents. A resident might state, for example, “I see them all the
time” and have indicated the questionnaire answer of “7 or more times
per week of sensory contact”.

One resident, however, who selected neutral in response to five of
the six affective/attitudinal questions, discussed in her post-test interview
how living with the demented made her profoundly unhappy,
pessimistic, uneasy, and ashamed. When asked about the apparent
discrepancy between her questionnaire responses and her interview
responses, she stated that she had answered neutral on the questionnaire
as a way of minimizing her discomfort with the situation. The
possibility that residents might be inclined to give answers on the
questionnaire that functioned to maintain some denial and/or to adhere
to social acceptability in their views was addressed in the data collection
procedure.

Criterion validity was established through the review of the
instrument by other Geriatric Social Workers and other geriatric
professionals (n = 8). Each reviewed and critiqued the instrument
separately. All indicated that the instrument seemed to have a high
degree of face and content validity. None identified major errors in the
design of the study or the data collection instrument.

Reliability was more difficult to estimate for this newly-devised
instrument, but test-retest (n = 8) in pre-testing indicated minimal
variance over a two week period. Except for the different (i.e. more
accurate) answers to the affective/attitudinal questions given by the
resident mentioned above, little significant differences emerged.
Agreement was 88% for the same or adjacent response. It was assumed,
therefore, that the instrument was sufficiently reliable and valid to yield
useful results.

Data Collection Procedures

Administration of the questionnaire varied slightly according to
the restraints and customs of each study site. At two nursing homes the
researcher attended Resident Council meetings to confirm residents’
general support for the study and to invite their individual participation.
At another nursing home the Resident Council was approached by the
Social Worker to obtain support. At three nursing homes residents were
pre-briefed individually by the Social Worker. One study site specified
that only the researcher could administer the questionnaire, and at two
other sites it was impractical to arrange for research assistants to
accompany the researcher. The team of four research assistants, all
Social Workers, joined the researcher at two sites to expedite the data collection process.

In all cases the researcher and/or the research assistants provided a full briefing and obtained informed consent from each resident in a private interview session that was usually conducted in the resident's room. In a small number of cases (approximately 5%) these prebriefings were held a week in advance of questionnaire completion at the request of residents who wanted ample time to consider whether they wished to participate. Most, however, wished to complete the questionnaire immediately following the prebriefing. Some residents (approximately 10%) preferred to discuss the study within more public areas such as a lounge or patio. It was emphasized within the prebriefing that residents needed to be honest and unashamed about their answers when completing the questionnaire. Based on the findings of the pretest that some residents might be inclined not to report negatively about integration, the statement that, "There are no right or wrong choices.", was added to the procedural instruction section at the beginning of the questionnaire to reinforce those directions. Most residents completed the questionnaires in their rooms, although a few at each nursing home preferred to use lounge areas. At one facility most residents filled out the questionnaire in the lounge.
Approximately three quarters required assistance with the questionnaire because of physical disability. Given a choice of assistance from the researcher, family member, research assistant, or other staff member, a few chose to work with a family member, about one in ten with a research assistant, and the remainder with the researcher. Approximately 10% were unable to finish the questionnaire in one sitting and kept the questionnaire overnight to complete at their leisure.

In addition to the data collected through the instrument, data was collected informally through notes taken by the researcher and research assistants of comments made by residents as they completed the questionnaire. A log was maintained and comments were thematically organized and quantified.

Assumptions

It was assumed that all study participants were able to understand the concepts of dementedness and non-dementedness sufficiently to be able to apply those concepts to the social environment of their nursing home. It was assumed that this understanding allowed them to provide answers to questions about the impact of integration upon them. It was assumed that the answers they gave on the questionnaires accurately reflected their feelings and thoughts about living with the demented. It was assumed that residents had sufficient English language skills and
knowledge of questionnaire completion methodology to be willing and able to participate.

**Limitations**

The study sites were not chosen at random by the researcher but in a purposive fashion to provide a range of different nursing home types. Staff at each site then self-selected for the study. Sites that had positive experience with outside researchers and were receptive to outside research being conducted, that were specifically willing to facilitate Social Work research, that had a Social Worker on staff with whom the researcher could liaise, that were of sufficient size to provide a sample of worthwhile number, were willing to involve residents in a study of integration and risk residents' dissatisfaction with integration issues being “stirred up”, and granted consented, were those that participated. Although the information obtained from the residents of these nursing homes might differ from that obtained from residents of other nursing homes that were different in terms of the factors mentioned above as well as other variables, it seems reasonable to assume that the large site sample size would have provided some reliability of results.

Some bias in the recruitment of study participants by nursing home staff may have occurred. Depending on the bias of each individual
Social Worker and Nurse, toward either including residents who were particularly dissatisfied with integration or including those who were particularly pleased with the situation, some potential participants may not have been given the opportunity to participate. Although an effort was made to compensate for this possibility of bias by inviting all nursing home staff members involved in selecting residents to be as inclusive as possible, and to err whenever possible on the side of inclusivity, it cannot be proved that the initial selection of potential study participants was unbiased.

Similarly, there may have been a pattern of self-selection for study participation by a nonrepresentative sample of residents. Those residents who were extremely dissatisfied with integration, who disdained or distrusted involvement in research, who tended not to join in with any nursing home activity, and who were unable to bring themselves to reveal their opinions and feelings, may have systematically excluded themselves from study participation. It can not be assumed, therefore, that the sample for this study is representative of the population of non-demented nursing home residents.

A possible limitation of this study derives from the inclusion of residents whose non-demented status was not definitively established. As was outlined within the methodology, a high incidence of inconsistency
was found between residents’ charted cognitive status and their apparent level of cognitive functioning. This made reliance upon previous test results sufficiently problematic that current informal assessments were used instead to establish residents’ eligibility for the study. As a result, some study participants may actually have been very mildly demented.

The fact that the researcher and the research assistants were strangers to the participants may also have affected the honesty of their answers and the reflection of their true thought and feelings in the answers they gave. While it might be argued that being unknown to the residents, guaranteeing confidentiality, and not being seen by them after the completion of the questionnaires would enhance residents’ willingness to answer honestly and risk revealing socially undesirable responses to integration, it might also be that residents experienced some degree of intimidation when faced with an unknown Social Work researcher asking them to provide information about their personal views on a somewhat sensitive topic. It has been my experience in working with this population that residents are more relaxed with those they know and as a result more revealing of their thoughts and feelings. I have also experienced that most residents have somewhat idiosyncratic ways of expressing themselves and dialoguing with others, and that knowledge of their expressive codes allows for much greater accuracy
in understanding them. I would assume, therefore, that on balance the fact that the researchers did not know the residents might have tended to slightly hamper rather than facilitate the accurate recording of residents' views in the questionnaires.

The cross-sectional design of this study is inherently limiting. Although it may provide information about residents' experiences and recommendations regarding integration at the time they completed the questionnaire, it cannot be claimed that those residents would provide the same information at a later date.

The quantitative questionnaire instrument used for data collection may also have imposed a cultural/educational limitation upon this study. Residents who felt their English language skills were poor or felt uncomfortable using a questionnaire may have self-selected for non-inclusion in the study. The less literate, less educated, and less English proficient may therefore be underrepresented in this study.

**Ethical Considerations**

Permission to conduct this study was obtained from the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects (Appendix B). Permission was also obtained from the Administrator
and/or Research Advisory Committee and/or Resident Council at each study site (Appendices C, D, E, F).

Each participant was fully briefed about the subject and purpose of the study, its voluntary and confidential nature, who was conducting it, and how to access them. All participants were offered follow-up counseling and/or referral for follow-up to deal with feelings, questions, or concerns that participation in the study may have provoked. They were informed that by completing and handing in a questionnaire their fully informed consent was understood to have been granted, as per the research protocol of the UBC Committee named above. This information was delivered verbally and a written copy was provided for their records. One site required that written consent also be obtained from each participant. Those residents signed consent forms (Appendix G) and were given signed copies for their records. All participants were offered copies of blank questionnaires for their records.

Confidentiality was maintained throughout the study. No resident names were attached by the researcher to questionnaires at any time in the research process, and any identifying marks that residents made were removed and/or disregarded.
**Statistical Procedures**

Quantitative data analysis was done using the SPSS for Windows (Norusis, 1992) computer program. Following data entry a uni-variate descriptive statistic summary was obtained. Frequency tables and central tendency, distribution, and dispersion statistics were computed for the range of answers to each question. Bi-variate cross-tabulations between all variables were then run and Pearson’s R correlation coefficients were computed to test for direction and statistical significance of correlation.

**Summary**

In this chapter the research design, sampling procedure, data collection instrument and procedures, demographics, validity and reliability, assumptions, limitations, ethical considerations, and the statistical procedures for data analysis were presented and described. A cross-sectional descriptive quantitative design was chosen for this study. Five sites in Vancouver were selected for the study to comprise a representative sample of typical nursing homes. The study was open to any non-demented person who had resided for two weeks or more at one of these nursing homes. A newly-devised large print questionnaire consisting of 15 closed questions divided into four sections was used. Section A established the amount and nature of residents’ awareness of
the demented. Section B measured various lifestyle impacts of integration and Section C measured a number of affective/attitudinal responses to integration. Section D asked residents for their integration policy recommendations. No demographic information was formally gathered. A sufficient degree of face, content, and criterion validity were established. A reasonable degree of reliability was assumed. Given the design and assumptions that were made, the study is limited by its cross-sectional nature, the lack of complete control over the eligibility requirement of non-dementedness, the biases that may have been introduced in site selection, potential participant selection, participant self-selection, and the possibility that the unfamiliarity of research staff may have hindered reporting. Approval for the study was obtained from all institutions involved as was fully informed consent from all participants, who were treated in an ethical manner. A range of univariate descriptive statistics and bi-variate cross-tabulation statistics were computed. In the chapter to follow the findings related to all of the instrument questions will be presented.
CHAPTER FOUR

Presentation of Findings

Introduction

In this chapter the findings from the questionnaire will be presented. Uni-variate statistical information about the residents' responses to each of the 15 questions will be outlined, organized into four sections to reflect the questionnaire. This will be followed by a presentation of the bi-variate analysis results.

Section A: Awareness of the Demented

Almost all residents (93%) had had some sensory contact with the demented during the previous week, nearly two thirds (63%) on a daily basis. Small numbers of residents had had no (7%) or only one (3%) contact. Four out of five residents (81%) had thought about the demented in the previous week, half of those (41%) daily. One in five residents (19%), however, reported that they had not thought about the demented even once. A roughly even split occurred between those with no demented friends (47%) and those with at least one (53%). Of those who reported having any demented friends, the greatest percentage (23%) had two. Sixty percent of those having any demented friends had 1 - 3 and 40% had 4 or more. For full results see Tables 1 and 2.
**Table 1**

**Frequency of Non-Demented Nursing Home Residents' Sensory Contacts With And Thought About the Demented (n = 100)**

<table>
<thead>
<tr>
<th>Experience</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 or more</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory contact with demented</td>
<td>7</td>
<td>3</td>
<td>9</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>63</td>
<td>100</td>
</tr>
<tr>
<td>Thought about demented</td>
<td>19</td>
<td>5</td>
<td>8</td>
<td>12</td>
<td>8</td>
<td>3</td>
<td>4</td>
<td>41</td>
<td>100</td>
</tr>
</tbody>
</table>
### Table 2

**Frequency of Friendship Between Non-Demented and Demented Nursing Home Residents (n = 99)**

<table>
<thead>
<tr>
<th>% of Non-Demented Residents Having Numbers of Demented Friends</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7 or more</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>48</td>
<td>10</td>
<td>12</td>
<td>10</td>
<td>7</td>
<td>2</td>
<td>7</td>
<td>4</td>
<td>100</td>
</tr>
</tbody>
</table>
Section B: Lifestyle Impacts of Integration

Most residents reported minimal impacts upon their lifestyle. More than two thirds (70%) never or rarely avoided recreational or social activities because the demented were involved, and two thirds (65%) never or rarely avoided areas of the nursing home because of their presence. A slightly smaller number (62%) never or rarely made an effort to avoid the demented in general. Almost three quarters (72%) never or rarely had their meals disrupted, and more than four out of five residents (91%) never or rarely had their sleep disturbed. Overall, approximately three quarters (Section B average response = 72%) never or rarely experienced negative lifestyle impacts as a result of their cohabitation with the demented. For full results see Table 3.

The minority findings are significant, however. Nearly one third (30%) did not participate on a regular basis (half or more of the time) in recreational or social activities because they wanted to avoid interaction with the demented. Over one third (35%) would regularly avoid common rooms and other areas of their nursing home because the demented were there, and a slightly greater number (38%) made a general effort to avoid them. Over one quarter (28%) regularly had
Table 3

**Lifestyle Impacts of Integration Upon Non-Demented Nursing Home Residents (n = 101)**

<table>
<thead>
<tr>
<th>Effect</th>
<th>Never</th>
<th>&lt;1/2 time</th>
<th>1/2 time</th>
<th>&gt;1/2 time</th>
<th>Always</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid activities</td>
<td>56</td>
<td>14</td>
<td>6</td>
<td>11</td>
<td>13</td>
<td>100</td>
</tr>
<tr>
<td>Avoid areas</td>
<td>42</td>
<td>22</td>
<td>5</td>
<td>12</td>
<td>19</td>
<td>100</td>
</tr>
<tr>
<td>Avoid in general</td>
<td>42</td>
<td>20</td>
<td>8</td>
<td>12</td>
<td>18</td>
<td>100</td>
</tr>
<tr>
<td>Meal disturbance</td>
<td>29</td>
<td>43</td>
<td>12</td>
<td>7</td>
<td>9</td>
<td>100</td>
</tr>
<tr>
<td>Sleep disruption</td>
<td>68</td>
<td>23</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>100</td>
</tr>
</tbody>
</table>
their meals disrupted and one in ten (9%) regularly had their sleep disturbed. Over one in four residents (Section B average response = 28%) experienced disruption to their daily routines and/or made a conscious effort to modify their lifestyle on a regular basis due to the presence of the demented.

**Section C: Affective/Attitudinal Impacts of Integration**

Over half of the non-demented residents (average response in Section C = 54%) had a neutral affective/attitudinal response to integration. For the six affective/attitudinal questions as a whole, almost one third (average response in Section C = 31%) had negative responses and half that number (average response in Section C = 15%) reacted positively to living with the demented. For full results see Table 4.

Of those who were not neutral, however, a pattern emerged of residents feeling unhappiness, dislike, unease, and pessimism, but also not ashamed, about living with the demented. For those who reported an affective/attitudinal response other than neutral, the ratio of unhappy to happy was 21 : 1 (42% vs. 2%), dislike to like was 7 : 1 (49% vs. 7%), uneasy to at ease was 3 : 1 (36% vs. 12%), and pessimistic to optimistic was nearly 2 : 1 (25% vs. 14%). In contrast to these figures, roughly equal numbers of residents felt unsafe and safe (29% vs. 28%), and the
<table>
<thead>
<tr>
<th>Affective/attitudinal range</th>
<th>Negative</th>
<th>Neutral</th>
<th>Positive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unhappy--happy</td>
<td>42</td>
<td>56</td>
<td>2</td>
<td>100</td>
</tr>
<tr>
<td>Dislike--like</td>
<td>49</td>
<td>44</td>
<td>7</td>
<td>100</td>
</tr>
<tr>
<td>Uneasy--at ease</td>
<td>36</td>
<td>52</td>
<td>12</td>
<td>100</td>
</tr>
<tr>
<td>Pessimistic--optimistic</td>
<td>25</td>
<td>61</td>
<td>14</td>
<td>100</td>
</tr>
<tr>
<td>Unsafe--safe</td>
<td>29</td>
<td>43</td>
<td>28</td>
<td>100</td>
</tr>
<tr>
<td>Ashamed--unashamed</td>
<td>7</td>
<td>66</td>
<td>27</td>
<td>100</td>
</tr>
</tbody>
</table>
number who felt not ashamed was almost four times the number
(27% vs. 7%) who felt shame.

Section D: Integration Policy Recommendations

Slightly more than four out of five residents (81%) recommended
as their first choice an integration policy that incorporated some degree
of separation of the demented and the non-demented. The largest
number (37%) recommended living in the same nursing homes and
mixing together for meals and other activities, but having rooms in
separate designated areas for the demented. The second most popular
arrangement, preferred by one quarter (25%) of the residents, was for
the demented and non-demented to live in entirely separate nursing
homes that would provide specialized care for each. The third most
popular separation policy, preferred by almost one in five residents
(19%) involved a degree of separation in between the above
arrangements, whereby they would live in the same nursing homes with
the rooms of the demented in separate areas and no contact during meals
or other activities. An equal number (19%) of residents indicated that
their first policy choice would be total integration of the demented and
non-demented, such that they would live together within
<table>
<thead>
<tr>
<th>Arrangement</th>
<th>First choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>The demented and non-demented live in separate facilities</td>
<td>24 25</td>
</tr>
<tr>
<td>The demented and non-demented live in the same facility with rooms in separate areas and they do not mix together for meals and other activities</td>
<td>18 19</td>
</tr>
<tr>
<td>The demented and non-demented live in the same facility with rooms in separate areas and they mix together for meals and other activities</td>
<td>35 37</td>
</tr>
<tr>
<td>The demented and non-demented live in the same facility with rooms in the same areas and they mix together for meals and other activities</td>
<td>18 19</td>
</tr>
<tr>
<td>Total</td>
<td>95 100</td>
</tr>
</tbody>
</table>
the same nursing homes, with rooms in the same areas of the homes, and they would mix together for their meals and other activities. For full results see Table 5.

**Bi-Variate Analysis Results**

Three variables - amount of contact, number of demented friends, and choice of integration policy - were significantly correlated with the following at $p<.05$:

Increased sensory contact with the demented was directly related to increased thought about them ($r = .42$), feeling pessimistic ($r = .23$), and feeling unsafe ($r = .20$).

Residents with at least one demented friend tended to feel slightly more at ease ($r = .29$), to like living with the demented ($r = .26$), and to opt for more integrated living arrangements ($r = .34$).

Those who recommended more separate policy options also tended to avoid social/recreational activities ($r = .32$) and contact in general with the demented ($r = .25$), to dislike living with them ($r = .48$), to feel uneasy ($r = .45$), unsafe ($r = .31$), ashamed ($r = .23$), and unhappy living with the demented ($r = .39$), and to have greater pessimism ($r = .22$). For full results see Table 6.

A close look at the correlation between increased numbers of demented friends and increased ease with integration, liking of
integration, and recommendation of integration policy, exemplifies the unevenness of the correlations that exist between all of the variables listed above. The correlation occurs as a general pattern through the range of numbers of friends, and does not occur as a perfectly evenly distributed correlation. It cannot be stated, therefore, that there is a threshold of a certain number of demented friends that correlates with increased satisfaction with integration as indicated by the three variables of ease, liking, and recommendation. Similarly, the level of neutrality did not evenly rise or fall as the numbers of demented friends increased. No statistically significant statements can be made about the correlations beyond their Pearson's r values. For full results of the correlations between numbers of demented friends and other variables see Tables 7, 8, and 9.
Table 6

Correlations Between Variables at $p < .05$

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correlated Variable</th>
<th>$r$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory Contact With the Demented</td>
<td>Thought About the Demented</td>
<td>.42</td>
</tr>
<tr>
<td></td>
<td>Feeling Pessimistic</td>
<td>.23</td>
</tr>
<tr>
<td></td>
<td>Feeling Unsafe</td>
<td>.20</td>
</tr>
<tr>
<td>Having Demented Friends</td>
<td>Feeling At Ease</td>
<td>.29</td>
</tr>
<tr>
<td></td>
<td>Liking Integration</td>
<td>.26</td>
</tr>
<tr>
<td></td>
<td>Integrated Policy Recommendation</td>
<td>.34</td>
</tr>
<tr>
<td>Policy Choice of Separation</td>
<td>Avoidance of Social/Recreational Activities With the Demented</td>
<td>.32</td>
</tr>
<tr>
<td></td>
<td>Avoidance of the Demented</td>
<td>.25</td>
</tr>
<tr>
<td></td>
<td>Disliking Integration</td>
<td>.48</td>
</tr>
<tr>
<td></td>
<td>Feeling Uneasy</td>
<td>.45</td>
</tr>
<tr>
<td></td>
<td>Feeling Unsafe</td>
<td>.31</td>
</tr>
<tr>
<td></td>
<td>Feeling Ashamed</td>
<td>.23</td>
</tr>
<tr>
<td></td>
<td>Feeling Unhappy</td>
<td>.39</td>
</tr>
<tr>
<td></td>
<td>Feeling Pessimistic</td>
<td>.22</td>
</tr>
</tbody>
</table>
Table 7

**Correlation Between Number of Demented Friends and Level of Ease With Integration (n = 102)**

<table>
<thead>
<tr>
<th>Number of Demented Friends</th>
<th>% Feeling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Uneasy</td>
</tr>
<tr>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
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<td>6</td>
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</tr>
<tr>
<td>7 or more</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
</tr>
</tbody>
</table>

Note, $r = .29$, $p < .05$. 
Table 8

Correlation Between Number of Demented Friends and Liking of Integration (n = 102)

<table>
<thead>
<tr>
<th>Number Demented Friends</th>
<th>Very Much Like</th>
<th>Somewhat Like</th>
<th>Neutral</th>
<th>Somewhat Dislike</th>
<th>Very Much Dislike</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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<td>3</td>
<td>18</td>
<td>10</td>
<td>17</td>
<td>48</td>
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<td>1</td>
<td>0</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>10</td>
</tr>
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<td>2</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>7</td>
<td>1</td>
<td>12</td>
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<td>0</td>
<td>2</td>
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<tr>
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<td>1</td>
<td>1</td>
<td>4</td>
<td>0</td>
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<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>5</td>
<td>44</td>
<td>29</td>
<td>20</td>
<td>100</td>
</tr>
</tbody>
</table>

Note. r = .26, p < .05.
Table 9

**Correlation Between Number of Demented Friends and Integration**

**Policy Recommendations (n = 102)**

<table>
<thead>
<tr>
<th>Number Demented Friends</th>
<th>Separation in Different Homes</th>
<th>Separation in Same Homes</th>
<th>Semi-Integration</th>
<th>Complete Integration</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>17</td>
<td>15</td>
<td>10</td>
<td>6</td>
<td>48</td>
</tr>
<tr>
<td>1</td>
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<td>12</td>
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<tr>
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<td>2</td>
<td>10</td>
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<tr>
<td>Total</td>
<td>25</td>
<td>19</td>
<td>37</td>
<td>19</td>
<td>100</td>
</tr>
</tbody>
</table>

*Note. r = .34, p < .05.*
Summary

Almost all residents had some contact with the demented, two thirds on a daily basis. A lesser number thought about the demented, half of those daily. A roughly even split occurred between those with no demented friends and those with at least one. Most residents reported that integration had minimal impact upon their lifestyle. One in four residents, however, experienced disruption to their daily routines and/or made a conscious effort to modify their lifestyle within the nursing home on a regular basis. Just over half of the residents had a neutral affective/attitudinal response to living with the demented. Of those who were not neutral, a pattern emerged of residents feeling unhappiness, dislike, unease, and pessimism, but also unashamed. Four out of five residents recommended an integration policy that incorporated some degree of separation of the demented and the non-demented. Increased contact was directly related to increased thought about the demented, pessimism, and feeling unsafe. Those with at least one demented friend tended to feel slightly more at ease, to like living with the demented, and to opt for more integrated living arrangements. Those who recommended more separation also tended to avoid social/recreational activities and the demented in general, to dislike living with them, to
feel uneasy, unsafe, ashamed, and unhappy living with them, and to have greater pessimism.
CHAPTER FIVE

Discussion of Findings

Introduction

In this chapter the findings from the questionnaire will be discussed in terms of the research question. Residents’ verbal comments and theory regarding integration psychosocial dynamics will be used to interpret the quantitative findings in relation to the research question. The findings will then be discussed as they relate to the sociological literature on integration, the integration editorial literature, the findings of previous clinical studies of integration, and to the findings of the previous client-centered study of integration.

Relation of the Findings to the Research Question

This study was designed to answer the question, “How do elderly non-demented nursing home residents experience integration, and how integrated do they want nursing homes to be?”. The findings suggest that a significant minority experience negative consequences as a result of integration, and the majority want nursing homes to provide some degree of separation of the demented and non-demented.

The results of Section A indicate that most residents (93%) experience integration on a daily basis, having sensory contact with and/or thinking about the demented. Just over half (53%) also
experience integration within their close social sphere, knowing at least one demented person within their nursing home whom they consider to be their friend. This suggests that integration is not a hypothetical concept to most non-demented residents of nursing homes, but is their lived reality. These results seem consistent with the findings of the studies of dementia prevalence within nursing home populations, which indicate that 40% to 85% of residents within any given nursing home are demented (Brice, 1986; Burnside, 1982; Mace, 1987; Peppard, 1986; US DHHS, 1980; US Congress OTA, 1987).

The Section B results, which encompass experiences of neutral and negative lifestyle impacts, can be interpreted within the context of residents’ comments on their answers. These statements suggest that a number of factors may interact to influence residents’ sense of whether or not integration is a significant problem for them. Some residents, as they completed the questionnaire, expressed their gratitude for and total dependence upon the housing and care they received within the nursing home, care that they said they could not get anywhere else. Typical comments were, “I don’t know what I’d do if it weren’t for this place and the help I get here.”, “I don’t like to complain.”, and “Where else could I go?”. These residents may not have been able to identify
integration in general and the lifestyle impacts of integration in particular as problematic, since the adoption of a critical stance would have contradicted their commitment to a posture of grateful acceptance of what was provided.

Other residents talked about using different minimizing strategies for the negative lifestyle impacts of integration. When filling out the questionnaire they attested to their resourcefulness in learning ways of preventing and mitigating those effects, such as taking out their hearing aids so they did not hear the demented, following a daily schedule determined by their knowledge of the times when the demented were not around within the nursing home so that they would remain in their private rooms except when they felt they could venture out without encountering them. These residents made comments such as, "I don't let them bother me." and "I've got it all worked out.". These residents may not have identified problematic lifestyle effects of integration because they had worked out and accepted their individual solutions to those problems.

Many other residents bitterly recounted stories of negative lifestyle impacts they had experienced in the past as a result of one or two particular demented residents, but these narratives typically focused upon an outcome whereby the demented residents had been moved or
otherwise dealt with so that they were no longer negatively impacted by integration. Although these residents expressed concern about the situation repeating itself, they focused upon their current satisfaction with integration and stated that they could therefore not report any negative lifestyle impacts.

In contrast to the residents discussed above, other residents did express strong dissatisfaction. These residents stated that they resented having to live with the demented because of the negative impacts it had upon their lifestyle. These residents made such comments as, "I have to stay in my room all the time if I want to get away from them.", "It's depressing.", "You can't talk to them and you never know what they'll do.", and "Why should I have to live with these people?".

These types of informal statements made by residents as they completed the questionnaire help to explain the neutral and negative responses that the quantitative findings show. It would seem that while the majority of residents, for a variety of reasons not identified within this study but alluded to in their side comments -- their uncritical acceptance of integration as a condition of being cared for in a nursing home, their negotiated acceptance of integration as a manageable challenge of nursing home life, and their current if temporary satisfaction with integration -- did not report negative lifestyle impacts
of integration, a significant minority felt resentful about integration and perceived their lifestyle to be negatively effected.

The high neutral response rate (54% on average) to the affective/attitudinal questions in Section C suggests that the intrapsychic dynamic involving the complex combination of feelings of guilt, sympathy, pity, and superiority identified by Hochschild (1973), Howsden (1981), and Novick (1982) may have been operative among residents. As residents contemplated and answered the questions about their affective/attitudinal response to integration almost all made side remarks about their concern and sympathy for the demented who "you feel so sorry for" and "can't help it". Virtually every resident made a point of saying they had "nothing against them" and that they wouldn't want to complain about those "worse off" than themselves, since "we all have to get along". A few clearly stated the causal link between those attitudes and their choice of answer on the questionnaire. They stated that because they felt it would be wrong to cast aspersion upon the demented, they could not report anything negative. Given their strong values of tolerance and charity it may have been that they could not bring themselves to report negative feelings and attitudes about living with the demented, since those answers would have contradicted how they felt they should regard them. Perhaps equally unwilling to report
positive affective/attitudinal responses which they did not honestly feel, it may have been that they circled the neutral answers on the questionnaire as the least problematic answer.

Brauner (1989) found the same tendency among the non-demented residents she studied to mask and under-report their negative feelings about the demented due to their over-riding commitment to Christian principles, which they felt they would violate by reporting “uncharitable” attitudes.

The psychosocial dynamic identified by Hochschild and elaborated by Howsden and Novick whereby non-demented residents are triply motivated to express charitable pity in order to obtain the three rewards of immediate social and moral superiority as pity dispensers and future benefit as pity receivers was evidenced in the comments residents made as they completed the questionnaire. This suggests that the 15% (Section C overall average) positive response rate and the 54% (Section C overall average) neutral response rate to the affective/attitudinal questions in Section C might at least partially be seen as indicative of residents’ reluctance to admit (to themselves as much as to the researcher and others) negative regard for the demented. The influence of this dynamic might also be evident in the non-neutral response pattern. Although the overwhelming majority of residents who braved a
response other than the socially acceptable one of neutrality reported feeling unhappy, dislike, unease, and pessimism, most also reported feeling not ashamed. While it might be argued that these represent the "true" feelings of residents, it may also have been that most residents, due to ingrained denial, were particularly unable to admit feelings of shame. Residents might have been able to declare feelings of unhappiness, dislike, unease, and pessimism since they could easily be understood as extra-referential, i.e. as feelings about integration in general in the nursing home and/or about other (demented) residents. Shame, however, is a more self-referential emotion, i.e. it is a negative feeling about oneself. To declare shame, therefore, may have suggested negative self-regard. This may have been too challenging an admission for most residents to make, with the result that four times as many indicated feeling not ashamed as indicated feeling ashamed.

The results of Section D provide a less ambiguous picture of residents' wants concerning integration, and strengthen the argument that Section C results indicating a low experience of negative affective/attitudinal response may not have reflected residents' actual level of dissatisfaction with integration. Although only 28% (Section B overall average) reported negative lifestyle effects of integration, and 31% (Section C overall average) reported negative affective/attitudinal
responses to integration, 81% recommended some degree of separation within nursing homes. Even if the least separated policy option, whereby the demented and non-demented live together in the same nursing home and mix together for meals and activities but have rooms in separate areas of the nursing home, is considered for the sake of argument as an integrated arrangement, and the numbers of residents opting for it and for total integration are added together, 44% remain who want a high degree of separation. This is a significantly greater percentage of residents than those who reported negative lifestyle impacts and affective/attitudinal responses. Thus many of the residents who reported neutral and/or positive response to integration were none-the-less sufficiently dissatisfied to recommend separation. This reinforces the argument that residents may have underreported their negative lifestyle impacts and affective/attitudinal responses to integration.

Relation of the Findings to the Sociological Literature on Integration

(1992) were born out by the results of this study which indicate that 30% avoided recreational or social activities, 36% avoided areas or common rooms, and 28% avoided the demented in general, all on a regular (50% or more of the time) basis.

Relation of the Findings to the Integration

Editorial Literature

The results of this study confirm the statements made in the integration editorial literature by Wolfson (1983), Ablowitz (1983), Salisbury (& Goehner, 1983), Mace (1985), and Getzlaff (1987) that a significant number of non-demented residents do not want nursing homes to be totally integrated but would prefer an arrangement incorporating some degree of separation. The negative lifestyle and affective impacts that the non-demented experience in integrated settings, which were reported and/or alluded to by Wolfson (1983), Ablowitz (1983), Gang & Ackerman (1983), Salisbury (& Goehner, 1983), Novick (1985), Rabins (1986), and Getzlaff (1987) were also consistent with those found in this study.

Relation of the Findings to Previous Clinical Studies of Integration

Although the findings of this study do not demonstrate as dramatic a negative affective impact upon residents as has been found by
Wiltzius et al. (1981), they are consistent with the trend indicated by the results of their study. Wiltzius et al. reported that 85% of non-demented residents responded to integration with "depression" and loneliness and 60% with anxiety and insecurity. These affective terms were not clearly defined in their study, but the term depression seemed to be used to describe a non-clinical state of unhappiness. Assuming that this affective state is comparable to the unhappiness measured in this study, and that the anxiety and insecurity measured by Wiltzius et al. can likewise be equated with the unease measured in this study, some comparisons can be made. Although the rates of experience of both of these negative affective states were much higher in the Wiltzius et al. study (85% vs. 42% unhappiness and 60% vs. 36% uneasy) the ratio indicators of these affective states in this study (21:1 unhappy to happy and 3:1 uneasy to at ease) suggests that the trend toward unhappiness and unease as identified in he Wiltzius et al. study is supported by the findings.

Similarly, the finding that increased contact with the demented correlates with increased pessimism seems consistent with the finding of Teresi et al. (1993) that contact with the demented correlates with increased demoralization. Again, the assumption must be made that the affective state of demoralization, which Teresi et al. did not define, is similar to the affective state of pessimism. While it can be argued that
they are not entirely equivalent, it seems reasonable to assume sufficient similarity to allow a gross comparison of the two findings, and to conclude that the correlation found by Teresi et al. between contact with the demented and demoralization was supported by the findings of this study.

Relation of the Findings to Previous Client-Centered Study of Integration

The findings generally confirm Brauner's (1989) results, although showed less negative response to living with the demented and less desire for separation. Neutral responses are roughly comparable (Section C average response of 54% vs. Brauner's 50% overall), but negative responses are lower in this study (Section C average response of 31% vs. Brauner's 50% overall), and some positive responses, which Brauner did not find, occurred (Section C average response of 15% vs. Brauner's 0%). Similarly, the numbers who recommended separate facilities and separate activities for the demented and non-demented were much lower (25% and 44% respectively vs. Brauner's 33% and 78%). These differences may partly reflect the different contexts of the studies. The residents in Brauner's study, undertaken soon after the integration of a previously separated nursing home, would likely have been reacting and adjusting to the loss of their familiar social milieu,
and could have used personal experience to consider integration vs. separation policy recommendations. Both factors may have inclined them to respond more negatively to integration than the residents of this study, who lived in nursing homes where integration had always been the norm and for whom separated nursing home living was an unknown, and therefore perhaps less attractive prospect.

Summary

The findings that a significant minority of non-demented residents experience negative lifestyle impacts and affective/attitudinal responses and that the majority want nursing homes to provide some degree of separation are generally consistent with the experiences and recommendations of non-demented residents reported in the sociological literature on integration, the integration editorial literature, the findings of previous clinical studies of integration, and with the findings of the previous client-centered study of integration.

The findings of the amount and nature of residents’ awareness of the demented, their level of support for specific integration and separation arrangements, and the correlations between variables of awareness, lifestyle impact, affective/attitudinal response, and integration policy choice represent new and useful descriptive
information about integration as it is experienced and recommended by the non-demented.
CHAPTER SIX
Conclusions, Implications, and Recommendations

Introduction

This study was designed to quantitatively describe the experiences and recommendations of elderly non-demented nursing home residents concerning integration. The study conclusions, implications for health policy, policy and clinical practice Social Work, and recommendations for further research are presented in this final chapter.

Conclusions

The impetus for this study arose from the researcher's clinical observations and from residents', family members', and colleagues' reports in various work settings that integration was problematic for the non-demented, and was a case mix policy they would like modified or abandoned. Although non-demented residents' dislike of integration seemed "common knowledge", there was very little literature on the subject, and most of the published mentions of integration were incidental. A debate over integration policy had developed in the literature by professionals, but consensus of expert opinion had not been reached, and more importantly, the voices of non-demented residents themselves had rarely been heard in that debate. No systematic investigation had been done of the experiences, views, and desires of
non-demented residents in order to understand integration from their perspective so that that understanding could be used in the (re)consideration of integration policy.

To address that paucity of understanding, this study was undertaken within five Vancouver nursing homes using a cross-sectional descriptive quantitative design. The findings were that almost all residents had some contact with the demented, two thirds on a daily basis. A lesser number thought about the demented, half of those daily. A roughly even split occurred between those with no demented friends and those with at least one. Most residents reported that integration had minimal impact upon their lifestyle. One in four residents, however, experienced disruption to their daily routines and/or made a conscious effort to modify their lifestyle within the nursing home on a regular basis. Just over half of the residents had a neutral affective/attitudinal response to living with the demented. Of those who were not neutral, a pattern emerged of residents feeling unhappiness, dislike, unease, and pessimism, but also unashamed. Four out of five residents recommended an integration policy that incorporated some degree of separation of the demented and the non-demented. Increased contact was directly related to increased thought about the demented, pessimism, and feeling unsafe. Those with at least one demented friend tended to feel slightly more at
ease, to like living with the demented, and to opt for more integrated living arrangements. Those who recommended more separation also tended to avoid social/recreational activities and the demented in general, to dislike living with them, to feel uneasy, unsafe, ashamed, and unhappy living with them, and to have greater pessimism.

Based on these findings, several conclusions can be drawn. Firstly, integration is an aspect of nursing home living that almost all non-demented residents experience. It can be seen as the norm. Secondly, individual residents experience different degrees of lifestyle impact as a result of integration, so that generalizations cannot be made about the way all residents are impacted. Integration does not impact the lifestyles of the majority of residents but does negatively impact a sizable minority. Similarly, and thirdly, individual residents respond affectively/attitudinally in different ways to integration, so that no one response profile can be drawn. Residents are most likely to have a neutral affective/attitudinal response, less likely to respond negatively, and least likely to respond positively. Fourthly, most residents do not recommend full integration but want some separation between the demented and non-demented.
Implications for Health Policy

The results of this study suggest that the long-standing policy of integration needs to be reviewed in light of its impact upon the non-demented residents of nursing homes. When introduced (in 1978 in British Columbia, for example), integration may have been a comparatively progressive policy. A generation ago the demented were typically referred to as “senile”, and were much less accepted by the general public. In the days before disability was de-stigmatized, the senile were regarded as hopelessly mentally deranged and were often hidden away from public view in the back wards of hospitals or back bedrooms of their families’ homes (Meacher, 1972). Integration would have challenged those prejudices against dementia by insisting that the demented were just as deserving of regular nursing home care as those with physical disabilities, and placing the demented within the respectable, normalized environments of general nursing homes. Integration may have once been, therefore, a laudable, progressive, humane policy in terms of its benefits to the demented.

It must be asked whether the social benefits that have accrued, and continue to accrue, to the demented as a result of integration have, and are, at some expense to the non-demented. No health policy can be supported that benefits some constituents while exposing substantial
numbers of others to negative side effects. The fundamental standard of care and the primary ethical professional obligation to do no harm both obligate health policy makers and those who maintain health policy to assess whether harm is occurring (or is likely to occur) as an iatrogenic outcome of policy, and if so to cease or amend pursuit of that policy. The results of this study indicating that many non-demented residents experience negative impacts as a direct result of integration suggest that integration needs to be reviewed and its abandonment or modification seriously considered.

Another health policy implication is suggested by the result that the great majority of non-demented residents do not want to live in totally integrated nursing homes but want some degree of separation provided. Just as it is the obligation of health policy makers to ensure that no harm is done to care recipients, it is the obligation of public health policy makers (and good business for private health policy makers) to ensure that policies are congruent as much as possible with the demands and preferences of care recipients. The fact that the majority of non-demented residents have directly expressed the wish for separation suggests that public and private health policy makers need to consider providing separate care.
The findings of this study give credibility to the argument made by Salisbury (& Goehner, 1983) and Novick (1985) that a policy of separation is in the best interests of the non-demented. It would seem that the policy of developing Special Care Units and other separate care programs and living arrangements for the demented, which has already been accepted as good health policy in terms of its benefit to the demented (Ohta & Ohta, 1988; Gutman, 1989; Holmes et al. 1990) may be good health policy in terms of benefit to the non-demented as well.

Implications for Policy Social Work

The ethical responsibility of the Social Worker is to advocate for change in the best interest of the client and for the overall benefit of society (CASW, 1994). Given the policy implications outlined above that integration needs to be reviewed to ensure that it is not harmful to the non-demented, and that it reflects the expressed wishes of the non-demented, the Social Worker’s obligation would seem to be to work with, and on behalf of, non-demented residents and other appropriate stakeholders in the integration issue toward the implementation of such reviews. This work will vary according to the setting, clients, interests, resources, opportunities and other aspects of each Social Worker’s situation. The possibilities for policy Social Work are too numerous to detail, but in general, Social Workers who work with the non-demented,
their families, seniors, and other directly involved clients might facilitate the work of these clients toward the implementation of the reviews, while Social Workers in other settings might advocate on their behalf for the implementation of the reviews.

Implications for Clinical Practice Social Work

The finding of this study suggest that a significant number of non-demented residents living within nursing homes are stressed by integration and may need support to prevent their quality of life from being seriously degraded. Social Workers in clinical practice within nursing homes may need, therefore to address this issue within the assessment, intervention, and evaluation phases of their work with individual residents and with residents groups. Social Workers might explore with non-demented residents how well they are dealing with integration, and to develop intervention plans with those wanting help to live more comfortably in integrated homes. I am not recommending the resident management approach articulated by Getzlaf (1987), whereby non-demented residents expressing dissatisfaction with integration and asserting their right to separate from the demented are "re-educated" out of their "intolerance and ignorance", but am proposing instead that concerns of non-demented residents be validated and ways found to meet their legitimate self-esteem, accomplishment, companionship,
safety, and other needs. On-going evaluation of the effectiveness of the intervention may be needed to ensure that residents are coping well as conditions (such as the addition of a demented roommate, increased ill health, etc.) change within the nursing home and within residents’ lives.

Another implication for clinical practice Social Work is that the issue of integration may need to be highlighted when prospective residents are touring nursing homes and considering moving in. It is the Social Worker’s responsibility to ensure that the best possible fit is obtained between the milieu and care the home provides and the care needs and preferences of residents. The decision to enter a nursing home must as far as possible be a fully informed one. Therefore the integrated nature of a home may need to be admitted and explained to prospective residents so that they can decide if that is the home they wish to enter. To ignore this crucial determinant of the social environment and thereby deprive prospective residents of the opportunity to consider their admission to an integrated setting “before it’s too late” may at best be negligent, at worst unethical.

Recommendations for Further Research

The findings of this study suggest the need for a number of further research efforts, particularly those that are client-centered. Several questions remain unanswered:
1.) What is the relationship between non-demented residents’ experience of, response to, and recommendations concerning integration and the characteristic variables of non-demented residents, i.e. ethno-cultural background, sexual orientation, age, gender, family configuration, education, occupational history, primary and secondary diagnoses, disability history, length of stay, etc.?

2.) What is the relationship between non-demented residents’ experience of, response to, and recommendations concerning integration and the characteristic variables of nursing homes, i.e. location, architecture, history, socio-spatial arrangement, type of demented and non-demented residents in care, degree of separation of the demented and non-demented, programming, staffing, etc.?

3.) What is the relationship between non-demented residents’ experience of, response to, and recommendations concerning integration and the variables of their relations with others, i.e. numbers and types of contact and relationships with non-demented residents, numbers and types of contact and relationships with staff, family, friends, and others, social history within the nursing home, etc.?

4.) What is the relationship between non-demented residents’ experience of, response to, and recommendations concerning integration and the characteristic variables of demented residents, i.e. cognitive and...
physical impairment, sociability, aggressivity, mobility, behavioral and verbal appropriateness, family involvement, previous accomplishments, etc.?

5.) What kind(s) of separate living arrangements are desired by non-demented residents, i.e. what do they regard as the significant variables of nursing home arrangement and where do they draw the line across individual and concomitant variables to designate discreet levels of separation?

6.) What is the relationship between the willingness of non-demented residents of integrated nursing homes to recommend separation and their willingness to undergo relocation to a new nursing home or the renovation/reorganization of their existing nursing home to obtain that separation?

7.) What is the relationship between the variable of having demented friends and feeling satisfied with integration and recommending it as a policy?

To answer these questions methodological issues need to be addressed. A much larger scale study that not only expands the number of residents involved but more importantly employs rigorous sampling methodology to ensure a quantifiably representative sample would provide results with a much greater degree of reliability and validity. A
longitudinal study design would provide considerably greater depth of understanding of non-demented residents' experiences and recommendations concerning integration, since it seems reasonable to assume that they would change and evolve over time as residents consider placement, move into a nursing home, settle in, become long-standing residents, and approach death or discharge, and post-discharge.

Similarly, a qualitative study design would allow for a more complete capture of the subtleties of residents' views and feelings, thereby enhancing content validity. Qualitative study would also be more consistent with the client-centered model, since it would provide residents with a less mediating mechanism of expression, and, if conducted with sufficient sensitivity, might to a significant degree ameliorate residents' tendency to attest to socially appropriate views and feelings. One strategy might be to conduct a series of confidential dialogues with individual residents so that familiarity between researcher and resident is built up, and within the context of that mutual understanding a frank dialogue about the pros and cons of integration can occur. Residents may be more willing to share negative and/or emotionally charged views if given plenty of opportunity to explain the "bigger picture" of their values, experience, and rationale to someone
they feel has some sympathetic understanding of what life in a nursing home can be like.

Research is not apolitical. Conducting research within any organization about a particular issue highlights it and stirs the political waters around it, whether or not those effects are intended or acknowledged by the organization and the researchers. Researchers can either ignore/minimize these effects, or acknowledge/maximize them. To study integration within a nursing home, especially as it is regarded by non-demented residents, is therefore to encourage the entire nursing home community (residents, staff, family, volunteers, funders, etc.) to consider and talk about this historically contentious issue. Researchers of integration can either attempt to minimize the political dimension of their work by emphasizing the distance and disconnection between their knowledge-gathering activity and integration policy-making, or can maximize the political impact of their work by explicitly connecting the study being conducted to policy (re)formation. If depoliticization is desired, the goal, if not the effect, will be to reinforce the disempowerment of residents, and those who participate in the study of integration will need to be dealt with as individualized opinion givers whose role is to be studied. If, on the other hand, politicization is the goal, the study will need to incorporate ways of empowering residents
so that those who participate become active (and hopefully lasting) influencers of integration policy. This will require that residents be fully involved in the design, implementation, and information dissemination phases of the study.
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APPENDIX A

Questionnaire
Facility Living Study

Introduction

The purpose of this study is to find out what it is like for you to live with confused people, and what you think about confused people living with other residents. This information will be useful to facility planners and administrators seeking to provide the kind of facilities residents want to live in.

This is a confidential study. Your name will not be used. Participation is entirely voluntary. You are under absolutely no obligation to fill out the questionnaire, and may withdraw from the study at any time. Whether you fill out the questionnaire or not will have no effect upon your care here, now or in the future. It usually takes 15 minutes to complete the questionnaire, but you may take as much time as you need. If you complete the questionnaire and hand it in, it will be understood that your consent has been given and that you have voluntarily participated in the study.
Study staff are available to help you fill out the questionnaire and to answer questions. They are also available to discuss concerns or feelings the questionnaire may raise for you, and can suggest appropriate referrals.

Elaine Stolar, Associate Professor and Director of the University of British Columbia School of Social Work, is the Principal Investigator of this study. Glen Paul, Master of Social Work student, is the Co-Investigator. Elaine can be contacted at 822-2277, and Glen at 681-7890 for further information about the study.

Procedure

The questionnaire is made up of 16 questions. A range of possible answers to each question is provided. Simply choose the one answer to each question that fits best for you. There are no right or wrong choices.

Definition

Confused people may not be sure who they and other people are, what time of day and time of year it is, and where they are. They may have difficulty learning new things and understanding what is going on around them. They may say and do inappropriate things. All of us can be forgetful and can have some of these thinking difficulties some of the time. Confused people have most of these thinking difficulties most of the time.
SECTION A

These questions are about the kind of contact you may have with confused people here. For each question circle the one number that best fits your experience.

In the past week how many times have you seen, heard, or come in contact with confused people?

0 1 2 3 4 5 6 7 or more

In the past week how many times have you thought about confused people?

0 1 2 3 4 5 6 7 or more

How many confused people are you friends with?

0 1 2 3 4 5 6 7 or more
SECTION B

These questions are about ways living with confused people may affect you. For each question circle the one word that best fits your experience.

Never = none of the time
Rarely = less than 1/2 the time
Regularly = about 1/2 the time
Usually = more than 1/2 the time
Always = all of the time

How often do you avoid recreational or social activities because confused people are involved?

Never Rarely Regularly Usually Always

How often do you stay out of areas or common rooms because confused people are there?

Never Rarely Regularly Usually Always

How often do you find that mealtimes or other daily activities are disturbed by confused people?

Never Rarely Regularly Usually Always
How often do you find that your sleep is disturbed by confused people?

Never  Rarely  Regularly  Usually  Always

How often do you make an effort to avoid confused people?

Never  Rarely  Regularly  Usually  Always

SECTION C

These questions are about the ways living with confused people may make you feel. For each question circle the one response that best describes your feeling most of the time.

neutral = neither one way or the other

How happy does living with confused people make you feel?

very happy  somewhat happy  neutral  somewhat unhappy  very unhappy

How ashamed does living with confused people make you feel?

very ashamed  somewhat ashamed  neutral  somewhat unashamed  very unashamed
How uneasy does living with confused people make you feel?

<table>
<thead>
<tr>
<th>Very uneasy</th>
<th>Somewhat uneasy</th>
<th>Neutral</th>
<th>Somewhat at ease</th>
<th>Very at ease</th>
</tr>
</thead>
</table>

How optimistic about your future does living with confused people make you feel?

<table>
<thead>
<tr>
<th>Very optimistic</th>
<th>Somewhat optimistic</th>
<th>Neutral</th>
<th>Somewhat pessimistic</th>
<th>Very pessimistic</th>
</tr>
</thead>
</table>

How safe does living with confused people make you feel?

<table>
<thead>
<tr>
<th>Very safe</th>
<th>Somewhat safe</th>
<th>Neutral</th>
<th>Somewhat unsafe</th>
<th>Very unsafe</th>
</tr>
</thead>
</table>

How much do you like living with confused people?

<table>
<thead>
<tr>
<th>Very much like</th>
<th>Somewhat like</th>
<th>Neutral</th>
<th>Somewhat dislike</th>
<th>Very much dislike</th>
</tr>
</thead>
</table>

**SECTION D**

This question is about confused people living together with other residents in facilities. Which of the following arrangements would you recommend? Indicate your first choice by putting the number (1) beside it, your second choice with a number (2), etc. You may recommend as few or as many as you like.
___ Confused people live in entirely separate facilities.

___ Confused people live in the same facilities as other residents but in separate areas, and they do not mix with other residents.

___ Confused people live in the same facilities as other residents but in separate areas, and they mix with other residents for meals, activities, etc.

___ Confused people live in the same facilities as other residents in the same areas, and they mix with other residents for meals, activities, etc.

___ Other (please outline) __________________________________________

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Thank you for taking the time to complete the questionnaire. You may use the back of this sheet to make any further comments.
APPENDIX B

The University of British Columbia Office of Research Services

Behavioral Sciences Screening Committee for Research

Involving Human Subjects: Certificate of Approval
APPENDIX C

Vancouver Hospital & Health Sciences Centre
Research Advisory Committee Approval
APPENDIX D

Yaletown House Society Approval
APPENDIX E

Broadway Pentecostal Lodge Approval
APPENDIX F

Louis Brier Home & Hospital Approval
APPENDIX G

Consent Form
Study staff are available to help you fill out the questionnaire and to answer questions. They are also available to discuss concerns or feelings the questionnaire may raise for you, and can suggest appropriate referrals.

The questionnaire is made up of 16 questions. A range of possible answers to each question is provided. Simply choose the one answer to each question that fits best for you. There are no right or wrong choices. It usually takes 15 minutes to complete the questionnaire, but you may take as much time as you need.

__________________________________________
Signature acknowledging that your fully informed consent to participate in this study has been freely given.

__________________________________________
Signature acknowledging that you have received a copy of this consent form for your own records.

Date: ________________________________