Autonomy, in Context:
Understanding Preferences for Decision-Making Involvement
Among Long-Term Care Residents

by

Laura Megan Funk

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to the required standard

[redacted]
Dr. N.L. Chappell, Supervisor (Department of Sociology)

[redacted]
Dr. M. J. Penning, Departmental Member (Department of Sociology)

[redacted]
Dr. L. Gamroth, Outside Member (School of Nursing)

[redacted]
Dr. P. Mackenzie, External Examiner (School of Social Work)

Supervisor: Dr. Neena L. Chappell

ABSTRACT

Long-term care facility residents can be empowered by participating directly in care or medical decision-making. This can also enhance their emotional and physical health. However, research on preferences for participation in decision-making reveals that there is almost always some portion of individuals who do not want to be involved in medical and/or care decisions.

This research explores the predictors of the preferences of cognitively intact LTC facility residents to participate in decision-making, through the multivariate analysis of data from semi-structured, face-to-face interviews with 100 residents sampled from six LTC facilities in Victoria, British Columbia.

Generally, a large proportion of respondents reported preferring full, independent involvement in four types of care and medical decisions. Residents with higher levels of formal education, a greater number of chronic conditions, and who are confident about the worth of their input tend to prefer more active involvement in decision-making. This research also suggests that predictors of the desire for independent control over decision-making are different from predictors of a preference for joint decision-making.
Implications for the empowerment of LTC facility residents and the meaning of decision-making in such environments are discussed.

Examiners:

[redacted]
Dr. N.L. Chappell, Supervisor (Department of Sociology)

[redacted]
Dr. M. J. Penning, Departmental Member (Department of Sociology)

[redacted]
Dr. L. Gamroth, Outside Member (School of Nursing)

[redacted]
Dr. P. Mackenzie, External Examiner (School of Social Work)

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CHAPTER 1: INTRODUCTION

Provincial health reforms in Canada involve providing "opportunities for individuals to participate with service providers in making decisions on health choices and policies" (Mhatre & Deber, 1992: 655). Public participation and empowerment at a broad level involves input into policy decisions, health services development and management. Vertinsky and his colleagues (1974) term this "detached" participation, in contrast to individual empowerment through patient participation in health care settings. Empowerment involves having "the ability to control the factors that determine one's life" (Robertson & Minkler, 1994: 300). At the individual level, patients can be empowered through involvement in information sharing, self-care routines and treatment regimens: they can also in many cases participate directly in medical or treatment decision-making. In fact, in the World Health Organization's recent evaluation of the health systems of 191 member states, "the extent to which patients are encouraged to help make decisions about their care" is a key element of health system responsiveness (WHO, 2000). Research on doctor-patient interactions in primary health care settings emphasizes the importance of encouraging direct patient involvement in decisions such as choosing between alternative treatments (Krantz et al., 1980). This thesis addresses the preferences of long-term care facility (LTC facility) residents to participate in a variety of care and medical decisions, using the multivariate analysis of data from semi-structured interviews with cognitively intact residents sampled from six LTC facilities in British Columbia's Capital Health Region[1].

[1] In 2002, health care restructuring resulted in a merging of health regions into the Vancouver Island Health Authority. At the time of data collection, however, this was the Capital Health Region.

The health effects of a number of psychosocial factors have been acknowledged, including the benefits of perceived control and responsibility, and perceived competence or self-efficacy (Gecas, 1989; Haber, 1996; Langer & Rodin, 1976; Minkler, 1984; White & Janson, 1986). Policies and programs which facilitate participation by individuals in personal decision-making, boosting their sense of control and self-efficacy, are a means of enhancing emotional and physical health, and reducing stress and anxiety.

The analysis of three qualitative datasets by Norton and his colleagues (1996) highlighted the importance of autonomy as one of seven domains of importance to LTC facility residents. The Canadian Long-Term Care Association emphasizes the importance of empowerment and participation: in some homes, able residents are being encouraged to become involved in care planning decisions (Kane, 1990). Asmundson and colleagues' (1996) Client Centred Care Model (based on discussions with recipients of LTC facility care) involves providing the chance to participate in care-related decisions. In British Columbia's Community Care Facility Act, Article 9.3(5), states: "a licensee must encourage a resident to participate in the development and review of his or her care plan" (B.C. Community Care Facility Act, 1996). Similarly, the definition of care planning by the American National Citizen's Coalition for Nursing Home Reform (1999) includes "critical input from the resident and/or family members." In British Columbia, 88% of LTC facilities hold patient care conferences "as required" for residents, which is shortly after admission (Reid, 1996).

Increases in the size of the elderly population, coupled with a trend towards community-based home-care, means that residents of LTC facilities are now most often very elderly (80+) individuals with either cognitive impairment or extreme physical frailty. Because this research addresses decision-making preferences, its scope is

restricted to residents experiencing dependence and loss of autonomy due to a variety of physical disabilities and chronic conditions, yet who still retain the cognitive ability to make various decisions.

Empowering capable residents through involvement in care planning and decision-making about their care and/or medical treatment is not only valued for promoting physical and mental health, but also for enhancing the quality of care in LTC facilities, representing an essential element of the civil right to autonomy, and addressing power inequities (Ashworth et al., 1992; Asmundson et al., 1996; Minkler, 1983; Morris, 1997; Tulloch, 1995; Van Maris et al., 1996). The emphasis on the active involvement of LTC facility residents reflects a number of related developments, such as the resident rights movement, individualized nursing care philosophies, the self-care movement, nurse-patient negotiation, and movements to incorporate consumer interests and individual responsibility into health care provision (Avis, 1994; Biley, 1992; Brearley, 1990; Dean, 1992; Happ et al., 1996; Trnobranski, 1994). This trend towards increased decisional participation in LTC facilities, which is currently most prominent in rhetoric, is also based on the assumption that individuals want and/or benefit from being active participants within health care settings (Thompson et al., 1993).

While the results of research on decision-making involvement suggest that individuals generally value autonomy and participation, there is also research that reveals variation in individual desires for active involvement in medical and care decisions. For instance, studies of both acute care patients and LTC facility residents demonstrate that while the majority of individuals desire participation, there is almost always a portion that prefers to remain passive in the decision-making process, for a variety of reasons. In work by Dennis (1990), nine out of 30 hospitalized patients were not interested in participating

in decision-making; Blanchard and colleagues found that 31% of cancer patients preferred not to participate in therapeutic decisions. This is also evident in LTC facilities. The work of Wetle and her colleagues (1988) revealed that 38% of residents did not want to be involved in "Do-Not-Rescusitate" decisions. Such findings are common, although the proportion preferring non-participation varies depending on the particular definition of involvement employed by researchers and the population being studied. In a review of research on patient preferences by Benbassat and colleagues (1998), patients preferring passive roles ranged from 9% to 78% in various studies.

Without an adequate understanding of resident participation preferences, care providers face considerable uncertainty regarding the ethical and effective empowerment of individuals who prefer to avoid decision-making. For instance, uncertainty exists regarding "whether physicians should respect patients' preferences. . . [or] attempt to convince the patient to agree to a participatory relationship" (Benbassat et al., 1998: 86). Blair (1994-5) advocates encouraging reluctant residents to become involved in decisions and care planning, as does Haber (1994), who believes it is in a patient's best interest to be informed and involved. However, decisions made under the encouragement of care providers may be inauthentic representations of resident autonomy; individuals involved despite reluctance may express invalid treatment preferences, in much the same way as informed consent lacks validity when an individual only reluctantly agrees to participate (Collopy, 1988; Waterworth and Luker, 1990). Respect for autonomy would require that individuals be free to choose their own levels of participation and control, and that preferences for involvement be respected (Happ et al., 1996; Wetle, 1991). The issue of preferences for participation is often ignored in the trend towards autonomy and individual decision-making rights (Moody, 1988), yet it has been argued that whether

individuals actually want to have their views taken into account should be a key concern in the process of eliciting patients' views (Sensky & Catalan, 1992). However, respecting personal preferences raises another concern: what if personal preferences for involvement are largely the outcome of socialized expectations? For instance, patients accustomed to a health care system in which non-participation has traditionally been the norm may appear to prefer non-participation. If these individuals are, as a result, not offered the chance to participate or are not encouraged to do so, a "Catch 22" situation has been created (Brearley, 1990).

Such ethical issues concerning empowerment in LTC facility settings continue to re-visit care providers. In addition, resident desires for control and involvement may affect the efficacy of empowerment interventions: some individuals may benefit more from active participation, while for others involvement may actually be a source of stress or discomfort (Clark, 1988; Krantz et al., 1980; Rodin, 1986; Smith et al., 1984). The latter effect is of particular concern among frail elderly residents of LTC facilities, many of whom are already experiencing a high degree of pain, discomfort, and emotional distress.

While previous research has explored the diversity of preferences for decision-making, most focuses on acute care, short-stay patients (Wetle, 1991); it is also limited to medical and "big ticket" (i.e. major, important) decisions, such as advance directives or the decision to have surgery. There is some research on the participation preferences of patients with cancer, but this research is based in an acute-care framework with an emphasis on newly diagnosed patients, the life-threatening nature of the disease, and the personal crisis associated with diagnosis. For instance, the discussion of denial as a coping strategy is more relevant for examining the participation preferences of those with

a sudden or imminently life-threatening condition than for elderly residents facing deteriorations in quality of life and function within the context of an institutional facility. Less is known about the participation preferences of long-stay patients with chronic conditions, particularly institutionalized elderly with high levels of chronic illness, frailty, and physical disability. For this group, understanding desires for involvement in non-medical care decisions appears equally as important as medical decisions. Predictors of preference for involvement may also differ markedly between long-term residents and short-term hospital clients.

Quantitative research by Terrie Wetle and her colleagues (1988) is an important contribution to the understanding of participation preferences. It is one of very few studies that consider LTC facility residents specifically, rather than medical patients. In their work, predictors of preferences for non-involvement in medical decisions among the institutionalized elderly included older age and immigrant status. However, only medical decisions were addressed, and the predictors included were not comprehensive. In fact, the majority of the research on preferred decision-making involvement focuses on socio-demographic and illness variables, which may leave as much as 80% of variation in involvement preferences unexplained (Benbassat et al., 1998).

This research project is a more comprehensive exploration of factors explaining participation preferences, based on theoretical and empirical literature. It also addresses a greater variety of care and medical decisions in an attempt to identify predictors of the desire for active decision-making participation and responsibility among LTC facility residents. This exploration involves multivariate analysis of data from semi-structured interviews with cognitively intact residents sampled from six LTC facilities in British Columbia's Capital Health Region.

An enhanced understanding of variation in resident preferences for decision-making involvement is important for informing the development of programs and policies to enhance autonomy. This research will also alert providers to the potential for problems in empowerment through decisional participation, such as coercion, a lack of attention to the authenticity of decisions made by individuals who are 'reluctant collaborators' in decision-making, and instances where individuals may be overwhelmed or uncomfortable with decision-making responsibility (Ashworth et al., 1992; Biley, 1992; Collopy, 1988; Dennis, 1990; Waterworth & Luker, 1990; Wetle et al., 1988). Lastly, this project will inform the conceptual understanding of decision-making, participation preferences, and the complexity of the person-environment dynamic.

The following chapter outlines the theoretical and empirical literature that forms the background for this thesis, discussing both previous research on decision-making participation preferences, and research on the institutional context which is relevant to understanding these preferences. Research questions are described at the end of this second chapter. The third chapter outlines the methods and procedures for collecting and interpreting the data utilized in this research. Results are presented in chapter four and key findings discussed in chapter five, along with discussion of the contribution and policy implications of the research.

CHAPTER 2: REVIEW OF THE LITERATURE

The following is a review of the literature on LTC facilities, autonomy, and decision-making preferences that informs this research. Key factors affecting preferences for decision-making involvement and the mechanisms through which these factors operate to either enhance or diminish interest in decision-making involvement are addressed. This review incorporates theories of decision-making preference, the effect of institutionalization, secondary control, the sick role, and the phenomenology of illness experience.

2.1 Conceptualizing decision-making participation preferences

"Decision-making," as defined by High and Rowles (1995: 102), is the "**act** of making a choice, reaching a conclusion, or making a judgment on an issue under consideration." It has also been defined as a **process** "by which people make choices among alternatives" (Lewis et al., 1997: 390). A variety of stages in the decision-making process offer opportunities for involvement, ranging from the initiation of the decision to the disclosure of information, the discussion of alternatives and evaluation, to actual decision-making and responsibility for outcomes (Everard et al., 1994; Guagnoli & Ward, 1998; Strull et al., 1984). In addition, involvement can also be initiated after the initial treatment decision is made (such as in the implementation of the decision), or can include involvement in care routines directly, or self-care (Degner & Beaton, 1987; Strull et al., 1984). There is therefore no standard definition of decision-making involvement, but rather a multitude of meanings that can be (and are) attached to the concept by individuals and by researchers (Allhouse, 1993).

As a distinct concept of its own, decision-making participation *preference* (in a health-care setting) is related to two groups of literature. In the first type of literature, authors discuss patient "participation preferences," focusing on professional-patient relations and interactions, consumerism, and individualized care. This research tends to examine socio-demographic and illness predictors and deliberates on the technical knowledge required to make health-care decisions (Cassileth et al., 1980; Guadagnoli & Ward, 1998; Strull et al., 1984; Thompson et al., 1993; Vertinsky et al., 1974).

Another type of literature, primarily psychological in nature, is also relevant to a discussion of participation preference, sometimes referring to it as the "desire for control" of process and/or outcome. This literature includes works that emphasize the importance of control-enhancement and perceptions of control. It draws attention to cognitive and behavioural coping and control strategies, often acknowledging both active and passive forms of control (Rodin, 1986; Rothbaum et al., 1982; Shaw, 1992; Smith et al., 1984; Woodward & Strudler-Wallston, 1987).

Many authors use both "the desire for control" and "the desire for involvement" or participation interchangeably (for instance, Degner et al., 1997). Active involvement in decision-making is one of a few ways that individuals can regain or maintain a sense of control during illness or a situation that threatens this sense of control. In addition, while control does not necessarily derive from active participation, neither does participation always result in an enhanced sense of control, for all individuals, in all situations. The nature of the participation and its context are important considerations in this respect.

Keeping this in mind, the desire for control is discussed simultaneously with participation and involvement preferences in this thesis, in reference to individual preferences for an active, goal-oriented, primary control *in decision-making*; actual

decisional authority (i.e., the "final say") is considered as a particular form of involvement in decisions. It could be argued that the desire for decisional authority or control has less relevance within a long-term care context, where consent is often "negotiated" (Moody, 1988). Yet if decisional control is actually an empowerment goal that providers hope to implement or promote, then knowing what residents might actually want, if offered the opportunity (and why) is an important topic for exploration. Additionally, even in a joint decision-making situation, there may be one individual with primary responsibility for the end decision (High & Rowles, 1995). Lastly, seniors themselves have identified the importance of control over decisions and empowerment as important elements of autonomy (Hofland, 1988; Raymond & Wentworth, 1993).

While some conceptualizations of involvement preferences may include the desire to be informed, many researchers view preferences for information as a factor related to, but conceptually separate from, preferences for involvement (Beisecker & Beisecker, 1990; Benbassat et al., 1998; Krantz et al., 1980; Strull et al., 1984). These two factors can be seen as two distinct ways to gain control (Dennis, 1990; Hack et al., 1994). Similarly, it may be that "many patients may actively seek information to satisfy an aspect of 'psychological autonomy' that does not necessarily include participation in decision making" (Sutherland et al., 1989). While there are strong associations between the desire for information and involvement (Cassileth et al., 1980; Hack et al., 1994), a conceptual distinction is further supported by research showing that more patients desire information than actually desire participation in decision-making (Allshouse, 1993; Blanchard et al., 1988; Ende et al., 1989; Strull et al., 1984). In the interest of simplicity and manageability, this research focuses on preference for involvement in decision-making, in

terms of control over outcomes or a decisional choice between alternatives, rather than the desire for information (Krantz et al., 1980).

In this thesis, it is also recognized that decision-making participation preference is not simple and linear; it is multidimensional and complex, varying in individuals over time, with experience, and between types of decisions (Allshouse, 1993; Benbassat et al., 1998; Hack et al., 1994). For instance, the nature of the decision affects the desire to be involved: patients tend to prefer more involvement in less technical decisions (Biley, 1992). Deber and her colleagues (1996) have argued for a distinction between "problem-solving" tasks (which usually require medical expertise and for which there is often only one best solution), and "decision-making" tasks (involving a choice between possible alternatives), for which individual desires and values are particularly salient. Research confirms that individuals are more likely to desire involvement in the latter kinds of tasks, which often have personal relevance, such as in terms of the acceptability of risks and benefits (Deber et al., 1996; Guadagnoli & Ward, 1998; Thompson et al., 1993).

2.2 The implicit continuum of decision-making participation preferences

Previous research on desired involvement in decision-making implicitly promotes a particular conceptualization of decision-making involvement preferences as a continuum through passive, collaborative and active levels of involvement. This continuum encompasses the desire to have no involvement in the decision, the desire to be consulted for input or to consult others, the desire for joint decision-making, and the desire to have the final say in the decision. Hack and his colleagues (1994) identify passive, collaborative and active role preferences; Degner and her colleagues (1997) discuss keeping, sharing or giving away control; and Dennis (1990) categorizes

respondents into patient, interdependent-participative, and self-reliant role preferences. All three studies subscribe to a continuum that relegates joint decision-making to somewhere in the middle between true passive and true active forms of involvement. This is based on the assumption that collaboration is somehow not quite "real" autonomy.

When exploring decision-making participation preferences in the long-term care environment, it can be argued that the conceptualization of decision-making participation should be applicable and relevant to this context. One important consideration is the salient role of family members in decision-making in LTC facilities (High & Rowles, 1995; Lewis et al., 1997). Degner and Sloan's (1992) qualitative research identifies dimensions of provider, patient and joint control in decision-making, yet also a separate dimension of family control. In addition, Collopy (1988), Wetle (1991), and others have discussed the right to "delegate" or "extend" autonomy to others. Traditional conceptualizations of individualistic personal autonomy neglect this important extension of autonomy, which is particularly salient for residents in deteriorating health (High & Rowles, 1995). Awareness of extended autonomy (and degrees of family involvement, from decision-making assistance through full responsibility) as a valid means of involvement in decisions could be incorporated into conceptualizations of decision-making preference, or a new model may be more appropriate. For instance, a shared decision-making model of negotiated consent might be justified by a reported lack of desire of many older patients to participate within an individualistic or lone autonomous figure model (Kapp, 1981). Work by Cicirelli (1992) considers an ordinal ranking of sub-types of autonomy based on a dimension of involvement by others in care decisions. While the author maintains that his conceptualization promotes the awareness of other types of autonomy, it is noteworthy that increasing involvement by others in decisions is

seen as lowering the level of individual autonomy, which is indicative of the continuum that conceptualizes collaboration between passive and active participation (Cicirelli, 1992).

Decision-making implies a choice between alternatives (Lewis et al., 1997). In a long-term care context, however, outcomes often involve the interests not only of the resident, but of care providers, other residents, and family members. This narrows the range of options in a given decision-making task. In fact, it has been argued that in a long term care context, resident consent is most often "negotiated." Multiple views and concerns are heard and reconciled, there is wide consultation with a variety of actors, and no one party has exclusive power of decision-making (Everard et al., 1994; Moody, 1988). According to High and Rowles (1995), however, there is usually one individual, often the facility administrator, with ultimate authority for the final decision. The existence of a final authority or decision-maker likely depends on the type of decision involved and the process of decision-making promoted within a particular institution.

Incorporating the complexity of decision-making involvement in a LTC facility environment may involve conceptually distinguishing preference for active involvement from preference for joint decision-making. Rather than a continuum through passive, collaborative and active levels of involvement (relegating joint decision-making to the middle of true active and true passive forms of involvement), another possible continuum encompasses the desire to have no involvement in the decision, the desire to be consulted for input or to consult others, and the desire for joint decision-making. For instance, while research by Beaver and her colleagues (1996) supported a dimension of passive-collaborative-active or control preferences, the authors also found another, albeit weaker, subscale in their women-only sample. This different dimension was that of sharing vs.

extremes: in other words, some women "were choosing all the roles that involved some degree of collaboration as preferential to those that involved no collaboration at all" (Beaver et al, 1996: 15). In this thesis, the conceptualization of decision-making preferences is one that distinguishes between the desire for active involvement (the primary focus of this research) and the desire for joint decision-making, and addresses them as two separate continuums.

Ultimately, the problem of the conceptual relevance of autonomous decision-making (active involvement) within LTC facilities reflects a discrepancy between the rhetoric of control and empowerment and its relevance within the context in which it is implemented. For instance, while management philosophy often espouses a commitment to resident rights and individualized care, the actual "implementation of care more often focuses on time and task management in which residents are expected to comply with routines perceived to be most efficacious for staffing and completion of tasks" (Tolley, 1997: 11). In this context, the reality of active involvement as full, independent control over decisions may not exist. This discrepancy points to the need to consider resident expectations about the reality of participation in the home as a potential predictor or correlate of preferences for participation. The conceptual relevance of both preference for active participation and preference for joint decision-making within the LTC context will be addressed further in the discussion.

2.3 Resident characteristics: previous research on predictors of preferences

An individual's preferred level of involvement in decision-making is influenced by a number of personal characteristics and life experiences with which he or she interprets the institutional experience. Personal values and expectations about the meaning of care as involving a trade-off of autonomy and an acknowledgement of dependence are important considerations (Ashworth et al., 1992; Trnobranski, 1994; Wetle, 1991). While it could be argued that these values are detrimental for perceived control, some individuals may have a personal desire to be relieved of the burden of responsibility for care decisions (Wetle, 1991; Wetle et al., 1988).

2.3a Acute and chronic illness experience

Physical illness acts as a stressor, and is associated with uncertainty, loss, anxiety and fear. It has been suggested that these and related psychological and emotional effects, such as an enhanced need for trust, can combine to reduce one's desire for personal control or active involvement (Anderson, 1996; Donaldson et al., 1991; Lupton, 1997; Waterworth & Luker, 1990). In other words, for many individuals, coping with illness or disability involves secondary control strategies and subordinating oneself to a professional authority figure, rather than exhibiting active consumer behaviour (Lupton, 1997; Rothbaum et al., 1982). Viewed from this perspective, dependency and a need for trust are rational responses to illness and associated distressing emotions, and are central features of the illness experience (Lupton, 1997). Resulting emotional dependence is not induced by the context, but rather, is sought from the context of the health care interaction because of the loss of control and emotional states involved in illness or disability (i.e. it is a psychological, not a sociological phenomenon). The context, however, including

interaction with others and institutional arrangements, can be influential in the illness experience (i.e. can also be viewed from a sociological perspective), and this will be addressed at a later point in this chapter.

Research generally shows that preference for an active, participatory role in acute-care medical decisions decreases with increasing severity of illness (Benbassat et al., 1998; Biley, 1992; Catalan et al., 1994; Ende et al., 1989). This process may be best explained by individuals' "perception of the severity of disease" rather than by objective disease variables (Sensky & Catalan, 1992: 1109). A great deal of the research concerning the psychological response to illness and the effect of illness severity on patient preferences for participation involves acute care situations and short-term hospital patients, and it remains to be seen how the issues mentioned here operate among those with long-term chronic illness and functional disability.

Those facing the harsh realities of living with chronic illness, disability, pain and/or other elements of poor physical health may particularly prefer to be relieved of decision-making responsibility. Studies of the phenomenological experience of chronic pain demonstrate how chronic illness and pain absorb individuals' attention and preoccupations, shaping their realities in ways that differ significantly from the lives of those in good health (Good, 1994). Physical and emotional resources are consumed, everyday life goals are subverted, and former self-images and "life maps" are lost (Anderson, 1996; Good, 1994; Marmoll-Jirovec & Maxwell, 1993). Under these conditions, it is understandable that decision-making may become less of a priority. During flare-ups or on particularly bad days, an individual may prefer that others make decisions about his or her care or treatment. The energy required to participate actively in decision-making may be lacking for individuals experiencing illness or pain; even the

most independent people may change their perceptions, and their preferences for active involvement, when faced with illness.

Thompson and his colleagues (1993) found that among a sample of HMO members, those who had chronic conditions tended to prefer less participation in decisions than those without chronic conditions. In addition, an increase in physical or functional dependency has been associated with a decrease in desired control over aspects of living (Marmoll-Jirovec & Maxwell, 1993). It has been suggested that LTC facility residents may attempt to "match" their involvement in decisions with declines in their perceived physical abilities (Marmoll-Jirovec & Maxwell, 1993). However, contradictory findings are also evident. For instance, whether chronic illness "fits" with an acute care "sick role" has been questioned (Turner, 1995); additionally, data from an observational study of hospital patients by Lidz and his colleagues (1983) reveal that patients with chronic diseases tend to be more active than patients with acute conditions.

2.3b Socio-demographic factors

The extent of one's personal experience with decisions in a medical or care setting, and one's experience of control throughout the life course, are examples of individual-specific factors related to the desire for active involvement in decision-making. For instance, it may be that residents with nursing backgrounds may be more likely to desire involvement in care decisions. However, many life experiences are also structured by group-specific characteristics, such as age, cohort, gender and culture.

While Hack and his colleagues (1994) did not find an effect of age on preferences for participation in medical decisions, the majority of other researchers have found a negative relationship of age with a desire for active participation; those at older ages tend

to want less active involvement (Benbassat et al., 1998; Catalan et al., 1994; Degner & Sloan, 1992; Ende et al., 1989; Strull et al., 1984; Wetle et al., 1988). Cassileth and his colleagues (1980) noted this effect while controlling for education.

While it has been suggested that some kind of developmental effect may lower the desire for involvement in decision-making over the life course (Beisecker, 1990), individuals' experiences living in an ageist society, or generational experiences (i.e. growing up in a time with different values) are equally plausible explanations. Both of the latter processes affect one's confidence in his/her ability to contribute to decisions and the appropriateness of doing so. For instance, the elderly, by virtue of exposure to the ontogenic fallacy equating "being old" with "being sick," may be particularly exposed to sick role beliefs and assumptions (Stahl & Feller, 1990). This may foster the belief that participation in planning one's care is inappropriate behaviour for a LTC facility resident (Trnobranski, 1994; Wetle, 1991). Indeed, passive behaviour more generally in institutions may, to some extent, reflect ageist stigmas and labeling which are internalized by elderly residents into their perceptions of self and their role (Agich, 1990; Cohen, 1988; Weinberg, 1987). This process starts prior to institutionalization, but it may continue and be exacerbated within LTC facilities. Additionally, today's cohort of seniors (because of previous experiences in a historically paternalistic health care system), may tend to defer to the authority of health care providers, and have less confidence in their knowledge compared to professional expertise.

Gender might also affect participation preferences. An overall lack of experience and/or comfort with "having the final say" may exist among older cohorts of women who have traditionally had little participation in family decisions due to women's subordination in a paternalistic society. However, care decisions in institutions often

concern issues or activities with which many elderly women are traditionally familiar, such as caregiving. These women may desire a **greater** say than men in their own care and treatment. It does appear that **men** are more likely to want to remain passive in decision-making, at least in hospital settings (Benbassat et al., 1998; Larsson et al., 1989); in fact, men's wives may assume an active position on their behalf, because women have traditionally been the "brokers" of the health care system (Blanchard et al., 1988). In a study by Vertinsky and his colleagues (1974), women were more likely to take active measures in response to anxiety in a clinical situation, perhaps reflecting greater concern or interest in health problems and health care. Gender differences in the desire for control among LTC facility residents may also reflect a qualitatively different experience of institutionalization for men and women. However, no effect of gender was identified by Thompson and his colleagues (1993), or by Wetle and her colleagues (1988): gender differences remain to be determined conclusively.

Higher levels of education have been associated with the desire to be involved in medical and treatment decisions (Benbassat et al., 1998; Cassileth et al., 1980; Sensky & Catalan, 1992; Strull et al., 1984; Thompson et al, 1993). One's level of formal education may affect the perceived worth of one's participation and expertise: "well-educated patients were more likely to have more illness-related knowledge or, at least, have the ability to determine the kind and amount of information they needed to make informed, rational decisions" (Hack et al., 1994: 287; Ashworth et al., 1992). It has also been suggested that exposure to psychosocial risk factors and low self-efficacy is greater among those with lower educational levels. Additionally, education can be seen as a proxy for socio-economic status, which is associated with perceived control and self-efficacy.

Illness and physical disability, age, cohort, gender and education might all contribute to some degree to an individual's preference for an active position in decision-making. It should be remembered, however, that these factors still leave a large proportion of variance in decision-making involvement preferences unexplained (up to 80%: Benbassat et al., 1998). In addition, in one of the only quantitative studies on involvement preferences among nursing home residents, neither the seriousness of illness, gender nor education showed significant effects (Wetle, 2000: personal communication). The next section addresses a possible key to explaining more variation in individual participation preferences: specifically, factors related to the health care system and the social and organizational context of interactions (Trnobranski, 1994).

2.4 Psychological processes from a sociological perspective: the context of decision-making

Below, the psychological manifestations of contextual, societal and institutional factors are detailed in an explanation of how the context of everyday life for the institutionalized elderly might affect their desire to be involved in decisions.

Expressed participation preferences, as described by Benbassat and his colleagues (1998), are closely related to realistic expectations and to normative assumptions about involvement. In fact, they are so related that distinguishing between these elements is methodologically problematic (Strull et al, 1984). Measurements intended to elicit residents' hopes for "an ideal state of affairs" may actually measure residents' expectations about how decisions are usually made, realistically, or their assumptions about appropriate role behaviour among LTC facility residents (Benbassat et al., 1998).

Realistic expectations and role assumptions are themselves significantly structured and influenced by the particular health care context or environment. However, studies on preferences for involvement, even in hospital or other health care settings, rarely focus on the role of the environment in shaping individual expectations and assumptions, or the effect this may have on the desire for active involvement in decision-making. This is surprising, given that socio-demographic and health variables may leave as much as about 80% of [variation in decision-making role preferences] unexplained (Benbassat et al., 1998: 85). Rather, unexplained or remaining variation is usually speculatively attributed to personal coping styles and "personality-based expectancies and beliefs" about control (Ende et al, 1989; Krantz et al., 1980; Rodin, 1986). This reveals an underlying theoretical assumption in much of the previous research, namely that individual preferences are individual-specific, rather than contextually-structured.

The role of the environment in structuring role identity, control beliefs, and coping strategies is worthy of attention, particularly for research on resident preferences and attitudes in LTC facilities. Some authors have suggested the possible role of the health care context generally in influencing individual preferences for control or participation. What appears as a lack of interest in decision-making may be a response to extensive and ongoing interactions, experience and socialization within a health care system that tends to limit participation and control (Brearley, 1990; Davison et al., 1995; Degner & Russell, 1988). An unwillingness to be involved has also been related by Trnobranski (1994: 735) to the "social and organizational context of the interaction" and paternalistic philosophies and hierarchies within institutions; and by Wetle (1991) to institutional settings that promote low self-efficacy and a lack of power in decision-making. Work by O'Connor and Vallerand (1994) and Mor and his colleagues (1995)

link resident perceptions of the actual degree of self-determination and flexibility in an institutional living environment to motivation for activities or behaviours within health care institutions. Further, in an observational study of hospital patients by Lidz and his colleagues (1983: 542), in-patients were much less likely to participate in decision-making than outpatients, possibly due to "regression and emotional dependency that develops in patients when they enter the hospital." In a study by Smith and her colleagues (1984), the authors (citing evidence that hospitalization leads to a loss of control) even assume that choosing to die in a hospital as opposed to a hospice or at home indicates "relatively less desire for control."

The organizational culture and structure of LTC facility environments combine to significantly structure resident experiences and shape beliefs, perceptions and expectations in ways that are relevant to autonomy and involvement. Assumptions made about the reasons behind variation in individual preferences for involvement affect care providers' reactions to expressed lack of interest in involvement. If personal idiosyncrasies are assumed to be the explanation, care providers might provide individualized assessments and respond to individual preferences (Beaver et al., 1996). However, if some patients are expressing preferences for non-participation simply because they are not usually offered participation within a health-care context (such as LTC), the above response on the part of providers may simply maintain the existing situation and do little to alter individual preferences for participation (Brearley, 1990).

2.5 The institutional context

A combination of factors related to institutional life and the provision of care create an organizational context in which long-term care residents are traditionally denied control or autonomy in decision-making. The most widely cited theorist in respect to the effects of institutional life is Erving Goffman, and others have used Goffman's work to argue that the dependency fostered by institutions represents an iatrogenic effect (Foldes, 1990; Lidz & Arnold, 1990). According to Goffman, a total institution is an organization "of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, 1961, xiii, quoted in McEwen, 1980). In fact, much research "suggests features of total institutions are hard to overcome," particularly in the actual implementation of care (Clark & Bowling, 1990).

Many authors assume that LTC facilities are total institutions (Goffman, 1961; Kane, 1990; Lidz et al., 1992; Ryden, 1985; Swain & Harrison, 1979). For instance, residents represent a segregated community, are treated alike in a group context, lack privacy and autonomy, and have a tightly scheduled, narrow range of activities. As a result, they tend to lose interest in individual commitments, values and goals, and lose identification with their actions; physical and mental dependence are promoted (Clark & Bowling, 1990; Kenny, 1990; Lidz & Arnold, 1990). Life in this institutional environment creates a distance between residents and staff, who "tend to conceive of one another in terms of stereotypes" (Kane, 1990: 27). In addition, individuals entering the facility are exposed to a re-socialization process whereby they adopt new identities as residents, identities that are subtly reinforced through defined roles (Kenny, 1990; Manning, 1992). These aspects of institutionalization may be exacerbated in a LTC

facility context by the strong presence of the medical model, which contributes to additional regimentation, dependency and stereotyping (Kane, 1990; Wetle, 1991).

In observational work by Clark and Bowling (1990: 1201) in two nursing homes for the elderly and a geriatric hospital ward, "only the ward setting conformed closely to Goffman's concept of the total institution." In addition, Kane (1991) argues that while LTC facilities do constrain autonomy, they are still not quite "total institutions." A more useful analytic approach, however, might consider degrees of conformity to the concept. There may be meaningful variation among different LTC facilities that affects resident dependency and desires for involvement between facilities.

Currently, however, there appears to be little consensus on what might differentiate total institutions, particularly "in ways important to understanding their differential impact on members" (McEwen, 1980: 152). Size might be one important element: larger facilities, for instance, may more closely conform to the fully "total" institution (Clark & Bowling, 1990). Timko and Moos (1990), however, found no effect of the number of residents on either resident or staff perceptions of resident influence or responsibility in the home, and they conclude that larger homes are no more regimented than smaller homes. Additionally, in research by Higgs and his colleagues (1998: 204), size was not significantly associated with resident satisfaction with autonomy, although to some extent, "fewer residents in smaller nursing homes wanted more say in the way their homes were run." These authors also compared nursing homes and hospital long-stay wards (the latter presumed to have greater "institutionalizing capacities"), and found high levels of satisfaction in both environments. While one possible measure of meaningful variation between institutional environments, size is also problematic because with

increasing organizational differentiation, facility units or floors might be more appropriate units of study, adding to the complexity of research (McEwen, 1980).

Bennett and Nahemow (1965) outline a continuum of the degree of institutional "totality," whereby high totality is associated with the following elements: a permanent residence design; activities which occur within the institution and are scheduled sequentially for everyone; formal indoctrination periods (concerning good vs. bad conduct); continual observation by staff; standardized objective rewards and punishments; residents barred from making decisions about their time or property; most personal property is removed; residents are recruited on an involuntary basis; and congregate living is the primary residential pattern. Similar criteria have been proposed by Davies (1989), and include the degree of openness versus closed-ness (i.e. can residents leave at will or are they constrained with force and physical barriers?), the extent of formal administration, the dominant mode of compliance, and the avowed institutional purpose. Regarding the work of Bennett and Nahemow, McEwen (1980: 150) notes: "although this kind of scale could well have served the needs of other researchers . . . who argue that total institutions lie along a continuum, it has remained unused." These and/or other aspects highlighting the extent of flexibility, regimentation, rigidity, and individualization might be useful in distinguishing between LTC facility environments. McEwen himself (1980: 154) suggests considering the following dimensions of variation: scope, or "the degree to which the organization sponsors or provides the context for its participants' social relationships"; the voluntariness of membership, the amount of surveillance of resident activity, the extent of hierarchy and social distance between staff and residents, the amount of staff consensus "about work

goals and practices (157), and the degree of participation by residents in organizational decision-making and organizational tasks (individually and collectively).

The purpose of looking at these kinds of differences in the institutional environments of LTC facilities, as mentioned by McEwen (1980), is to facilitate the study of the differential effects of institutions on residents. In this thesis, the focus is on understanding participation preferences and factors that may relate to these preferences within LTC environments. The potential influence of the LTC context on socialization, coping and adjustment, and the effect of these on the desire for participation in decision-making are described in the following review.

2.5a Role expectations: is participation in decisions appropriate for a resident?

As mentioned, measurements designed to tap into how individuals feel decisions should be made may reflect normative anticipations about socially endorsed roles as the result of socialization. Socialization represents group processes "which make members comply with rules for behaviour in the group" (Nystrom & Segesten, 1994: 126). It is notable that at least among the general population, there appears to be an association between responsiveness to social norms, or a tendency to respond in a socially desirable way, and lower preferences for involvement or control (Smith et al., 1984: 422). This suggests a relation between social role conformity and a lowered desire for participation.

While individuals have expectations and beliefs about care before their entry into a facility, these expectations and beliefs may be fundamentally shaped by the institutionalization experience and re-socialization into a resident role. Non-participation, at least in an institutional environment, might reflect role conformity and learned

expectations. Those with more traditional assumptions about the role of a person receiving care may be uneasy about being asked to actively contribute to decision-making, because this violates their beliefs about how things should be.

Cohen (1988) has argued that autonomy is primarily determined by one's perceptions of self and one's appropriate role. Roles consist of "typified expectations and typified responses" defining patterns of actions, emotions and attitudes; roles shape actors (Berger, 1963). They are socially defined sets of norms, usually with some attention to the status associated with a role. The sick role, described by Turner (1995), is a functional deviance that legitimizes social withdrawal from roles and responsibilities, and encourages cooperation with professionals to facilitate recovery. Sick role conformity may affect one's beliefs about the appropriateness of certain behaviours in a medical setting. Observations of decision-making in hospital settings have revealed that many patients believe that decision-making is the physician's task (Lidz et al, 1983). In addition, Degner and Sloan (1992) suggest that learned role expectations (among even newly diagnosed cancer patients) might partially explain the desire to leave treatment decisions with physicians. Although Turner (1995) has argued that the sick role is not applicable to the old and chronically ill (for whom compliance and submission do not necessarily lead to recovery), other authors maintain that the sick role is promoted in an institutional setting, and is to some extent adopted by LTC facility residents (Allshouse, 1993; Solomon, 1982; Tobin, 1995). Ultimately, however, a "resident role" is perhaps a more appropriate concept capturing the variety of expectations associated with living in an LTC facility setting. Some of these expectations include dependency and compliance, closely related to the sick role and to concepts of "good patients" and "bad patients" in

hospitals, because LTC facilities are modeled after hospitals and reflect a bio-medical perspective (Kane & Caplan, 1990; Wetle, 1991).

Allshouse (1993), in discussing hospital settings, notes that at a basic level, the traditional rules and regulations and standard operating procedures of health care institutional facilities foster the passivity and submission found in the sick role. LTC facilities may also (unknowingly) promote dependency and conformity to a resident role in a similar fashion. The constraints on resident participation in everyday living activities in LTC facilities can fuel the assumption that non-participation is appropriate.

Research on satisfaction needs to be interpreted with caution: high levels of satisfaction with levels of involvement, identified by Larsson and his colleagues (1989), may really reflect an underlying cultural fit or balance: "patients have the influence they expect and consider natural" (833). In an institutional culture of "total care," both residents and staff often assume that all aspects of a resident's life are under the authority and administration of staff, or that entry into the facility means passing responsibility to others (Avis, 1994; Clark, 1988; Morris, 1997). This facilitates a "resident role." The adoption of a dependent and compliant resident role has also been attributed to a process of coping with a loss of control and depersonalization within the institution, which will be discussed at a later point (Taylor, 1979).

2.5b Confidence and outcome expectations: can I contribute meaningfully, and will my participation make any difference to the outcome?

An antecedent of participation, conceptualized as social interaction, is that an "individual sees himself or herself as having the right to speak and be listened to" (Ashworth et al., 1992: 1435). If a LTC facility resident places little worth in his or her contribution, and has little confidence in his or her ability to contribute meaningfully to decision-making, he or she may feel uncomfortable with active involvement. As a result, residents may express lower levels of desired control in care and medical decisions, preferring to place more trust in the opinions of staff and/or family members. In fact, it has been suggested that "nurses' efforts to engage the patient in her own care can easily be a source of bewilderment and may even be taken by an individual who doubts her worthiness to contribute as evidence of the nurse's lack of care" (Ashworth et al., 1992: 1436).

Residents' assessments of their abilities to participate may be affected by their acceptance of the sick role and their beliefs about the knowledge required to make a decision. The technical nature of the decision, therefore, may affect confidence appraisals for that particular decision, and educational levels might affect confidence appraisals across all decisions (Avis, 1994; Biley, 1992; Deber et al, 1996; Thompson et al, 1993).

Institutionalization has been associated with a lowered perceived capacity for self-care among residents (Tobin, 1995). The lack of privacy, individualized care and opportunities for self-determination in many LTC facilities might promote a loss of feelings of competency and self-esteem among residents, and related changes in self-views (Foldes, 1990; Wetle, 1991). Similarly, for Nystrom and Segesten (1994), self-confidence is an antecedent of power, yet for LTC facility residents, feelings of

powerlessness stemming from the environmental context serve to lower resident confidence. Enhancing autonomy in "everyday" or micro decisions about care may increase a resident's "sense of confidence and mastery necessary to advocate for involvement in the 'macro' issues" (Wetle, 1991: 286). In addition, just as sick role beliefs may affect one's perception of the value or worth of one's contribution in a decision-making situation, socialization into a passive resident role and the internalization of resident stereotypes might also lower residents' beliefs in their abilities to participate. In fact, confidence tends to be eroded within health care situations more generally, due to power and status differentials (Ashworth et al., 1992).

People judge not only their own ability to achieve an outcome, but also whether they think their efforts will actually produce the desired outcome; that is, whether they "can be efficacious in [their] environment" (Gecas, 1989; Haber, 1994). Outcome expectations are identified by many theorists, notably by Bandura (1986) in research on self-efficacy (Gecas, 1989). Gecas (1989) and Schwarzer and Fuchs (1995) address outcome expectations as beliefs in the responsiveness of the environment and perceived situational barriers. In other words, beliefs about the responsiveness of the environment to individual action are a key element of efficacy expectations (Gecas, 1989). Similarly, Blair (1994-5) argues that participation requires "that all parties. . . think that their participation will make a difference" (38). If outcomes are frequently attributed to external causes, efficacy expectations for involvement will be low, and residents may feel that their involvement in care decisions will be unlikely to affect their health or happiness in the LTC facility - as a result, they may be less likely to desire involvement.

While expectations for the efficacy of involvement are usually attributed to personality-based beliefs such as locus of control, they can also be affected by experiences in the LTC facility context - in particular, the erosion of opportunities to make everyday decisions in total institutions (Wetle, 1991). The organizational realities of living in an institution include administrative constraints and the structures, routines and rules required in facilities designed to provide care for a group (Clark, 1988; Lidz & Arnold, 1990; Wetle, 1991). Rosalie Kane and her colleagues (1990) emphasize the constraints on "everyday autonomy" (decisions such as when to wake up, or eat) imposed by regulation, routine, restricted opportunities for privacy and independence, resource limitations and the lack of individualized services in institutions. As a result,

> . . . of exposure to a lack of control, individuals come to believe that their behaviour and outcome are unrelated. Thus, after exposure to a lack of contingency in one situation, individuals often seem to 'give up', assuming that they have no influence over outcomes in other contexts - even ones in which such control actually exists. . . (Kenny, 1990: 572).

Residents may be frustrated with LTC facility constraints, which generally mean that the ideal outcome is not attainable and that resident choices are rarely actualized. The perceived freedom of choice and previous experience with control and autonomy within the facility may significantly affect resident perceptions and attitudes (Agich, 1990; Dunkle et al, 1982; O'Connor & Vallerand, 1994; Wetle, 1991). One study found that a lack of perceived choice or available options was reported by many patients as an obstacle to their actual involvement in hospital discharge planning (Dunkle et al., 1982). In addition, meaningful involvement for residents may require the absence of pressure to comply with staff or administrative wishes in the decision itself, which is often not the case in a process of "negotiated consent" (Moody, 1988).

In sum, the lack of involvement in everyday decisions in LTC facilities, and the lack of *meaningful* involvement in care decisions, may promote apathy among residents or a frustrated retreat into passivity. It may also lower resident beliefs in their ability to contribute meaningfully to decision-making when the opportunity does arise.

2.5c Coping style: is participation something I am used to and comfortable with in this environment?

It is commonly assumed that coping styles are attributable to individual control beliefs and personality, and differences in reactions to stress or lack of control (Beaver et al., 1996; Hack et al, 1994; Krantz et al, 1980; Rodin, 1986). However, coping styles and adaptation processes are also highly dependent on the context that generates the stress or lack of control. Most of the work on coping reactions and their effect on participation preferences examines dependency as a response to acute health care problems, surgery, short-term hospitalization, or diagnoses of an imminently life-threatening condition (Degner & Sloan, 1992; Lidz et al, 1983; Lupton, 1997; Vertinsky et al, 1974). In such instances, denial as a coping strategy, and the need to put one's trust in medical staff in order to manage fear and anxiety, can be seen as key explanations for a reluctance to participate in decisions (Hack et al, 1994; Lupton, 1997).

The above research has limited relevance for those living with chronic conditions and functional disability, and for those faced with extended periods of institutionalization. While newly institutionalized residents may cope with similar stress responses, fear, anxiety and dependency, the institutionalization experience differs from hospitalization in that a resident often (but not always) expects to spend the rest of their life in the facility.

The effect of "being institutionalized" on subsequent adjustment and coping is particularly relevant when considering the decision to enter the LTC facility. In qualitative interviews conducted by Iwasiw et al (1996) with twelve newly-admitted residents of LTC facilities, those who felt they had no choice in the decision felt particularly unhappy and powerless. Some of those interviewed "had actively opposed admission, or unhappily acquiesced" (Iwasiw et al., 1996: 384). The implications of this for future coping and adjustment within LTC facilities should be considered. However, a longitudinal study by Davidson and O'Connor (1990) revealed that while perceived control of the decision to enter a LTC facility had positive effects on health during the first month, it actually had a negative effect between the second and fourth months. In contrast, acceptance of the decision to enter a LTC facility was associated with positive health and morale between the second and fourth months after admission. The authors conclude that acceptance of the decision has an important long-term coping function.

Research by Kahana and colleagues (1987) relevant to long-term adaptation found substantial continuity between coping strategies before and after institutionalization, but only measured coping up until the third month after institutionalization – which may have been insufficient to measure changes in coping styles. Yet even at this point, the authors note some change on individual coping items. They conclude that coping styles are primarily trait-like and stable, yet they also have "dynamic components" as people adapt to institutional realities (Kahana et al., 1987: 196). It remains to be determined conclusively how involvement in and acceptance of the decision to enter a LTC facility can affect resident coping responses over the long term, and how long-term adaptation in an institutional environment (including but extending beyond coping with short-term relocation stress) can affect resident preferences for participation.

One of the most commonly cited theories regarding the iatrogenesis of passivity and dependency in institutions is Seligman's (1992) learned helplessness theory, which posits that "helplessness develops when individuals experience uncontrollable life events, believe that they can do nothing to change the outcome of these events, and develop inappropriate expectations that outcomes of future events will also be beyond their control" (Barder et al., 1994: 597). Barder and her colleagues (1994) find that long-term care facilities, which closely represent "total institutions," make residents more vulnerable to both depression and learned helplessness than either rehabilitation or acute care environments.

A similar, more adaptive phenomenon observed by Goffman (1961) is "conversion," which involves accepting one's new identity and attempting to "make the best of dismal circumstances" (Manning, 1992: 108). A related explanation for dependency as a coping strategy is secondary control, which involves a change in one's perception of the problem and attempts to actively accept or adjust to the environment (Rothbaum et al, 1982). In four separate studies, hospital routines were regarded by patients as a necessary part of hospital life, and many patients were willing to relinquish certain freedoms and responsibilities and accept the situation, "toeing the line" by exhibiting what was perceived as appropriate behaviour, such as compliance and obedience (Biley, 1992; Dennis, 1990; Iwasiw et al., 1996; Waterworth & Luker, 1990). In fact, these studies reveal a kind of "active passivity" such as Timothy Diamond (1992) observed as a resident skill that operates to reproduce the status quo within LTC facilities.

Viewing LTC facility constraints as a tolerable fact of life (rather than a problem) might, of course, be related to individual personality differences. But it is also institutionally induced. Secondary control theory proposes that some forms of passivity

are a means of exerting control *in an environment in which the exercise of primary, goal-oriented control is not feasible or unlikely*, which has traditionally been the situation in LTC facilities (Rothbaum et al., 1982; White & Janson, 1986). Resident adaptation and coping hinges on patient perceptions of reality as limiting choice or autonomy, as evident in the experiences of daily life in the institution. Secondary control, as a type of coping, involves accepting and adapting to the environment, attempting to "fit in," lowering expectations or changing the self (rather than one's surroundings), and/or disengagement from certain goals (Chipperfield et al., 1999; Rothbaum et al., 1982; White & Janson, 1986). In LTC facilities, secondary control also involves attempts to please staff and fulfill the role of the good resident - for some residents, this goal takes priority over individual independence and other personal values (Biley, 1992; Dennis, 1990; White & Janson, 1986).

Residents accustomed to coping with daily life in the facility by lowering their expectations and "going with the punches" may be less inclined to actively participate in decisions when the opportunity does arise. Since active involvement in decision-making is one of a few ways to gain primary control, those used to a secondary control strategy might be expected to desire a less active role in decisions. Similarly, just as with learned helplessness, they may also lose interest in personal values and goals, which may affect their desire to be involved in decisions about their care.

Secondary control and learned helplessness both help explain passive behaviour among LTC facility residents as reactions to the institutional context and a loss of interest in personal values and goals. In contrast to learned helplessness, however, secondary control, as a process of psychological coping, may actually facilitate adjustment to the realities of daily life in LTC facilities. This is a different viewpoint than envisioned by

Taylor (1979), who argues that passive coping styles are associated with anxiety and depression, and thus maladaptive.

The difficulties distinguishing between learned helplessness and secondary control methodologically is apparent. For instance, "the mere observation of behaviours associated with learned helplessness is not sufficient evidence to conclude that learned helplessness is actually occurring" (Barder et al., 1994: 597). The conceptual distinction is also not clear: secondary control and learned helplessness represent two slightly different perspectives on a phenomenon that could prove particularly important in considering resident preferences for active participation. Given the lack of clear conceptual and methodological distinctions, only one of these concepts is considered within the context of this thesis. Secondary control was selected because it is a concept that allows for a greater degree of agency among individuals. Secondary control, because it involves accepting the situation, actually allows individuals to regain personal control by using cognitive reappraisal, and avoiding the negative emotions associated with loss of personal control (experienced by those who develop learned helplessness).

2.6 The institutionalization experience – length of stay

The socio-psychological processes through which the culture, constraints and routines of LTC facilities can affect decision-making preferences include coping and adjustment mechanisms, role socialization, and a variety of habits, beliefs and expectations. The longer a resident stays in the LTC facility, the greater the potential for declines in resident assessments of their abilities (perhaps independent of actual declines in health); decreases in their expectations of efficacious outcomes; and for increases in beliefs reflecting the inappropriateness of active involvement. Coping strategies may also

become more passive and oriented towards achieving secondary control. These are all factors conducive to a lowered desire for participation, which raises the possibility that an individual's length of exposure to the institutional environment may be associated with their desire for involvement in decisions.

Differential exposure to the effect of the institutional culture and organizational constraints on control and autonomy may partially explain differences in preferred decision-making involvement. However, contradictory findings exist in relation to the effect of length of institutionalization on residents.

Short-term reactions to institutionalization, or the stress of relocation, might explain low levels of interest in decision-making involvement among newer residents. Observational work by Brooke (1989), who studied the long-term process of adjustment to a nursing home environment, noticed initial periods of disorganization and later periods of increased self-confidence given increased experience and familiarity with the environment (which might suggest increased desire for participation). Additionally, Davison and colleagues (1995) found that the more recent the diagnosis of prostate cancer in men, the more passive their preference. While the authors attribute this to the emotional reaction to the diagnosis, the existence of a similar effect among newly institutionalized residents should be considered. For instance, the stress of relocation to a new environment has been associated with distress, anxiety, confusion, and depression (Manion & Rantz, 1995) – these may be associated with passive behaviour in the **early** stages of admission to a LTC facility.

As Brooke (1989: 66) notes, "we know far more about the early deleterious effects of institutional life than about the longer-term process of becoming socialized into it." Preferences for involvement might change over time as residents are institutionalized and

re-socialized within the new environment. Some authors propose that preference for participation may actually decline over time: Vertinsky and his colleagues (1974), in cross-sectional research on hospitalization, note that socialization and/or learned helplessness might explain associations between longer hospital stays and decreased desires for participation. Longer periods of institutionalization were also associated by Morganti and his colleagues (1980) with lower control priorities and a greater satisfaction with lower levels of choice (a cross-sectional study). A panel study by Arling et al. (1986) and cross-sectional research by Ryden (1984) also revealed a negative association of perceived control with institutionalization. Yet, in a cross-sectional survey of 100 nursing home residents by Shaw (1992), length of stay was not significantly related to perceived control.

Those with longer periods of residency may show increased psychic dependency and learned helplessness, or may also tend to use secondary control strategies, and be more unused to, or uncomfortable with, an active role in decision-making. Research by Ryden (1984) demonstrated a tendency for those with longer stays in intermediate care facilities to have lower morale. While this finding was non-significant, this was probably due to small sample sizes - the direction of this relationship should be noted.

Taylor (1979) suggests a temporal pattern of reactions to hospitalization, whereby those who initially respond or cope with anger or opposition eventually, under a situation of long-term loss of control, become passive and compliant, as repeated attempts to gain primary control "fail to produce results." These individuals may either attempt secondary control strategies, or lapse into learned helplessness, both of which are passive responses.

Iwasiw and his colleagues (1996) found that the effect of hospitalization on patient perceptions and behaviour was sudden and abrupt (residents adjusted over a

period of just two weeks). However, there may be a continuation and accumulation of an institutionalization effect over time. Socialization into the resident role and identity, while abrupt, may produce a habituation to the new identity over time (Berger, 1963). In other words, individuals may become more accustomed to and comfortable in their roles and identities over time, such that when the role and/or associated expectations for the role change, the individual "has difficulty keeping up with the expectations newly directed toward" him or her (Berger, 1963: 124). Individuals with longer lengths of stay in a "total institution" context, and longer experience in the dependent and compliant resident role, may experience more role habituation and be less comfortable with new expectations for active participation.

Associations between length of residence and increased passivity may actually be the result of a crude selection effect related to coping effectiveness. Relocation into an institution may have social and psychological impacts such as helplessness, hopelessness and apathy, which increase the risk of mortality: psychological adjustment may be the key to survival in the first few months (Aldrich & Mendkoff, 1963). However, since positive adaptation to the institutional context often entails secondary control strategies (Shaw, 1992) those who survive may lose interest in decision-making over time.

Barder and her colleagues (1994) note that the effect of length of stay may not be linear: its effects on learned helplessness and the desire for information in their research were most significant among those who have resided in a facility for between two to six months. Additionally, the specific predictors of participation preferences may differ markedly between short and long-stay residents. It could be that there are different explanations for passivity among new residents and long-term residents.

2.7 Summary

There is little research on decision-making participation preferences among the institutionalized elderly. The research that does exist suggests that factors such as gender, age, education, and illness might play important roles. The long-term care environment (the medical-institutional model of group care), through a combination of constraints on control and autonomy, staff behaviour and institutional culture, might also affect preference for involvement in decision-making. Individuals who do not believe their involvement will make a difference to their life in the facility, who do not have confidence in their ability to contribute to decision-making about care issues, who are less comfortable with or unused to taking an active role in their care, and/or who think that active involvement or resident control is inconsistent with appropriate behaviour for a resident, may prefer low levels of involvement in making choices or decisions.

2.8 Research questions

The purpose of this research is to explore predictors of preferences for decision-making involvement among residents of six LTC facilities in the Capital Health Region of British Columbia. While recognizing that socio-demographic and illness factors might be important, it is believed that a resident's adjustment to life in a LTC facility context and the context itself also have potentially significant influences on preferences for active involvement in decision-making about care and medical treatment.

This research draws upon sociological, gerontological and psychological theories. The experience of institutionalization and role socialization, the impact of organizational and structural constraints within LTC facilities, the micro-interactions and phenomenonological illness experiences of residents in the home, as well as theories of

secondary control and adaptation are all relevant when considering the desire for an active decision-making role. This literature informs the variables selected for inclusion in this research. Specifically, the following questions are posed:

1. What are residents' desired levels of involvement in various types of care decisions?
2. What are the associations between socio-demographic and illness factors and overall preferences for decision-making involvement?
3. What are the associations between cognitive-adaptive factors (belief in the appropriateness of active involvement, confidence, outcome expectations, and secondary control) and overall preferences for decision-making involvement?
4. What are the associations between length of residence (institutionalization) and institutional totality and overall preferences for decision-making involvement?
5. What is the relative importance of length of residence (institutionalization), institutional totality, cognitive-adaptive factors, and socio-demographic and illness factors in explaining preferences for decision-making involvement?

CHAPTER 3: RESEARCH METHODS AND PROCEDURES

3.1 Research design

While the questions and variables developed for this research are based on the contributions of previous qualitative work in the field, a cross-sectional survey design was utilized for the standardization of responses, enhancing the data's reliability (Singleton & Straits, 1999). Survey research is appropriate for measuring attitudes and orientations (Babbie, 1998: 256), for studying several independent variables simultaneously for their effect on a dependent variable (Carriere, 1998), and for gathering detailed information about a large group (Singleton & Straits, 1999). In this research, this design is used to examine associations with cognitive-adaptive, socio-demographic and illness variables that may explain interest in decision-making involvement. Doing so extends the previous work of qualitative researchers in a way that allows for an exploration of the statistical associations between variables. Survey research is also useful more generally in that a survey can address a wide range of topics efficiently, allowing for flexibility in data analysis (Babbie, 1998).

One disadvantage of survey research is that causal inferences made using surveys (as in this thesis) are made with less confidence than with experiments (Singleton & Straits, 1999). This is particularly a problem with cross-sectional surveys. For instance, researchers "cannot establish or measure the temporal order of the independent and dependent variable" (Gray & Guppy, 1994: 50). Additionally, unknown variables that are not statistically controlled for in the analysis might be causal agents affecting the dependent variable (Gray & Guppy, 1994). Survey measures can also be influenced by systematic measurement error (Singleton & Straits, 1999), which occurs when the

operationalizations of concepts is inadequate. This is a particular concern when researchers construct their own measures, rather than relying on established, tested measures of concepts (Gray & Guppy, 1994). It is also difficult to make changes to the measures once the survey commences (Babbie, 1998), and survey research can often miss the context of social phenomena, and lack relevance for respondents (Singleton & Straits, 1999).

Another concern with survey research relates to its reliance on verbal responses or self-reports, rather than on observations or administrative records. Self-reported opinions may be poor predictors of behaviour (Haug & Lavin, 1981) for various reasons. One of these is the tendency of some respondents to report opinions or intentions that reflect socially desired values or conform to social norms of appropriate behaviour (Gray & Guppy, 1984). The interview is essentially a social interaction, and subject to response effects related to aspects of the interaction, such as embarrassment or a dislike for the interviewer, as well as social desirability (Singleton & Straits, 1999). Another concern with self-reports is that many individuals may simply not be consciously aware of some of their feelings or opinions (Gray & Guppy, 1994). Verbal responses are also subject to problems of recall, which is a particular concern among elderly populations with cognitive impairment.

In this thesis the focus is not on respondents' actual behaviour but on desires or preferences for participation. Survey research is appropriate for measuring attitudes and opinions, and is also less subject to problems of observer bias inherent in participant observation. The survey approach was used for its efficiency in gathering a wealth of detailed information and the flexibility it permits in data analysis, including statistical analysis. Qualitative research has been conducted on participation preferences among

both hospitalized patients and LTC facility residents; the research design used in this thesis might provide an additional perspective complementing this previous work.

Selected open-ended questions were included to help in the interpretation of the quantitative data, and to encourage respondents to elaborate on their satisfaction (or dissatisfaction) with decision-making involvement, their perceived autonomy within the LTC facility environment, and the extent to which their health affects their desire to be involved in decisions. Qualitative notes based on additional unsolicited comments made by respondents were also recorded by the interviewers. This was not a planned step in the data collection process, yet these observations were an important aid in the interpretation of the data.

The dependent variable is the desire for involvement in decisions (measured in three forms). Independent variables are those believed *related to, and affected by*, the context of institutionalization (cognitive-adaptive variables described earlier), as well as more concrete contextual variables (length of residence and size of facility). Control variables include resident characteristics (socio-demographic and illness variables). The units of analysis, and the units of observation, are individual residents.

This chapter outlines the sampling procedures used in this research, including the selection of long-term care facilities, the development of the sampling frame, and the means of selecting and approaching respondents. The dependent and independent measures utilized in the analysis will also be presented in detail. Other research procedures also described include the informed consent process and the survey administration. Ethical concerns are also outlined, and the techniques of data analysis are discussed.

3.2 Participants and sampling

British Columbia continuing care classifications (Bossons, 2001) include five standardized levels of care. Those at the personal care level are generally mobile and require little assistance with activities of daily living (ADLs), such as bathing and eating. There are three intermediate care levels: level one represents individuals who are independently mobile, require moderate ADL assistance and daily professional care; individuals at intermediate care levels two and three both require more help with more basic ADLs (including walking supervision) and require nursing care. Individuals classified at the extended care level generally have severe chronic illness and disability, requiring much assistance with basic ADLs and 24-hour nursing care.

There are an estimated 194 non-profit LTC facilities providing primarily intermediate care in British Columbia. Based on information from a survey of Intermediate Care Facilities in B.C, and from a list of all LTC facilities from Ambience Consulting (Bossons, 2001), it is estimated that these facilities provide care for between 15,235 and 22,863 individuals in B.C. (Chappell, 1996).

The facilities selected for inclusion in the sampling frame for this research were all non-profit, in order to control for funding differences between profit and non-profit facilities that might significantly affect residents' preferences for participation (funding might affect the delivery of care, care philosophy, the socio-demographic characteristics of residents, or nurse-patient ratios, for instance). The results are therefore not generalizable to for-profit institutions. Information from both the above-mentioned Intermediate Care Facility Study (Chappell, 1996) and Ambience Consulting (Bossons, 2001) was supplemented with additional information on facilities from a knowledgeable

professional in the field to compile a list of 27 non-profit LTC facilities in the Capital Health Region providing care for either intermediate or extended care clients (or both).

Only facilities that were integrated intermediate care facilities, serving residents with any diagnosis (including dementia) were considered for this research. Based on a survey of all intermediate care facilities in British Columbia in 1996 and Director of Nursing estimations, an estimated 35% of residents have no diagnosis of dementia, and 23% of those with dementia have only mild dementia (Reid, 1996). Of the 27 facilities initially on the sampling list, LTC facilities that provided only extended care or primarily extended care were removed. Intermediate care facilities were preferred in order to maximize the number of eligible participants (those who would be in adequate cognitive and physical health to participate).

After the removal of extended care facilities, 16 facilities remained on the list. These facilities were phoned and administrators were asked for their estimates of the percentage of residents with dementia at the facility. Two facilities were removed from the list because the majority (i.e. over 75%) of their residents were estimated to have dementia. Another facility was removed because it was a facility for Chinese-Canadian elderly, leading to concerns about language barriers. This reduced the total sampling frame of LTC facilities to 13. Attempts were also made to ascertain the extent of variability in length of stay (administrators or delegates were asked for this information), but this information was not available and contacts did not feel comfortable estimating variability or even the average length of stay for residents of their particular facility.

Administrators of eight facilities, selected randomly from this list of 13 facilities, were sent a formal letter requesting permission to contact residents for the research (see Appendix A). One facility declined, citing over-surveying of its residents. Another

facility had a lengthy ethics review process that could not fit into the project timeline. A nursing strike actually disrupted this process of facility contact – some LTC facilities were burdened with problems relating to the strike, and this put the research "on hold" for about one and a half months. Contact was re-established with administrators or delegates after this period. In the end, six facilities in the Capital Health Region agreed to participate in the study. The number of beds in these facilities ranges from 70 to 279. The number of beds on a floor (crudely marking the "size of unit") ranges from 21 to 69.

Following receipt of permission for the research, a list of potential participants was compiled by an administrator or delegate (director of care or social worker) after consultation with the researcher. To reduce response incoherence and invalidity, this facility contact person was asked to read the survey instrument and informed consent form, and to identify residents cognitively capable of answering the survey questions and of providing informed consent. At three of these facilities, this was done in consultation with staff nurses. At one of the smaller facilities, the director of care felt she knew most residents well enough to apply the criteria mentioned above – for a few residents about whose capability she was unsure, staff were consulted. Similarly, at another facility, the social worker, who meets with all residents and does a psychosocial history (including cognitive function), selected all residents who were "oriented around person, place and time." For those about whom she was unsure, other staff members were consulted. At another facility, those selected came from an existing list of "able voters" for which inclusion required alertness (no diagnoses of dementia or significant short term memory loss) or a score below 6 on a Reisberg scale of cognitive function (Reisberg et al., 1982).

There is a particular concern that a nurse or staff member's judgment of cognitive ability may not be as reliable a measure of resident competence as a standardized

diagnostic cognitive exam (such as the MAS-R). For example, a recent study found that nurses tended to rate residents with higher social skills and less aggression as competent, whereas the MAS-R revealed that this was not necessarily the case (Reid & Chappell, 2000). Similar discrepancies between staff assessments and successfully completed interviews were noted by Van Maris and his colleagues (1996). This raises the concern that in some research, "subjects identified by a facility as eligible research subjects [are], in fact, too demented to understand what the researcher was saying" (Cassell et al., 1988: 93).

Staff involved in the assessments have almost daily contact with the residents and know how they relate and react in various situations. While performance on cognitive assessments tests might, for some residents with mild dementia, vary by the day of the week or even the time of day, staff who know the residents on a consistent basis over time might in these cases be a better judge of the overall suitability of an individual for the sampling frame.

While there is a concern that individuals may have been included in the sampling frame that should not have been, additional steps were taken to address this by removing some individuals from the list before they were contacted. For instance, when the researcher contacted the staff nurse on duty to notify them that residents would be approached on that day, the nurse often asked to review the researcher's list. The researcher allowed the staff nurse to "veto" names before individuals were contacted, when the individual was too physically or mentally ill (on that particular day) to participate. This added another safeguard in the selection process to ensure those contacted were capable of participating. Additionally, in five cases, residents who were approached were judged by the researcher to be incapable of answering the questions due

to cognitive deficits or severe communication difficulties – these interviews were not completed. The number of residents removed from the sampling frames for these reasons are reported in Table 1. Also, notes were made in cases where an interview was completed, but the interviewer remained unsure about the respondent's cognitive ability – four respondents were "flagged" for the purposes of analysis.

TABLE 1

Sampling profile at each participating LTC facility

Facility	Number of Beds	Initial Eligibility	Total Removed	Final Eligibility	Total Interviewed	Rate of Refusals
A	279	38	8	30	17	43%
B	75	25	0	20	13	35%
C	83	32	1	26	16	33%
D	147	39	3	27	18	33%
E	108	48	6	29	20	31%
F	70	31	0	21	16	24%

There is the issue that these selection procedures do not maximize eligible participants in the research, and this is a valid concern. However, resident names were only removed from the list at the nurse's advice, and those residents that were physically

too ill to complete the survey (i.e. had the flu) were re-tried on another occasion. Additionally, the use of staff selection means that a greater number of participants would be included in the initial frame of eligibility than would occur if cognitive tests were used (Van Maris et al., 1996).

In summary, while interviewer-administered mental competency tests are the ideal way of determining eligibility for inclusion in research studies, the length and complexity of these tests made them unsuitable for this research, given the available time and resources. In addition, it has been noted that capacity assessments should be considered relative to the risks and benefits of specific projects - this research entails minimal risk to participants, and the use of staff selection of potential participants is acceptable.

One hundred residents (82 female, 18 male) of six LTC facilities in the Capital Health Region (Victoria) were administered the survey developed for this research (Appendix B). The survey project was conducted over a five-month period from July to November of 2001.

At two facilities, contact with residents was preceded by an introduction to the project by the researcher at a resident council meeting. At two other facilities, the administrator or staff member mentioned the survey to residents at the council meeting. Two facilities had no such introduction. As mentioned, all the facilities were non-profit. In one facility, most residents (85%) share rooms with one other individual.

Details of the sampling frames and refusal rates for the six LTC facilities are presented in Table 1 above. The total number of residents considered eligible to participate in the study was 213 (and ranged from 31 to 48 residents for each facility). Attempts were made to contact all eligible residents. If one resident was not available (i.e., not in his or her room) at the time, their room was returned to at another point in the

day, and/or on another day. On average, when residents were unavailable, two more attempts were made to contact them on other occasions.

In each facility, some individuals were removed from the sampling frame because they were deceased or hospitalized. As mentioned earlier, some were also removed on the advice of the nurse or care aide on duty, who felt that the resident was not capable of participating (due to cognitive impairment and/or illness). In five instances, contact was made with residents but the interview was not initiated, because it was deemed by the researcher that the interview could not reasonably and/or ethically be completed due to cognitive impairment or communication problems (hearing or comprehension). These numbers are presented in Table 1 above as the "total removed" from the sampling frame, with revised sampling frame numbers represented as "final eligibility" (more detailed breakdowns of these numbers were not recorded).

In total, there were 53 refusals among the total of 153 residents who were contacted, which represents a 35% refusal rate. Residents refusing to participate were asked to offer a reason for their decision. Reasons for non-response might have significant implications for the interpretation of the research findings: those who refuse to participate, for instance, may be those who would refuse to participate actively in care or medical decisions (Brearley, 1990). A common reason given for refusals included being tired or feeling unwell. Many residents also cited a lack of interest, and some cited interview fatigue (having been recently interviewed for other research projects). Other residents felt incapable of contributing useful information ("I don't want to waste your time", "I can't tell you anything", "I'm too old"). The survey data may therefore be biased by a greater representation of those who would normally want to participate in decision-making. Those who are feeling too unwell to participate in the survey, or who

cannot be convinced that their opinions are worthwhile or that their capacities are adequate, may be less likely to feel they can make their own decisions.

In a number of instances, the necessity of signing the informed consent form may have resulted in the refusal. For each resident approached, the nature of the questions, the length of the interview, and his/her freedom not to participate were all outlined prior to asking whether the resident would agree to be interviewed (a preliminary consent). After this, either the researcher or another interviewer would begin the interview by reading the informed consent form (Appendix C), and asking for a signature. Three residents, who initially agreed to participate, refused to continue when asked to sign. Additionally, while specific numbers of instances were not recorded, impressionistic observations made by the interviewers were that many residents, when presented with the form to sign, seemed uneasy or uncomfortable, and it was necessary to reassure them about the content of the document (the estimate of cases is about 15%, although this cannot be confirmed). It is the interpretation of this researcher that these residents were uncomfortable with signing, rather than being uncomfortable with the conditions outlined in the form, because most often the residents already knew the nature of the questions, the length of time required, and the confidential nature of the information (and had provided verbal consent) before the informed consent document was read and they were asked to sign.

Elderly individuals may be particularly distrustful of legalistic sounding forms and documents to sign. They may have been warned by family members not to sign anything. Some have visual impairments or literacy difficulties that prevent them from being able to read the document. Furthermore, if there are no risks involved to seniors by participating, and if they have been informed that the data are confidential, they may become suspicious of why they are required to sign (if they have already given verbal

consent to be interviewed). They may also have concerns about putting their name on paper, despite assurances that the form cannot be matched with the response sheet.

Ethical concerns with the process of informed consent are a particular issue in LTC facilities. Informed consent must be voluntarily given and not coerced, yet for institutionalized residents, there is a complex combination of factors such as the compliant resident role, the desire to trust and please one's caregivers, peer pressure, and fear of retaliation, that may constitute undue pressure to participate in the study (Cassel, 1988; NSERC, 1998). This may be exacerbated by hearing and vision impairments restricting the comprehension of informed consent, and even by the "reward" for participation in the form of the social interaction in the interview context (Cassell, 1988; Cohen-Mansfield et al., 1988). The potential for unintentional coercion in a LTC facility environment is not a sufficient reason to forgo research in these contexts, particularly if the research poses minimal risk. What it does require, however, is that extreme care be taken to ensure the least risk of coercion possible, by ensuring residents can comprehend what is expected of them (simplifying language, for example), and allowing residents time to contemplate and discuss their participation. This also involves approaching residents without introduction by staff, in their own rooms, and making it especially clear that the decision not to participate will not endanger pre-existing entitlements to care or services received by residents.

As mentioned, the researcher described the study verbally to potential respondents (the language often needed to be simplified for understanding), as well as providing a written copy of the explanation for residents (see Appendix C). Respondents were assured of the extent to which their identities would be protected (no personal information would be released; the data would be analyzed in aggregate form; the names of the facilities

would also not be released). Respondents were also informed that their confidentiality would be protected (the data would be safely stored, without personal identification, and eventually destroyed). Of course, full confidentiality is difficult to assure in settings where there is long-term close contact between staff and residents, and particularly in small facilities (Cassell, 1988). Residents were encouraged to ask questions and contemplate their participation, if they desired.

Residents who consented to participation were interviewed by the researcher or interviewer (see Appendix B). Response options were visually presented to respondents on large-print laminated cards to facilitate comprehension and response accuracy. Due to the volume of interviews, three other interviewers were used at various times throughout the survey. These interviewers were trained by the researcher regarding the purpose of the questions and guidelines for interviewing elderly individuals. They also signed oaths of confidentiality.

Interviewer-administered questionnaires can be intrusive into the private lives of residents, which necessitates that the researcher be sensitive to ethical issues and take steps to ensure that the interview process and survey content do not disturb the resident. The survey instrument used in this research is minimally intrusive, but a primary concern was that the length of the interview and the informed consent process would be a burden for the resident. For this reason, if the interviewer suspected that the respondent was becoming fatigued, informed consent was verified again and an offer to continue at another time was made. In no instances, however, was it necessary to postpone the interview.

However, while fatigue was not a large problem, comprehension was often a difficulty. While data on question comprehension was not systematically recorded, it was

often necessary (in an estimated 40% of cases) to repeat questions two or three times to respondents. Additionally, for some respondents, the pre-set answer categories were very confusing and (in an estimated 40-50% of cases) respondents did not understand distinctions such as between "strongly agree" and "somewhat agree." Additional difficulties with the survey measures are outlined in the results chapter of this thesis.

3.3 Measurement

The survey instrument is primarily closed-ended in nature, and seeks information about resident preferences for involvement in four types of LTC facility decisions: end-of-life care, room transfers, medication changes, and mealtimes. The use of occasional open-ended questions encouraged the respondent to elaborate on his/her decision-making preferences and experience with decision-making in the facility. The instrument was pre-tested with four long-term care residents and revised accordingly before being administered to the project participants. For parsimony, only indicators that represented the most salient of the factors that can be identified through a literature review were selected for inclusion in the instrument. These include factors closely related to a resident's adaptation and adjustment within the institutional environment, their length of stay, and factors related to individual resident characteristics (socio-demographic and illness variables). A more exploratory measure of institutional totality was planned as a separate short closed and open-ended questionnaire to be completed by the facility contact after the interviews with residents.

3.3a The dependent variable: preference for decision-making involvement

The dependent variable in this research is preference for decision-making involvement. In existing research, decision-making involvement preference has been measured and studied in many ways, for a variety of decisions and situations.

Measures of the desire for decision-making responsibility may yield different (e.g., more positive responses) results than measures of actual behaviour (Beisecker, 1988). It is also especially difficult to distinguish between expectations and preferences. Measurements intended to elicit residents' hopes for an "ideal state of affairs" may actually measure residents' expectations about realistic outcomes (Benbassat et al., 1998). Responses may also reflect normative anticipations about socially endorsed roles as the result of socialization. Some findings suggest "some relation between a lower desire for control and a higher tendency to respond in a socially desirable way" (Smith et al, 1984: 422). Social desirability and role conformity are particular problems in the measurement and study of desires and involvement in decision-making among the institutionalized elderly.

An interesting means of measuring desired involvement was utilized by Dennis (1990), and entails the use of Q-sort methodology to classify respondents (medical-surgical patients). The Client Control Q-set is used to identify the importance placed by respondents on behavioural, cognitive and decisional control over various situations and events that occur during hospitalization. Using principal component factor analysis and the principles of Q-methodology, Dennis identified the following factors based on 45-item "Q-sort" questionnaires: preference for a "patient" role in the decision-making process, preference for an "interdependent and participative" role, and preference for a

"self-reliant" role. Unfortunately, the complexity of this analysis and the length of the measure made it unattractive for use in this thesis.

Another approach to measuring decision-making preferences is the card-sort technique used by Degner and Russell (1988), Degner and Sloan (1992), Hack et al (1994) and others. Two sets of cards represent forms of involvement that the physician and patient can assume (on a continuum), as well as roles that the patient, family and physician can assume. The card-sort technique, wherein respondents are asked to state their preferred card (of two presented at a time) until an ordering among five becomes evident, provided flexibility in terms of possibilities for response recoding and re-combinations. The researchers labeled cards "active", "collaborative", or "passive" and explored various combinations of preferences based on the respondents' ordering. Respondents generally make between 5 to 10 paired comparisons between various cards in this method. While this method of eliciting preferred levels of participation worked well in the patients studied by Degner and colleagues (1997), it has not been tested on older populations and is of questionable applicability to LTC residents, for whom clearer, less time-consuming measurement of the concept is needed.

The five response options used by Degner et al (1997), representing various active, collaborative and passive modes of participation, was also used by Strull and his colleagues (1984) to study the level of participation patients actually have and what they prefer to have. These five response categories reflect a continuum from "clinician should make the decision" to "patient should make the decision". This scale was adapted by Wetle and her colleagues (1988) to examine institutionalized residents' preferences for participation in medical decisions generally, as well as preferences for DNR decision-making specifically. These authors also asked about levels of perceived participation and

resident satisfaction with this involvement (Wetle et al., 1988). The response categories used by these authors were employed in this thesis research to measure preference for active involvement and preference for joint involvement, which will be discussed further.

Ende and his colleagues (1989) utilized three situation-specific vignettes of differing levels of illness severity in their measure of desired involvement. In these vignettes, respondents are asked, "who should make the following decisions" for three different types of decisions corresponding to each vignette (Ende et al., 1989). Response categories range on a continuum from "you alone" to "the doctor alone." These vignettes are also the basis of measurements by Thompson et al. (1993) and Catalan et al. (1994).

One problem with the "Autonomy Preference Index" vignettes (Ende et al., 1989, above) is that they present decisions requiring substantial technical-medical expertise, with only one good solution that needs to be identified. Deber and her colleagues (1996) term these "problem-solving tasks," as opposed to "decision-making tasks" involving a choice between alternatives (usually requiring consideration of patient values and goals). These authors developed the Problem-Solving Decision-Making Scale, consisting of three vignettes representing problems related to mortality, morbidity and quality of life outcomes. Patients are asked, "who should decide?" for four problem-solving and two decision-making activities (identified as separate factors: Deber et al., 1996). Similarly, Thompson and his colleagues (1993) developed the "Desire for Involvement Questionnaire" designed to measure desired input in situations where medical expertise is not required. Their vignettes concern a decision between two treatments equally medically appropriate, yet differing in effects on patient lifestyles, side effects, and quality or quantity of life. The vignettes developed by Deber and colleagues (1996) and Thompson and colleagues (1993) are the basis for the construction of the vignettes used

in this thesis, because having a choice between relevant alternatives is a truer conceptualization of decision-making than what Deber and her colleagues (1996) term "problem-solving tasks."

Possible decision-making situations applicable for studying decision-making preferences in a LTC facility context have been identified by High and Rowles (1995), and include: decisions about daily living (such as mealtimes); the physical and social environment (such as the use of furniture or participation in social activities); treatment and health care (such as medications); financial matters; transfers (such as moves within the home); competence, and crisis or life/death decisions (such as end-of-life treatment). The vignettes used in this thesis are based on four of these decision-making situations (daily living; treatment and health care; transfers/moves; life/death decisions).

Decision-making participation preferences of residents in this thesis are operationalized in measures tapping into relevant, situation-specific preferences. The measures obtain information on the preferred degree of involvement in the four decisions, presented as specific vignettes involving a problem and decision that may be encountered by residents: bedtimes, changes in medications, room transfers, and end-of-life decisions. The vignettes reflect both institutional caregiving and medical care. While previous research focuses on medical and "big ticket" (i.e. major) decisions such as advance directives, Wetle (1991) has suggested that for the institutionalized elderly, involvement in the micro or everyday decisions may be the most important. The selected decisions in this thesis reflect the multidimensional nature of decision-making involvement preferences by considering both "big ticket" and "everyday" decisions. Additionally, preference for decision-making involvement may vary by the personal relevance

attributed to the decision or the amount of knowledge required for an informed choice, and this dimension is also reflected in the selected vignettes.

The four vignettes and their specific wording as explained to respondents are presented in Table 2. Vignette A represents the decision about what time the resident goes to bed. This represents an everyday, commonly occurring decision requiring little technical knowledge. A decision almost as common, but which appears to require more technical (i.e. medical) knowledge is the decision about medications represented in Vignette B. Technical and less technical decisions are also reflected in two "big ticket" items of less common occurrence: the decision to move a resident to another room in the facility (less technical) represented in Vignette C; and the decision about advance directives or living wills (which may appear more technical) represented in Vignette D.

With each of the four vignettes, it is possible that a resident has actually encountered a similar situation - in which case, their feelings about who "should" make the decision may be affected by who actually did make it. Therefore, after reading the vignette, residents were first asked whether they had encountered the situation, who made the decision, and whether they were happy with the involvement they had.

Whether or not a similar situation has occurred, the respondent was asked: "who should make the decision?" If the respondent mentioned only one individual, the individual was identified (i.e., self, staff, personal physician, family member, friend or other). The respondent was then asked whether anyone else should be involved, and if so, who this should be.

Not all respondents have family available to whom they can extend autonomy, and this must be kept in mind when interpreting answers to the questions regarding the involvement of others in the decision-making process. Whether or not a family member

or friend was available to help the respondent in making decisions was noted and is presented in the following chapter.

TABLE 2

Vignettes used in the survey instrument

Vignette	Wording
A	Suppose you were interested in going to bed late in the evening, although most people go to bed early. Who do you want to decide what time you go to bed?
Vignette	**Wording**
B	Suppose you are in pain, and there are two kinds of medications you can take. One medication would make you very sleepy but work better for your pain. The other medication would keep you alert but would work less well for the pain. Who do you want to decide which medication you should take?
Vignette	**Wording**
C	Suppose you were told that the staff wanted to move you to another room in this same facility. Who do you want to make the decision about whether you should move?
Vignette	**Wording**
D	You may have heard about arrangements that people can make, *in advance*, about what medical procedures they do or do not want at the end of their life. Who would you want to make the decision about what medical procedures you will receive in the last days of your life, if the decision were made today?

The questions ascertain not only the amount of involvement in the decision that the individual desires for him/herself, but also the extent to which a joint decision-making situation was preferred (where "equal say" represents the highest preference for a joint

decision). If a joint decision of any kind was preferred (i.e., more than one person was preferred to be involved), a question about how the decision should be made was asked (i.e., I should decide, others should provide input; I should decide but strongly consider the preferences of others; there should be equal say in the decision; others should decide but strongly consider my preference; others should decide and I should provide input).

Situation-specific measures (vignettes) are used because they may provide more accurate results "in situations in which there is a great deal of experience with the specific health care settings," such as LTC facility residency (Smith et al., 1984: 424). It is generally believed that most measures should be situation-specific (Turner & Martin, 1984). General survey measures tend to be too vague and open to varying factors and interpretations. Offering specificity through the use of vignettes enhances the precision of the results for individual vignettes, as well as enhancing the variability of the overall indicator (Gray & Guppy, 1994). Additionally, participation preferences are multidimensional, and situation-specific measures can better incorporate this multidimensionality. The use of multiple measures (four vignettes) also helps to capture the full range of the concept of participation preferences (Gray & Guppy, 1994).

Dichotomous measures (e.g., I prefer to participate vs I prefer to leave decisions to my doctor), used by Cassileth et al. (1980) and Blanchard et al. (1988), have been acknowledged as the least useful measures of participation preferences (Benbassat et al., 1998). These measures, because they represent a forced choice between two extreme alternatives, can bias responses towards a greater desire for involvement (Ende et al., 1989). To address this concern, multiple-item measures with ordinal response categories were utilized in this thesis. These (as well as continuous measures) are acknowledged as superior by Degner and Sloan (1992) and Benbassat et al. (1998). The questions asked in

this thesis research permitted the construction of two distinct continuums of involvement (e.g., the extent of preference for active involvement; and the extent of preference for joint involvement). A number of analysis strategies for the data are possible as a result.

For the purposes of the first analysis, response categories were collapsed to create a categorical variable for each vignette: preference for full, independent control in decision-making (coded as 1) versus preference for all other levels of involvement (coded as 0). A continuous dependent variable was constructed by summing the number of times respondents indicated a desire for full, independent control in decision-making across the four vignettes. While Kapp (1981) notes a lack of desire by many older patients to participate within an individualistic or lone autonomous figure model, this form of the dependent variable (participation preferences) is one way to test this claim, and represents a means of measuring participation preferences that puts the highest weight on the "lone autonomous" model of participation in decision-making. If a resident expresses a desire for independent decision-making responsibility for all four decisions, he or she scores high on the dependent variable representing preference for full, independent decision-making involvement (control). The range is between 0 and 4. The mean score on this variable was 1.7 (SD=1.2).

A second dependent variable was also constructed for use in a second regression analysis. For each vignette, a score on a continuum of one (others decide alone) through five (own decision alone) was computed. Scores ranging from 2 through 4 represent levels of independent control within a joint decision-making process, if this was desired (others have final say but consider my input; we have equal say; I decide but consider others' input). A sum of the scores on this continuum across all four vignettes was used in this second analysis. This second form of the dependent variable (also continuous) more

accurately reflects the **level, extent, or degree** of desire for active involvement in the four decisions. The mean for this variable (hereafter referred to as preference for active involvement) was 14.7 (SD=3.6), and the range was from 4 to 20.

As discussed in the literature review, participation preferences can involve two conceptually distinct continuums. Most measures of preferred participation in decisions reflect a conceptualization placing joint decision-making between active and passive extremes, with active decision-making being the ideal, in terms of autonomy. Similarly, the two variables above measure the desire for active or independent involvement (based on dichotomous and ordered versions). In this research, a separate regression analysis was performed to explore predictors of the extent or level of preference for joint decision-making. This involves placing the desire for equal, joint decision-making at the highest end of a continuum; joint, but unequal, input in the middle; and independent decision-making by one party at the lowest end. A third score for each vignette was constructed that reflected this continuum, whereby the desire to have one person alone decide represents the lowest score (0), joint-consultative situations represent the middle score (1) and equal decision-making represents the highest score (2) on "preference for joint decision-making." This third dependent variable was constructed for each of the vignettes and then summed across all four. Potential scores on this measure would range from 0 (one-party decision-making desired for all four decisions) to 8 (equal say, joint decision making desired for all four decisions). A higher score represents a greater desire for joint decision-making, summed across all four decisions. Actual scores ranged from 0 to 6, and the mean score for this variable was 2.1 (SD=1.5).

Considerations of resident satisfaction with levels of involvement were briefly addressed, but not specifically probed in this research. For instance, if desired levels of

involvement are greater than what residents actually have, there may be dissatisfaction among residents. To look at this, one would evaluate levels of satisfaction with one's current level of involvement. If satisfaction is high, then desires presumably coincide with expectations. However, as Benbassat and his colleagues (1998: 85) note, "analyses of patient satisfaction with their health care according to their preferred participation in decision-making have not produced consistent results." Questions of the association between satisfaction and desired role preferences are, in the interest of manageability, left for further research to address more thoroughly. However, they are tentatively addressed in this research with open-ended questions asking about experience with the decision mentioned in the vignette, and whether the respondent would have liked a different amount or type of involvement in this decision. Another item asks the resident to identify how much involvement he/she feels is realistic to expect in the facility, and whether this is his/her preferred amount of involvement.

3.3b Independent variables

Length of Residence. This variable was measured in months of residence at the particular LTC facility. While data were collected on lengths of stay in previous facilities, methodological problems arose in distinguishing between types of facilities and determining which to include as institutions. Residents mentioned a variety of facilities, including retirement residences, assisted living residences, and acute care hospitalization. Residents also had more difficulty recalling their lengths of stay in previous facilities. Due to the problems inherent in adding together the total lengths of stay in various types of facilities, data on previous residences were not included in this variable.

Institutional Totality. Differences in the "totality" of LTC institutions, if meaningful variation can be detected, might be associated with differences among respondents' participation preferences. O'Connor and Vallerand (1994) distinguish between facilities in terms of the extent of "opportunities for self-determination in the living environment," as it might affect motivation. Ideally, observational data should be used to collect information to differentiate between LTC facilities based on their degree of institutional totality. However, as McEwen (1980: 153) notes, the cost involved "often dictates using the cheapest and most available measures," such as size or patient-staff ratio. As discussed earlier, several authors have identified important elements that might differentiate between total institutions "in ways important to understanding their differential impact on members" (Bennett & Nahemow, 1965; McEwen, 1980, p. 152l; O'Connor & Vallerand, 1994). According to Bennett and Nahemow (1965), for instance, high totality would be associated with the following: a permanent residence design; activities which occur within the institution and are scheduled sequentially for everyone; formal indoctrination periods (concerning good vs. bad conduct); continual surveillance by staff; standardized objective rewards and punishments; few chances for resident self-determination; most personal property is removed; involuntariness of membership; and congregate living as the primary residential pattern. Similar criteria proposed by other authors include staff consensus about work practices and the extent of formal administration (McEwen, 1980; O'Connor & Vallerand, 1994). It may also be the case that resident self-reports of the "home-likeness" or flexibility of the environment could be used. Yet McEwen (1980) notes that this is somewhat circular, if the intent of distinguishing between institutions is to look at differential effects on resident adaptations.

An exploratory synthesis of a few measures of institutional totality was created for this thesis research which relies heavily on an adaptation of Bennett and Nahemow's (1965) criteria while incorporating some elements suggested by O'Connor & Vallerand (1994) and McEwen (1980). An "institutional totality" survey (Appendix D) was designed for self-administration by facility administrators or care directors. The instrument includes questions about the number of group-scheduled activities, the ratio of private to shared rooms; the ratio of involuntary to voluntary admissions; the amount of personal property residents can bring with them to the facility; the mandate and function of the resident council; and the staff-resident ratio. This information was gathered through open-ended questions. Additional information concerning the amount of freedom or self-determination residents have in various decisions was collected through closed-ended questions about the extent to which the facility permits flexibility (on a scale of 1 to 10, where 1=no choice and 10=full choice) in seven domains, for cognitively intact residents. The domains addressed were daily living decisions, decisions about the physical and social environment, treatment and health care decisions, major financial decisions, transfer decisions, and crisis or life-death decisions (decisions identified by High & Rowles, 1995).

The method of analysis involved an examination of the responses to the questions. Additionally, scores were assigned to each of the questions on the survey for which this could be done, based on the answers provided. Some questions showed so little variation in responses that these questions were omitted in the total score. Other questions revealed responses that were virtually uncodable. Attempts were made to distinguish between the six LTC facilities based on the responses to the survey. However, several attempts to create an overall score for the LTC facilities based on the survey revealed only minimal

variation. Further discussion of the measure's outcomes, its usefulness, and scoring difficulties are discussed in the following chapter, along with the discussion of the data.

Information on facility size (measured as the number of beds in the facility) was also recorded as a crude indicator of institutional totality, and eventually utilized in place of the above measures in the regression analyses. However, as noted in the literature review, size may be insufficient as a measure of the extent of flexibility or choice within a particular facility.

Secondary Control. Barder and her colleagues (1994) define secondary control as preference to "give away" control over health care. This is a narrow indicator not only insufficient to capture the concept of secondary control, but it also overlaps with the dependent variable used in their research. LeSage et al (1989), understanding secondary control as a conscious decision not to perform an activity or behaviour, also measure it simplistically by asking whether individuals ever make decisions to not do something they are capable of doing. Barder and her colleagues (1994) measure secondary control as self-efficacy for control over their health care, grounding this choice in the tenuous assumption that secondary control is the result of low self-efficacy. Kahana and his colleagues (1987), while not measuring secondary control explicitly, measure an escape dimension of coping that includes cognitive restructuring. These measures of secondary control reflect a limited understanding of the concept. Measurement has been refined by authors such as Heckhausen and Schulz (1998), and Chipperfield et al (1999), but resulting measures are still applicable primarily to control over functional losses associated with aging, and would need to be adapted to address situations in which the environment may generate a loss of control.

Menec, Chipperfield and Perry (1999) utilize three questions to measure secondary control: expecting less, seeing control as less important, and accepting that it can't be done as well as before. With these questions in mind, a similar scale was constructed for this research that would be appropriate with the current population and setting. The six-item Likert scale consists of attitudinal questions. Higher scores represent greater use of secondary control strategies. Unfortunately, the resulting reliability alpha for the scale (.41) is unacceptably low. Single items and their frequency distributions for this scale are presented in Table 3.

Analysis of bivariate correlations of the single items with the dependent variable and stepwise regression of the scale items on the dependent variable revealed that one item in particular reached the .05 significance criterion for inclusion in the model. This item is: "it is important for my well-being to be on the staff's good side." As an element of secondary control, this item reflects the attempt to actively accept or adjust to the environment, including "toeing the line" and exhibiting perceived appropriate behaviour (Iwasiw et al., 1996; Rothbaum et al, 1982; Waterworth & Luker, 1990). This single-item measure is used in the regression analysis. Responses were originally coded to four categories (strongly agree, somewhat agree, somewhat disagree, strongly disagree), but an examination of the frequency distribution of the item revealed that one category (strongly disagree) had only 5.2% of the distribution of responses. This item was therefore dichotomized (agree vs. disagree) for analysis.

TABLE 3

Single items for "secondary control" and frequency distributions

Item	Frequency	
The best advice to a new resident is to just "roll with the punches."	Strongly Disagree: 6.1% Somewhat Disagree: 10.2%	Strongly Agree: 25.5% Somewhat Agree: 57.1%
It is important for my well-being to be on the staff's "good side."	Strongly Disagree: 5.2% Somewhat Disagree: 12.4%	Strongly Agree: 33.0% Somewhat Agree: 49.5%
I would take some small risks to my safety to remain independent.	Strongly Disagree: 9.2% Somewhat Disagree: 33.7%	Strongly Agree: 7.1% Somewhat Agree: 49.0%
Staff should be flexible to my specific desires.	Strongly Disagree: 4.1% Somewhat Disagree: 22.4%	Strongly Agree: 12.2% Somewhat Agree: 61.2%
STRICT routines are necessary here.	Strongly Disagree: 0% Somewhat Disagree: 21.2%	Strongly Agree: 28.3% Somewhat Agree: 50.5%
Having control is more important to me these days than before I came here.	Strongly Disagree: 5.3% Somewhat Disagree: 24.5% Neither/the same: 37.2%	Strongly Agree: 7.4% Somewhat Agree: 25.5%

Outcome Expectations. Outcome expectations reflect the belief in the efficacy of participation, in terms of achieving desired outcomes. This concept was measured using a six-item Likert-type scale developed for this thesis research. Item wordings for this scale and frequency distributions are presented in Table 4. Higher scores on this scale indicate a greater belief in participation effectiveness. Reliability analysis revealed that the removal of one of the items would increase the reliability alpha from .56 to a moderate

alpha of .72, and this item was removed ("my wellbeing here is under staff control"). The items on this scale also load on a single factor on a principal components analysis with varimax rotation.

TABLE 4

Single items for "outcome expectations" and frequency distributions

Item	Frequency	
A resident's opinion is taken seriously here	Strongly Disagree: 1.8% Somewhat Disagree: 15.6%	Strongly Agree: 18.8% Somewhat Agree: 64.6%
My well-being in this facility is under staff control.	Strongly Disagree: 23.5% Somewhat Disagree: 60.2%	Neither agree/disagree: 2% Somewhat Agree: 14.3%
My participation in decisions here makes a difference.	Strongly Disagree: 0% Somewhat Disagree: 4.2%	Strongly Agree: 62.5% Somewhat Agree: 33.3%
It does not really matter what I think, staff will just go ahead and do what they want.	Strongly Disagree: 55.6% Somewhat Disagree: 39.4%	Strongly Agree: 0% Somewhat Agree: 5.1%
My involvement in decisions often lacks meaning.	Strongly Disagree: 57.3% Somewhat Disagree: 38.2%	Strongly Agree: 0% Somewhat Agree: 4.5%
There are enough choices and decisions for me here.	Strongly Disagree: 0% Somewhat Disagree: 3.1%	Strongly Agree: 79.4% Somewhat Agree: 17.5%

Confidence. A six-item scale measuring confidence was constructed for the survey and had an alpha reliability of .59. A higher score indicates greater confidence in the worth of one's contribution to decision-making. All original items included in the scale and their frequency distributions are presented in Table 5. Given the low alpha reliability, a

stepwise regression of the items on the dependent variable was performed to see if any of the items might be selected for use as single-item measures of the concept.

TABLE 5

Single items for "confidence" and frequency distributions

Item	Frequency	
I know what is best for me.	Strongly Disagree: 5.1% Somewhat Disagree: 25.5%	Strongly Agree: 16.3% Somewhat Agree: 53.1%
I cannot make decisions about my own care.	Strongly Disagree: 16.2% Somewhat Disagree: 46.5%	Strongly Agree: 5.1% Somewhat Agree: 32.3%
My opinion about my care is as important as what the staff thinks.	Strongly Disagree: 2.1% Somewhat Disagree: 20.8%	Strongly Agree: 17.7% Somewhat Agree: 59.4%
I lack the ability to decide about medical problems.	Strongly Disagree: 9.2% Somewhat Disagree: 36.7%	Strongly Agree: 15.3% Somewhat Agree: 38.8%
My input into care and medical decisions would be valuable.	Strongly Disagree: 1.0% Somewhat Disagree: 22.9%	Strongly Agree: 14.6% Somewhat Agree: 60.4%
I lack the confidence to comment about the care I receive.	Strongly Disagree: 24.5% Somewhat Disagree: 32.7%	Strongly Agree: 12.2% Somewhat Agree: 30.6%

Two items reached the .05 significance criteria for inclusion in the model, and also loaded on the same factor in a principal components factor analysis with varimax rotation. The two items were: "I know what is best for me," and, "my opinion is just as important as what the staff thinks." From these two items, one dichotomous variable was constructed such that agreement with both statements was coded as a 1 on this variable, and disagreement with both, or disagreement with one of the two items were coded as 0. This

coding scheme compensates for "agreement response bias" (confidence questions might particularly be affected by social desirability). The two-item combined variable was used in the regression analysis.

Normative Assumptions. For this variable, a five-item Likert-type scale was constructed such that higher scores would indicate greater awareness of normative expectations for passive and compliant behaviour in the facility. The reliability analysis revealed a low alpha statistic for this scale (.57). Stepwise regression analysis of the items on the dependent variable revealed that two items reached the .05 significance criterion for inclusion in the model. These items were: "residents are entitled to their opinion, in ANY matter," and "residents should make things easy on the staff." However, the latter item, when asked of respondents, proved a less valid measure of normative assumptions about decision-making than the former. The item is based on the assumption that making things "easy" on staff involves not being involved in decision-making. In practice, it appeared that this item was interpreted by many residents in the context of activities of daily living – that is, many of those who agreed with the statement did so because they felt that making things "easy" on the staff involved making one's bed and doing activities of caring for oneself, rather than in the context of decision-making. As a result, this item had less practical relevance for the phenomenon under examination, which is decision-making involvement. As a result, only the item "residents are entitled to their opinion, in ANY matter" was selected for inclusion in the model as a single-item measure of normative assumptions. All original items included in the scale and their frequency distributions are presented in Table 6. Originally constructed as an item with four response categories (strongly agree, somewhat agree, somewhat disagree, strongly

disagree), an examination of the frequency distribution for this item revealed a low frequency of respondents who "strongly agreed" (1%) resulted in its recoding as a dichotomous variable with response categories representing agreement vs. disagreement.

TABLE 6

Single items for "normative assumptions" and frequency distributions

Item	Frequency	
It is appropriate for residents to challenge the way things are run here.	Strongly Disagree: 7.0% Somewhat Disagree:26.0%	Strongly Agree: 15.0% Somewhat Agree: 52.0%
A good resident does not often complain.	Strongly Disagree: 4.1% Somewhat Disagree: 23.7%	Strongly Agree: 17.5% Somewhat Agree: 54.6%
Residents should try to make things easy on the staff.	Strongly Disagree: 0% Somewhat Disagree: 6.0%	Strongly Agree: 31.0% Somewhat Agree: 63.0%
Residents are entitled to their opinion, in ANY matter.	Strongly Disagree: 1.0% Somewhat Disagree: 22.2%	Strongly Agree: 19.2% Somewhat Agree: 57.6%
It is a resident's duty to sit back and let the staff take over.	Strongly Disagree: 7.1% Somewhat Disagree: 34.7%	Strongly Agree: 6.1% Somewhat Agree: 52.0%

3.3c Control variables

Gender: For this analysis, men were coded as 1 and women as 0.

Age: This is a continuous variable measured in years.

Education: This variable is measured on an eight-point ordinal scale, for which higher scores equate to higher levels of formal schooling:

0 - some elementary school
1 - elementary school completed
2 - some junior secondary school
3 - junior secondary completion
4 - some senior secondary school
5 - senior secondary completed
6 – trade school
7 – some college or university
8 - college/university diploma or degree

Physical Health: This variable was measured in the questionnaire by the standard measures of self-perceived health, self-reported number of chronic conditions, and self-reported limitations in basic activities of daily living (ADLs). Non-basic ADLs were excluded due to their decreased relevance in an institutional context (i.e. "cooking" abilities). Respondents were asked whether they were able to do the following: eat, dress and undress, get about the facility (mobility), get in and out of bed (transfers), use the toilet, and take a bath OR shower. Residents were asked whether they were able to perform the activity without help, and if they required help, they were asked whether help was needed from a person, a device, or a person and device. If they were unable to do the activity even with help, this was also noted. The exact wording of these items is available in Appendix B (Q#35). In order to limit the number of independent variables operating in

the regression analysis, it was necessary to select just one of the measures of physical health for inclusion in the model. The measure of ADLs was not favoured because these items were heavily influenced by facility regulations (i.e., whether or not a resident can take a bath/shower without assistance was often determined by facility policy). Because the measure of chronic conditions was highly correlated with both perceived health and ADLs (significance levels of $p<.001$ and $p<.05$, respectively), it was selected for inclusion in the analysis. A bivariate correlation matrix for these three measures of health is presented in Table 7.

TABLE 7

Bivariate correlation matrix for health measures

Health measure	**ADLs**	**Self-Perceived Health**	**Number of chronic conditions**
ADLS	1.00	-0.06	0.23*
Self-Perceived Health	-0.06	1.00	-0.32***
Number of chronic conditions	0.23*	-0.32***	1.00

***p<.001 ; ** p<.01 ; *p<.05

Entry Decision. Whether the decision to enter the facility was one's own decision or that of others might influence adaptation within the facility and acceptance of the decision (Iwasiw et al., 1996). This variable is dichotomous, representing whether the resident

reported being the person who made the decision (coded as 1), or reported others as making the decision or a joint decision being made (coded as 0).

3.4 Data analysis

Information was initially obtained from frequency distributions. Next, bivariate correlations were examined. The Pearson correlation was used to test for the existence of a bivariate, linear association between pairs of continuous or quantitative variables used in the analyses. Additionally, the Chi-Square statistic was utilized to examine the existence of bivariate associations in selected cross-tabulation tables, based on "how close the expected frequencies fall to the observed frequencies" (Agresti & Finlay, 1997). The minimum recommended expected cell frequencies for Chi-Square procedures is 5; where counts fell below this standard, categories were collapsed. For continuous variables, collapsing categories involved dividing the distribution into roughly equal proportions. For instance, an analysis of the cumulative percentage in frequency outputs allows for a recoding of the variable into those that fall above and below the median. One-way ANOVA methods and independent samples t-tests were also used to compare means of preferred active involvement among groups. For instance, the average of preferred involvement was compared across groups created based on residence in the same facility. Groups were also constructed based on residence in small vs. large facilities; and based on residence in facilities with active resident council mandates vs. less active council mandates, as well as other groupings. Means for these groups were compared and the P value of the test statistic examined to look for significant differences among means.

Predictors of the dependent variables were explored through multivariate analysis of selected independent and control variables on preference for decision-making involvement. As noted, four different medical and care-related decisions were examined: end-of-life decisions, a move to another floor or unit; a choice of medications; and mealtimes (the four vignettes). Multivariate regression analysis allows for the introduction of several explanatory variables, and facilitates examination of the strength and significance of associations between variables. OLS linear regression was selected because the dependent variables were continuous.

OLS linear regression analysis was performed by entering the variables in three cumulative models ("blocks" in SPSS). Age, gender, education and the number of chronic conditions were entered first, followed by length of stay, facility size, and entry decision; followed by outcome, confidence, secondary control, and appropriateness. The logic used is that the socio-demographic and health variables are established prior to entry into a facility; exposure to an institutional environment follows; and the inclusion of the cognitive-adaptive variables last in the model reflects the assumption, in this thesis, that these variables are largely adaptive in response to the LTC facility context.

Separate regression analyses were also performed on each of the component scores corresponding to each of the four vignettes. Thus *for each dependent variable*, a linear regression analysis was performed using the summed-vignette form of the measure. Four separate regressions were then performed regressing the same independent variables on the vignette-specific form of the dependent variable. Where the vignette-specific form of the dependent variable was dichotomous rather than continuous, as with the first and third form of the dependent variables, binary logistic regression analysis procedures were utilized. Separate regression analyses were also conducted to assess the impact of length

of stay, facility size and the control variables on the cognitive-adaptive variables (role expectations, efficacy expectations, confidence and secondary control).

Analyses were accomplished through the use of SPSS 10.0 (Statistical Package for the Social Sciences). The data were tested for compliance with OLS assumptions prior to proceeding with the analysis. Satisfying the assumption of normality requires an examination of whether observations of a variable show a normal distribution about their mean, a particular concern with small sample sizes. Sample sizes over 30 may be adequate for a good approximation of normality (Agresti & Finlay, 1997). A skewed or asymmetrical distribution might indicate problems of normality (Levin & Fox, 1994). Skewness and kurtosis statistics for the variables were examined, and one of the variables (length of stay) was logarithmically transformed to adjust for skewness. Gender is also skewed, as expected; facility size is also skewed, and this is a direct measurement result of the selection process. Histograms of the variables used in the analysis were also employed for the purpose of checking for the "fit" of the normal distribution and for extreme deviations from normality for each of the independent and control variables.

Skewness statistics are also useful for checking for outliers in the data, as are scatterplots (of the independent variable by the dependent variable). There are a few outliers in the data, but they do not dramatically affect the normal distribution - that is, they do not unbalance the linear regression equation.

Multicollinearity occurs when explanatory variables "overlap," which inflates standard errors in a regression analysis and renders the regression coefficient less meaningful (Agresti & Findlay, 1997). One means to detect multicollinearity is to examine the correlation matrix - correlation coefficients of .80 or greater (closer to 1) reflect a potential multicollinearity problem (Bohrnstedt & Knoke, 1988). None of the

independent or control variables displayed a bivariate coefficient of higher than .37 (confidence and appropriateness of involvement). Another means of assessing multicollinearity is to check the collinearity diagnostics. If the tolerance value is close to zero (i.e. less than .1), then the variables are multicollinear; large Variance Inflation Factors (for instance, greater than 10) also reflect a multicollinearity problem (Menard, 1995). The smallest tolerance level was for length of stay (.81). The greatest VIF was 1.24 for the same variable. Tolerance levels and VIFs for all variables used in the regression analyses are reported in Table 8.

TABLE 8

Measures of Collinearity: Tolerance and VIF for regression of desired active involvement, independent and control variables

	Collinearity Statistics	
Variable	**Tolerance**	**VIF**
Gender	0.846	1.182
Facility size	0.933	1.071
Education	0.898	1.113
Age	0.857	1.167
Length of stay	0.809	1.236
Entry decision	0.814	1.228
Chronic conditions	0.855	1.170
Outcome expectations	0.934	1.071
Appropriateness (SI)	0.849	1.178
Secondary control (SI)	0.931	1.075
Confidence (SI)	0.881	1.135

SI – statistics are presented for single-item measures of these variables.

Homoscedasticity is "a condition in which the variances of two or more population distributions are equal" (Bohrnstedt & Knoke, 1988: 233). The conditional standard deviations of the distributions should be the same at each "x" value (equal conditional variance). Heteroscedasticity, or differing variances, is a particular concern in regression analysis if there are less than 20-30 cases per independent variable. This regression assumption (i.e., homoscedasticity) was tested by examining scatterplot diagrams (of the dependent variables against the independent variables) for variability around the total fit line. The variable of age is of some concern in this respect, but there are more than 20-30 cases on this variable and there can be some expected variance in age due to other factors (gender, etc).

Lastly, since regression models assume the relationship being examined is linear, or at least linear enough to be approximated with a linear equation (Agresti & Findlay, 1997), this must also be examined. Scatterplots of the dependent variables against the values of the independent variables are one way of assessing linearity (Agresti & Findlay, 1997). When examining scatterplots, assessing whether a straight line or a curvilinear line is more appropriate to account for the observed data is the primary concern. Scatterplots were examined to check for even distribution across the total fit line, and were judged to be adequate. Also, the skewness statistics have already been assessed as adequate (if variables are skewed, this might create a curvilinear relationship with the dependent variable).

3.5 Qualitative analysis

While not a pre-planned aspect of the data collection, interviewers often took notes on the survey form to record respondents' comments relevant to interpreting and explaining their answers to the pre-structured survey questions. The unexpected information obtained from these notes was analyzed qualitatively, using a thematic analysis procedure based on grounded theory (Glaser & Strauss, 1967). This information was analyzed because it was felt that it added to an understanding of participation preferences and the meanings of participation for residents (tapping into the conceptual relevance of decision-making in LTC facilities). Some of the comments recorded could be compared or contrasted with previous qualitative findings that formed the basis of the research questions for this thesis; others reflect the theoretical work used to select measures for this research (i.e., comments reflecting outcome expectations). Other recorded comments were those that challenged some of the theoretical assumptions behind the research. For instance, comments reflecting the norm that residents should **not** be dependent, at least in activities of daily living, challenge the idea that institutionalization creates an "induced dependency." Some comments also were noted because they seemed to add to the context of participation in LTC facilities and/or reflect the current situation of participation (i.e., comments which indicated that the current system of participation is a reactive one, based on complaints).

The analysis procedure was based on the constant comparative method from grounded theory (Glaser & Strauss, 1967). This method involves a combination of coding and theory development and "is concerned with generating and plausibly suggesting (but not provisionally testing) many categories, properties and hypotheses" (Glaser & Strauss, 1967). This method, applied to the data mentioned above, involved the following stages:

each comment was coded into as many categories as possible, as categories emerged. Key themes or categories emerged both from important or significant sayings with particularly layered meanings (i.e. "I would like more involvement but don't NEED much"), and from comments which appeared with the greatest frequency. While attempts were made to count the codes or the frequency of responses, these numbers should be interpreted with caution. The notes used for this analysis were not part of a systematic data collection procedure and should not be considered 'pure' text. Comments used to contribute to "themes" were also those that were relevant in terms of providing background and context to respondents' answers (i.e., comments not relevant to the issue of decision-making participation, autonomy, or involvement more generally were omitted).

Based on the constant comparative method (Glaser & Strauss, 1967), a decision about the categorization or coding of a comment was made by comparing it with previous comments in a category. As this happens, theoretical properties of categories emerged, and categories were then compared. These categories provide information useful for analyzing and interpreting the quantitative data, as well as new topics and themes for discussion, and will be presented in the following chapter.

CHAPTER 4: RESULTS

4.1 Sample characteristics

One hundred residents (82 female, 18 male) of six LTC facilities were interviewed. The average age of the respondents was 85 years, and it ranged from 60 to 106. The average length of stay (to date) in the facility was 30 months. The average level of formal education among these respondents was between "some senior secondary" and "secondary school completion" (mean=4.7). The most frequently cited level (22%) was secondary school completion. The average number of reported chronic conditions was 7.

4.2 Univariate results

Selected descriptive statistics are presented in Table 9. Means, standard deviations and coding for the independent and control variables used in the regression analyses are presented in Table 10. This information for the dependent variables is in Table 13.

When asked whose decision it had been to move to a long-term care facility, 43% of residents said it had been their decision entirely; 25% felt it had been a joint decision with family or doctors; and 32% felt that others had made the decision. Twenty-four percent of respondents had, before being at the current facility, been in another type of LTC facility or hospital ward. Twelve percent of respondents felt that they did **not** have a family member or close friend available to help them in making decisions. The other 88% who felt that they did have someone available included 32% who cited a daughter, 19% who cited a son, 18% another family member, 14% a friend, 4% a spouse, and 1% their care manager as the person available to help.

TABLE 9

Selected descriptive results

Whose decision was it to move to a LTC facility?

Own decision	Joint decision	Others' decision
43%	25%	32%

Do you have a family member or close friend available to help in making decisions? If yes, who?

None	Daughter	Son	Other family	Friend	Spouse	Other
12%	32%	19%	18%	14%	4%	1%

About how long have you lived in this facility?

Six months or less	Six months to one year	One to two years	Two to three years	Over three years
20%	14%	25%	16%	25%

Activities of daily living: those who report not needing help and those who report they do

ADL	Need no help	Need any help
Eating	97%	3%
Dressing	85%	15%
Mobility	20%	80%
Transfers in and out of bed	95%	5%
Toileting	94%	6%
Bathing or showering	41%	59%

Other selected chronic conditions

Chronic Condition	Yes	No
Depression	23%	77%
Chronic Pain	29%	71%
Significant memory loss	12%	88%

Compared to others your own age, would you say your health is. . .

Excellent	Good	Fair	Poor/Very Poor
22%	45%	22%	11%

How much involvement do you think you can realistically expect/can you have in decision making about your care?

No involvement	A little involvement	A moderate amount of involvement	Lots of involvement
8%	43%	25%	24%

Twenty percent of respondents had been in the facility six months or less; 14% had been there over six months to a year; 25% between one and two years; 16% between two and three years; and 25% had been there for over three years. The average length of stay to date was 30 months.

TABLE 10

Means, standard deviations, and coding for independent and control variables used in regression analyses

Variable	Mean	SD	Coding
Gender	0.18	0.39	1=male; 0=female
Facility size	129.72	72.79	No. of beds in facility, ranging from 70 to 279
Education	4.74	2.07	Ranges from 1 (some elementary) to 9 (diploma or degree completed)
Age	85.27	7.94	Actual no. of years (60-106)
Length of stay	1.25	0.48	Months of residence (1-168) **(log)**
Entry decision	0.43	0.50	1=self decided; 0=others decided
Chronic conditions	7.29	3.68	Ranges from 0-17 (from list of 33)
Outcome expectations (alpha=.72)	16.59	2.75	Ranges from 5 to 20 (5 items); higher score=belief that active involvement will make a difference
Appropriateness	0.76	0.43	Single-item: belief that residents are entitled to their opinion in ANY matter (1=agree; 0=disagree)
Secondary control	0.80	0.40	Single-item: belief that it is important, for your well-being, to be on the staff's "good side" (1=agree; 0=disagree)
Confidence	1.42	0.73	Sum of two items (1= agree on both; 0=disagree on one or both). Items include "I know what is best for me" and "my opinion is as important as what the staff thinks"

* note: where variables are logged, reported means and SDs are for the transformed variables.

Twenty-two percent of respondents reported they are in excellent health; 45%, good health, 22%, fair health, and 11% poor or very poor, compared with others their own age. Most of the respondents needed assistance with two basic activities of daily living (personal mobility and bathing); they tended to need less assistance with eating, dressing, getting in and out of bed, and using the toilet. Respondents were asked, for example, whether they could eat without help, with some help from a device, with some help from a person, with some help from a device and a person, or were unable to. This was reflected in a five-point scale in which higher scores indicated less ability to perform the ADL independently.

Looking at the activities separately, only 3% of people needed help with eating; 5% needed assistance getting in and out of bed; 6% needed help with toileting; 15% needed assistance with dressing; and 80% needed help with getting about the facility (in 74% of cases, the assistance was in the form of a walker or wheelchair). The item on taking a bath or shower without help proved problematic, as assistance with bathing is a regulatory requirement in some LTC facilities. If a resident responded to this item by saying that everyone is required to have help, interviewers emphasized, "could you take one if they'd let you?" Nevertheless, only 41% reported needing no assistance with bathing or showering. Most others (59%) reported needing the assistance of a person or person and device. Overall combined scores representing ability in these six ADLs together ranged from 6 to 19, out of a possible 30 (mean = 9).

Despite the combined or overall scores of fairly high function for activities of daily living, many respondents reported a number of chronic conditions. Selected chronic conditions that arose from the literature review as being of particular importance included depression, chronic pain, and memory loss. Reports of these chronic conditions were

examined: 23% of respondents reported depression; 29%, chronic pain; and 12%, significant memory loss. The average number of chronic conditions reported was 7, and ranged from 1 to 17. Based on these measures of health status, there appear to be surprisingly high levels of function among the respondents: changes to LTC facility entrance criteria over the last several years in British Columbia have tended to restrict occupancy at LTC institutions to those with extreme frailty (or cognitive impairment). It may be that the concept of "frailty" is not adequately captured in this thesis' self-reported measures of physical health status.

One of the survey questions asked respondents to consider how much involvement they could generally expect, or how much involvement they feel they could realistically have in decision-making about their care. Eight percent of respondents felt they could expect no involvement; 43% a little involvement; 25% a moderate amount of involvement; and 24% felt they could have a lot of involvement. Respondents were then asked to explain their answer: this revealed a wide variety of interpretations of the question. Overall, about 28% of residents cited some characteristic of themselves that explained the level of involvement they felt they could have. For instance, residents expecting a high level of involvement sometimes justified this by reporting that they "still had their marbles" and were functioning at a level high enough to warrant a lot of involvement. About 29% of respondents cited some characteristic of the facility or the staff that warranted their answer to this question – for instance, some residents who felt they can only have a limited amount of involvement in decisions justified this by arguing that there are too many residents and/or too few staff to be able to provide high levels of decision-making involvement for all residents. Lastly, about 42% of residents had some problems distinguishing between the involvement they currently have and the

involvement they could possibly have. These respondents explained their answer to the preceding question by arguing that they felt they could have the particular level of involvement simply because that was what they currently felt they had within the facility. Neither the level of involvement residents felt they could have, nor the types of explanations they gave for this answer, were significantly related to the dependent variable measuring the desire for full, independent involvement.

Descriptive results for the vignettes are presented in Table 11. With regards to Vignette A (who should decide what time you go to bed), 72% of respondents felt that one person alone should make the decision. This includes 65% who felt that they should be the one to decide and 7% who wanted others to decide. The other 28% (n=28) who desired a joint decision, included 9% who wanted themselves to have the final say; 6% who desired equal say, and 12% who wished others to have the final say in a joint decision. A total of 19% of respondents either wanted others to decide or themselves to have little say in a joint decision. Most people (77% of respondents) prefer to go to bed early rather than late. As a result, these respondents were required to imagine a situation in which they wanted to go to bed late one night. One of the facilities participating in this research had shared rooms, and many residents in this facility were considering their room-mate when answering this question. Additionally, some residents need assistance getting ready for and into bed, and staff need to be there to help. This would have influenced some of the respondents' answers.

Vignette B concerned a choice between two kinds of medications. The difference between them related to the impact on the resident's quality of life (control of pain vs. remaining alert). Forty-nine percent of respondents felt that this should be something decided by one person. This includes 29% who felt that they should be the one deciding

and 20% who felt that someone else should decide (usually a staff nurse or doctor). The 51% of respondents who desired joint decision-making includes those who wished themselves to have the final say in a joint decision (13%), those who wanted equal say (7%), and those who felt that others should make the final decision (28%).

TABLE 11

Descriptive results for vignettes

Vignette or Decision	% of respondents wanting full, independent control	% of respondents wanting a joint decision	% of respondents wanting little say in joint decision, or someone else to make decision	Most frequently named as "other person" that should be involved
Vignette A: Bed-times	65%	28%	19%	staff
Vignette B: Medication choice	29%	51%	50%	doctor
Vignette C: Room transfer	30%	59%	26%	staff
Vignette D: Advance directive	46%	50%	11%	doctor and family

A total of 50% of residents either wanted others to make the decision about medications or wanted themselves to have little say in a joint decision. This was a confusing question for some respondents and had to be explained or repeated in many instances, in order to clarify that the difference between the medications was in their effect on quality of life, rather than on health status.

A decision about whether the resident should move rooms was the subject of Vignette C. Forty-two percent of respondents preferred that one person alone make this

decision, including 31% who felt this should be their own decision and 11% who felt that someone else should decide (usually the staff/administration). The 59% who wanted a joint decision include 36% who wanted themselves to have the final say in a joint decision; 7% who desired equal say; and 15% who wanted someone else to have the final say. For this vignette, 26% of respondents either wanted someone else to make the decision, or wanted little say in a joint decision-making situation. The wording of this vignette strongly implies the involvement of staff, who initiate the decision to move rooms.

Vignette D described a decision, made in advance, about what kinds of medical procedures will or will not be performed in the last days of a person's life. One-half of respondents wished this decision be made by one person. This includes 46% who wanted themselves alone to make the decision and 4% who wanted others to decide. Others who desired a joint decision include 34% who wished themselves to have the final say in a joint decision; 8% who desired equal say; and 7% who wanted others to decide. For this vignette, 11% of respondents either wanted someone else to make the decision or preferred little say in a joint decision-making process about advance directives. Many residents (60%) either had not discussed advance directives or similar arrangements, or could not remember doing so or signing anything indicating their preference.

While specific data were not recorded, it is an impressionistic estimate that at least one third of respondents were confused with this question and/or the idea of deciding "in advance." In these cases, attempts were made to clarify this concept, but it is possible that in some instances, if a respondent reported wanting their son to decide, he/she was actually choosing to have a surrogate decide at the time he/she is unable to. This itself, however, represents an active decision to appoint a surrogate. Another noteworthy

finding in relation to this vignette is that a bivariate correlation revealed a statistically significant association between depression and the desire for full, independent control over advance directives (see Table 12). The Chi-Square statistic (4.24) was significant at $p<.05$ (df=1). These findings indicate that those with self-reported depression are more likely to want full, independent involvement in decisions about advance directives (65% vs. 41%).

TABLE 12

Cross-tabulation table for depression and desired involvement in "advance directives" (Vignette D)

	Does not report depression	Reports depression
Does not desire full, independent control in decision about advance directives	59%	35%
Desires full, independent control in decision about advance directives	41%	65%
Total	100%	100%

Note: As the number of respondents = 100, n for each cell = %

In summary, residents preferring that others make decisions, or that they themselves have little say in joint decisions, represent the largest proportion of respondents (50%) for everyday decisions requiring technical expertise (change in medications); 26% of respondents for "big ticket" decisions not requiring technical expertise (room transfer); 19% of respondents for everyday decisions not requiring technical expertise (bedtime); and lastly, 11% of respondents for "big ticket" decisions involving technical expertise (the advance directive vignette). Note, however, that the

advance directive and medications vignettes only appear to involve more technical expertise than the other two vignettes. These questions were worded to minimize the effect that technical expertise might factor into a respondent's decision about the question.

In each of the vignettes, from one-quarter to one-half of respondents reported that they wished a joint decision be made. In the first vignette (bed-times), 49% of those who were mentioned as those who should be involved were self; 42% were staff (nurse, aides etc); and 9% were "other" (usually administration). In the second vignette (medications), 61% of all those mentioned as "should be involved" were self; 31%, a physician; 4%, a staff member (nurse, usually); and 4% were family members. Mentioned in the third vignette (room transfer) were self (48%); staff/administration (48%) and family (4%). Considered in the fourth vignette (advance directives) by respondents as being involved in a joint decision were oneself (42%), doctors (26%), family (25%), friends (4%) and staff/admin (3%). Aside from the last vignette (advance directives), family does not appear to be mentioned to any large extent. The detailed breakdown of who should be involved in the joint decision does appear to make sense, however. Residents tended to cite staff as the most important others to be involved in joint decisions for the vignettes involving bedtimes and room transfers (those requiring the least medical-technical expertise, but also those most relevant to the interests of the staff and/or administration). Residents also tended to cite physicians as the most important to be involved in the decision about medications. For the decision about advance directives, both doctors and family received about equal recognition as the other who should be involved in the decision.

Whether or not one had experienced a situation similar to the vignette was noted in the survey. Overall, 23% had experienced a situation similar to Vignette A(bedtimes). Eighty-six percent of these made the decision on their own and the vast majority (21 of 23 cases) were satisfied with how the decision was made. Note, however, that one observation resulting from this research is that satisfaction with how the decision was made was often equated with satisfaction with the outcome of the decision itself. Only 10% of respondents had experienced a situation similar to that in Vignette B (medications) and most of these had decided on their own. The majority (9 of 10 cases) was satisfied. A somewhat greater number (22%) had experienced a situation similar to Vignette C (room transfer). Most of these decided on their own and the majority (20 of 22 cases) was satisfied. Finally, 40% reported experiencing a situation similar to Vignette D (advance directives), and over half of these decided on their own. Once again, the majority (35 of 40 cases) was satisfied with the way the decision was made.

For each vignette, respondents who wanted full, independent decision-making were coded separately (for analytic purposes) from those who wanted some kind of joint decision and those who wanted one other person to make the decision. Constructing this dichotomous measure of the dependent variable was done to isolate the most independent residents. There are four different vignettes, and it is feasible that the greater number of different situations in which someone chooses to make the decision entirely on their own represents a desire for greater control or involvement. The sum of the desire for full, independent involvement (full, independent=1, all other=0) for all four vignettes represents the first form of the dependent variable, ranging between 0 (no decisions in which they wanted self only to decide) and 4 (all decisions, they wanted self only to decide). The mean for this variable was 1.7 (SD=2); frequencies and coding are presented

in Table 13. In vignette A (bedtimes), 65% desired they alone make the decision; in Vignette B (medications), 29%; in Vignette C (room transfers), 30%, and in Vignette D (advance directives), 46%. Overall, 21% of respondents always thought the decision should be joint or made by someone else; 22% expressed the desire for self decision-making in one vignette; 29% in two; 22% in three; and 6% in four.

For the second analysis, a dependent variable representing the desire for active involvement was constructed that summed the four vignettes based on a score for each vignette representing the degree of involvement or control desired by the individual. Scores for each vignette range from 1 (full independent decision-making desired) and 5 (others make the decision), with joint decision making in the middle of the continuum. The summed variable ranges between 5 and 20, with a mean of 14.68 (SD=3.55). The coding for this variable is presented in Table 13.

For the third form of the dependent variable, representing the desire for joint decision-making, actual scores ranged from 0 to 6 (of possible 0-8) but responses at the higher end of the measure were rare, with less than 10% of cases scoring either a 5 (7%) or a 6 (1%). These scores were recoded into "4"s for the purposes of analysis. The mean for this variable was 2.0 (SD=1.3); coding and frequencies are presented in Table 13.

TABLE 13

Coding and frequencies for dependent variables used in regression analyses

Preference for full, independent involvement in decisions: greater score representing greater number of four different vignettes for which respondent desires full, independent decision-making (i.e. self only) involvement

Score	Frequency	Coding
0	21%	0 of 4 vignettes
1	22%	1 of 4 vignettes
2	29%	2 of 4 vignettes
3	22%	3 of 4 vignettes
4	6%	4 of 4 vignettes

Preference for active involvement in decisions: greater score representing more active involvement/control desired, summed across all four decisions

Mean	Standard Deviation	Range
14.68	3.55	5 to 20, where 5=desire to have others decide in all four vignettes and 20=desire to it to be one's own decision in all four vignettes.

Preference for joint decision-making: greater score representing greater desire for joint decision-making, summed across all four decisions

Score	Frequency	Coding
0	14%	Least desire for joint decision-making
1	27%	
2	23%	
3	16%	
4	12%	
5	7%	
6	1%	Greatest desire for joint decision-making

4.3 Bivariate results

For each of the vignettes, bivariate analyses (cross-tabulation, Pearson's r) were performed to determine whether or not an association existed between whether or not someone had experienced a situation similar to that described in the vignette and their preference for full, independent involvement in that decision, if it were to be made again. The only vignette for which previous experience with the decision was related to the desire for full, independent control was the first vignette (bed-times). This correlation suggests that those who had previously experienced a similar decision about the time they go to bed were more likely to want full, independent control of this decision. The Chi-Square statistic for this cross-tabulation was 6.33 ($df=1$; $p<.05$).

Bivariate correlations between variables used in the regression analyses are displayed in Table 14. Analyses of the relative strength of the bivariate correlations and estimates of variances explained utilized the r-squared value. A statistically significant bivariate correlation with the dependent variable representing the desire for full, independent decision-making (summary measure) was found for education ($r=0.21$; $p<.05$), in the positive direction, which would suggest that those with higher education desire more control. Confidence was also positively correlated ($r=0.28$; $p<.01$) with this dependent variable, indicating that more confident residents are more likely to want more independent involvement in decisions. Education explained approximately 4% of the variance in the desire for full, independent involvement, whereas confidence, a relatively stronger predictor, predicted about 8% of the variance.

When preferred involvement is measured as the degree of preferred active involvement (summed for all four vignettes), education was still positively and significantly associated at the bivariate level ($r=0.28$; $p<.01$), as was confidence ($r=0.37$;

$p<.001$). The number of chronic conditions ($r=0.21$; $p<.05$) was also positively associated with desired active involvement at this level of analysis. Analyses of the r-squared values for these associations with the desire for active involvement reveal that the number of chronic conditions explains less (4% explained) variance relative to education (8% explained), and that confidence explains relatively the most variance (approximately 14% of the explained variance in desired active involvement). Interestingly, the direction of the association between chronic conditions and the desire for active involvement was different than expected – those with more chronic conditions, it appears, are more likely to want greater active involvement in decision-making. This finding is related to another bivariate correlation between the number of chronic conditions and responses to the question "I have the ability to decide about medical problems" ($r=0.21$; $p<.05$), which suggests that those with more chronic conditions are more likely to believe they have greater ability to make medical decisions. Additionally, in an open-ended question included in the survey, residents were asked how they thought their health affected their desire to make decisions. Comments reflective of the above finding would include: "The sicker I get the more I want to decide, I'm a stubborn Scotsman"; "I can get above health problems to be involved"; " I feel I need to be involved regardless of health"; "I would get involved to distract myself, to keep thinking"; "The more unhealthy you are, the more decisions you need to make"; and, "Now that I'm in such pain I want to take control of my destiny."

Significant associations at the bivariate level were also found between the third form of the dependent variable (the desire for joint decision-making involvement) and outcome expectations ($r=0.24$; $p<.05$), suggesting that those who believe their involvement will make a difference are more likely to express a desire for joint

involvement. The r-squared value for this association indicates that outcome expectations might explain about 6% of the variance in the desire for joint involvement. The fact that there are different associative factors related to preference for joint involvement and preference for active involvement supports a conceptualization of the two as different.

Bivariate correlations also revealed that the reported number of chronic conditions and perceived health were negatively correlated ($r=-0.32$, $p<.01$), revealing that those with more chronic conditions tend to report poorer self-perceived health. Chronic conditions was also positively correlated with ADLs ($r=0.23$; $p<.05$) revealing that those with more chronic conditions also tend to report needing more assistance with basic activities of daily living.

Interestingly, neither perceived health nor ADL impairment had a significant association with the desire for full/independent or active involvement; the summary measure of the desire for active involvement did, however, correlate with chronic conditions ($r=0.21$; $p<.05$). While the predicted relationships between "whose decision was it to enter the facility" and the desire for both full, independent involvement (summary of dichotomous measures for the four vignettes) and active involvement (summary of scale measures for the four vignettes) was not significant at the bivariate level, the relationship was in the assumed direction: those who felt they had no control over their entry into the LTC facility wanted less active involvement. Also, while neither facility nor unit size were significantly associated at the bivariate level with the desire for full, independent involvement or the desire for active involvement, the direction of these relationships is in the assumed direction. With increasing facility and unit size, individuals may want less control.

TABLE 14
Bivariate correlations for variables used in regression analyses

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Gender	1.00	/										
2. Fac.size	0.10	1.00	/									
3. Educat.	0.17	0.03	1.00	/								
4. Age	-0.21*	-0.01	-0.24*	1.00	/							
5. Stay	-0.05	-0.17	0.01	0.14	1.00	/						
6. Entry	-0.15	-0.02	0.05	0.12	0.21*	1.00						
7. Chronic	-0.22*	-0.05	-0.12	0.07	-0.09	0.19	1.00	/				
8. Outcome	-0.07	-0.07	0.01	-0.09	0.14	0.06	-0.05	1.00	/			
9. Approp	0.14	0.03	0.04	-0.70	0.12	-0.12	0.06	0.10	1.00	/		
10. Second.	0.10	0.10	0.02	-0.04	-0.14	0.12	0.01	0.02	0.01	1.00	/	
11.Confid.	-0.06	-0.11	0.05	-0.06	0.16	0.16	-0.00	-0.03	0.21*	0.06	1.00	/
12. Preference for full, independent involvement	-0.01	-0.06	0.21*	-0.03	0.18	0.14	0.17	-0.15	0.09	-0.17	0.28**	1.00
13. Preference for active involvement	-0.04	-0.12	0.28**	-0.10	0.14	0.13	0.21*	-0.05	0.19	-0.17	0.37***	.796***

*p<.05; ** p<.01; *** p<.01

Note: Preference for joint involvement is not included in this table.

Other bivariate associations of particular interest include that between the decision to enter the facility and length of stay ($r=0.21$; $p<.05$), suggesting that those with longer lengths of stay are more likely to report having made the decision on their own. Confidence and the belief in the appropriateness of active involvement were also positively associated ($r=0.21$; $p<.05$), indicating that those believing that active involvement is appropriate have greater confidence in the worth of their contribution to decision-making.

Cross-tabulation tables between the independent and dependent variables (and associated Chi-Square statistics) were also examined. Many of the variables had to be re-coded before cross-tabulation analysis to allow for expected cell frequencies of five or greater. Specifically, age, education, chronic conditions, facility size, length of stay, and outcome expectations had to be recoded to collapse categories. Additionally, all of the three summary forms of the dependent variable that were used in this particular analysis were collapsed into dichotomous variables (based on the median). Apart from those significant Chi-Square statistics reported earlier (in relation to depression and preference for full, independent control over the fourth decision, advance directives; and experience with a similar situation and preference for full, independent control over the first decision, bed-times), significant relationships were found between confidence and preference for full, independent control in the four vignettes ($x^2=8.3$; $p=.00$); between confidence and preference for active involvement in the four vignettes ($x^2=8.5$; $p=.00$) and between outcome expectations and the desired level of active involvement in the four vignettes ($x^2=4.0$; $p=.05$). The level of confidence that a resident has, as well as his/her belief that something will be done in response to their concerns, is associated with a greater desire to be involved in decision-making. Additionally, cross-tabulation analyses

of the independent variables with the dependent variable measuring preference for joint involvement revealed a statistically significant Chi-Square value for outcome expectations (x^2=3.9; p=.05), indicating an association between the belief that something will be done about one's concerns, and the desire for joint decision-making.

ANOVA and t-tests used to compare the means of different groups did not yield significant results, with two exceptions. When two groups of residents were created based on whether or not their facility had a more active resident council mandate, there was a significant difference between the two means (t= -2.06; p<.05). Those in a LTC facility with a more active council mandate appear to be less likely to prefer joint involvement; they are also more likely to be "disgruntled" (a variable created based on resident comments – see pg. 120-121) – the Chi Square value for this association is 8.05 (df=1; p<.01).

4.4 Multivariate results

Regression of the independent and the control variables in three models was first conducted using the dependent variable representing the number of vignettes (ranging from 0 to 4) for which the respondent desired full, independent decision-making (see Table 15). In the initial model, education and the number of chronic conditions emerged as significant. That is, those with more education (b=0.23; p<.05) and more chronic conditions (b=0.22; p<.05) were likely to want full, independent decision-making. This model explained only 5% of the variance in the dependent variable. These relationships, however, remained significant (b=0.21; p<.05 for education, and b=0.23; p<.05 for chronic conditions) with the addition of facility-related variables in the second model, which still only explained 7% of the total variance in the dependent variable. Education

and chronic conditions also remained significant predictors (in the positive direction: b=0.20; p<.05 for education, and b=0.22; p<.05 for chronic conditions) when cognitive-adaptive variables were added in the third model. This third model explained a greater amount (16%) of the total variance in the dependent variable. Additionally in the third model, confidence emerged as a significant predictor (b=0.28; p<.01) in the positive direction. Those with more confidence were more likely to prefer full, independent control in more of the four vignettes. In the third model, the standardized beta squared was used as an estimate of variance explained for each significant variable. Education explained about 4% of the variance in the desire for full, independent involvement; chronic conditions, 5%; and confidence explained relatively the most variance (8%). The total variance explained by all predictors in each of the three models was 5%, 7% and 16%, respectively.

Separate logistic analyses on each of the four vignettes were performed using the vignette-specific dichotomous measures of this variable. These analyses are presented in Appendix E. For Vignette A (bedtimes), secondary control (single-item measure) was a statistically a significant predictor in the negative direction (p=.03), indicating that those who did NOT feel it was important to be on the staff's good side were more likely to want full, independent control over their bed-time. Specifically, when a resident expresses that it is important to be on the staff's "good side," this decreases the odds that he/she will desire full, independent control over the decision about bedtimes by about 82%, controlling for other variables in the model (OR=.18)

TABLE 15

Impact of independent and control variables on the desire for full, independent involvement in decision-making

	Model 1			Model 2			Model 3		
Variable	**B**	**Beta**	**p**	**B**	**Beta**	**p**	**B**	**Beta**	**p**
Age	-0.01	-0.05	ns	-0.01	-0.08	ns	-0.01	-0.07	ns
Gender	-0.01	-0.00	ns	-0.04	-0.01	ns	0.10	0.03	ns
Education	0.13	0.23	<0.05	0.12	0.21	<0.05	0.11	0.20	<0.05
Chronic cond.	0.07	0.22	<0.05	0.08	0.23	<0.05	0.07	0.22	<0.05
Length stay				0.48	0.20	ns	0.36	0.15	ns
Entry decision				0.13	0.05	ns	0.12	0.05	ns
Facility size				-0.00	-0.00	ns	0.00	0.02	ns
Outcome							-0.06	-0.14	ns
Confidence							0.68	0.28	<0.01
Secondary Cont.							-0.44	-0.15	ns
Appropriateness							0.04	0.02	ns
a	1.16	---	ns	0.98	---	ns	1.85	---	ns
R^2	0.05	---	---	0.07	---	---	0.16	---	---
F	2.38	---	ns	2.03	---	ns	2.60	---	<0.01
df	4	---	---	7	---	---	11	---	---

Additionally, the two-item measure of confidence was predictive (p=.02) in the positive direction, indicating that when a resident expresses greater confidence in the worth of their contribution, this increases the odds that he/she will desire full, independent control over bedtimes by about 225%, controlling for other variables in the model (OR=3.25).

Confidence was also predictive of desired full, independent control (p=.03) for Vignette B (medications): confidence increases the odds that a resident would desire full, independent control over the medication choice by about 269%, controlling for other variables in the model (OR=3.69). Similarly, the odds of desiring full and independent control over the medication decision increased by about 16% for each additional chronic condition reported (OR=1.16; p=.05). No variables emerged as significant predictors of the desire for independent involvement in a decision about room transfers (Vignette C). Lastly, outcome expectations predicted desired independent control (p=.01) in a negative direction for the advance directives vignette (D). Each unit increase in the belief that participation will make a difference is decreases the odds that a resident will desire full, independent control over the decision about advance directives by about 21%, controlling for other variables in the model (OR=.79).

In summary, predictors of the number of vignettes for which respondents preferred full, independent control, in the overall analysis included education and chronic conditions, with confidence explaining most (8%) of the overall variance. The only common predictor of preference for full, independent involvement across the four vignettes was confidence, which was a strong predictor in the vignettes about bedtimes and medications. Otherwise, secondary control predicted the desire for full, independent control of bedtimes; chronic conditions predicted the desire for full, independent control

of medication changes; and outcome expectations predicted the desire for full, independent control of decisions about advance directives.

Next, regression analyses were run using the desire for active involvement (from 1 to 5 for each vignette), summed across the four vignettes. In the first model, which explained 12% of the variance in the dependent variable, education ($b=0.29$; $p<.01$) and the number of chronic conditions ($b=0.26$; $p<.01$) were significant predictors in the positive direction. Again, these remained significant (education at $b=0.28$; $p<.01$, and chronic conditions at $b=0.27$; $p<.01$) in the same direction with the addition of the facility-related variables in the second model (which explained 13% of the variance in the dependent variable). With the addition of the cognitive-adaptive variables in the third model (which explained 25% of the variance in the dependent variable), the effects of education ($b=0.26$; $p<.01$) and chronic conditions ($b=0.25$; $p<.01$) remained, and as in the first analysis, confidence also emerged as another predictor of desired active involvement in the positive direction ($b=0.33$; $p<.001$). This indicates that residents with more formal education, a greater number of chronic conditions, and greater confidence in the worth of their contribution to decision-making are more likely to want greater levels of active involvement in decision-making. These results are presented in Table 16. Examination of the standardized beta-squared values for the third model in this analysis revealed that chronic conditions explain about 6% of the variance in desired active involvement; education, 7% of the variance; and confidence explains relatively the most variance (11%) in the dependent variable.

Separate analyses were then run with each of the four vignettes (using the measure of the desire for active involvement as the dependent variable). Results in table form for these analyses are presented in Appendix E. For Vignette A (bed-times), no

TABLE 16

Impact of independent and control variables on the desire for active involvement in decision-making

	Model 1			Model 2			Model 3		
Variable	**B**	**Beta**	**p**	**B**	**Beta**	**p**	**B**	**Beta**	**p**
Age	-0.05	-0.10	ns	-0.06	-0.13	ns	-0.04	-0.10	ns
Gender	-0.46	-0.05	ns	-0.28	-0.13	ns	-0.07	-0.01	ns
Education	0.49	0.29	<0.01	0.48	0.28	<0.01	0.44	0.26	<0.01
Chronic cond.	0.25	0.26	<0.01	0.26	0.27	<0.01	0.24	0.25	<0.01
Length stay				1.15	0.16	ns	0.52	0.07	ns
Entry decision				0.30	0.04	ns	0.31	0.04	ns
Facility size				-0.00	-0.07	ns	-0.00	-0.04	ns
Outcome							-0.06	-0.05	ns
Confidence							2.40	0.33	<0.001
Secondary Cont.							-1.38	-0.15	ns
Appropriateness							0.80	0.09	ns
a	14.65	---	<.0.001	14.54	---	<0.001	14.10	---	<0.001
R^2	0.12	---	---	0.13	---	---	0.25	---	---
F	4.20	---	<0.001	3.00	---	<0.001	3.84	---	<0.001
df	4	---	---	7	---	---	11	---	---

statistically significant predictors emerged in the first or second models. For the third model, secondary control, a single-item indicator, was predictive in the negative direction ($b=-0.22$; $p<.05$), and belief in the appropriateness of active involvement, another single-item indicator, was predictive in the positive direction ($b=0.21$; $p<.05$). That is, those who believed that they were entitled to their opinion, and those who felt that it was **not** important to be on the staff's "good side," tended to want more active involvement in a decision about their bed-time. This full (third) model explained 12% of the variance in the desire for active involvement. Examination of the standardized beta-squared for this model reveal that both secondary control and the belief in the appropriateness of active involvement explained about 4% of the variance in desired active involvement.

For the Vignette B (choice between medications), the full (third) model explained 14% of the variance in desired active involvement. Length of stay ($b=0.23$; $p<.05$) emerged as significant in the positive direction for the second model, but this effect disappeared in the third model, while the number of chronic conditions ($b=0.24$; $p<.05$) and confidence ($b=0.35$; $p<.001$) emerged as significant in the positive direction. Examination of the standardized beta-squared values for the significant predictors suggests that chronic conditions explain 6% of the variance in desired involvement for this vignette, and that confidence explains relatively more variance (12%).

Education was the only predictor for desired involvement ($b=0.23$; $p<.05$ in the positive direction) in Vignette C (room transfer), and this variable remained significant across all three models. Those with greater levels of formal education tended to want more active involvement in decisions made about room transfers. The full (third) model explained 11% of the variance in the dependent variable for this vignette, yet education only accounts for 5% of this variance (based on standardized beta-squared values).

For Vignette D (advance directives), the number of chronic conditions and education were significant predictors of desired active involvement in all three models: For education, b=0.21; b=0.20; and b=0.20 for the three models respectively ($p<.05$ for all). For chronic conditions, b=0.22; b=0.23; and b=0.21, respectively ($p<.05$ for all). Outcome expectations were also a significant predictor in the third model (b= -0.30; $p<.01$), but in the negative direction, indicating that those who had little faith in the responsiveness of the facility to their concerns were more likely to want to be actively involved in this decision. The third, full model for this vignette explained 16% of the variance in the dependent variable. Examination of the standardized beta-squared values suggests that education and chronic conditions (both explaining about 4% of the variance) are weaker predictors than outcome expectations (explaining about 9% of the variance) for this vignette.

To summarize, predictors of the level of desired active involvement across the four vignettes included chronic conditions and education, with confidence again explaining the most variance in the dependent variable. Predictors of desired active involvement among the four vignettes again differed. The desired level of active involvement in the decision about bedtimes was predicted by secondary control (as in the analysis explaining preference for full, independent control) and by the perceived appropriateness of active involvement (both explaining about equal proportions of variance in the dependent variable). As in the analysis of predictors of the desire for full, independent control, both chronic conditions and confidence predicted the desire for active involvement in the decision about medications, with confidence again explaining more of the variance. A significant predictor of the desire for active involvement in the decision about room transfers was education. This was not revealed in the analysis of

predictors of the desire for full, independent involvement. Lastly, outcome expectations predicted the desire for active involvement in the decision about advance directives. It also predicted the desire for full, independent control in this decision. However, additional predictors included chronic conditions and confidence (though outcome expectations remained the strongest predictor).

Linear regression analyses of the impact of independent and control variables on preference for joint decision-making revealed that only outcome expectations significantly predict the desire for joint decision making ($b=0.24$; $p<.05$ in the third model). This indicates that those who believed that the facility was responsive to their concerns tended to want joint decision-making. However, the third model only explained 5% of the total variance in the dependent variable (attributed to the variable measuring outcome expectations). Results of this analysis are presented in Table 17. In separate logistic analyses of the impact of independent and control variables on preference for joint decision-making (versus the desire for one-party decision making) for each of the four vignettes (see Appendix E), no variables emerged as significant for Vignette A, B or D. For Vignette C (room transfer), facility size emerged as significant in the second model, and remained significant ($p=.03$ in the negative direction) with the addition of the cognitive-adaptive variables. Each increase in facility size in this analysis decreased the odds that a resident would want joint involvement by about 1%, controlling for other variables in the model ($OR=.99$).

In four additional analyses, the cognitive-adaptive variables (confidence, outcome expectations, secondary control and appropriateness of involvement) were treated as separate dependent variables, and regressed on the independent and control variables. The results are presented in Appendix E. There were no statistically significant predictors of

outcome expectations in a linear regression, or secondary control in a logistic regression. For residents who believe that active involvement is appropriate, the odds that the resident expresses confidence in the worth of his/her opinion increases by about 204%, controlling for other variables in the model (OR=3.04; p=.04). Only entry decision predicted the belief in the appropriateness of active involvement (OR=.31; p=.05), but in an unexpected (negative) direction: the belief that it was his/her decision to enter the LTC facility decreases the odds that the resident will express the belief that active involvement is appropriate by about 69%, controlling for other variables in the model. The implications of these findings will be discussed in the following chapter.

TABLE 17

Impact of independent and control variables on the desire for joint decision-making

	Model 1			Model 2			Model 3		
Variable	**B**	**Beta**	**p**	**B**	**Beta**	**p**	**B**	**Beta**	**p**
Age	0.00	0.02	ns	0.01	0.05	ns	0.01	0.08	ns
Gender	0.16	0.05	ns	0.12	0.03	ns	0.12	0.04	ns
Education	-0.08	-0.12	ns	-0.07	-0.11	ns	-0.07	-0.11	ns
Chronic cond.	-0.05	-0.13	ns	-0.06	-0.15	ns	-0.06	-0.15	ns
Length stay				-0.46	-0.17	ns	-0.56	-0.20	ns
Entry decision				-0.04	-0.01	ns	0.01	0.01	ns
Facility size				0.00	0.01	ns	0.00	0.01	ns
Outcome							0.13	0.24	<0.01
Confidence							-0.31	-0.11	ns
Secondary Cont.							0.07	0.02	ns
Appropriateness							0.34	0.11	ns
a	2.37	---	ns	2.56	---	ns	-0.01	---	ns
R^2	-0.01	---	---	-0.01	---	---	0.05	---	---
F	0.78	---	ns	0.83	---	ns	1.46	---	ns
df	4	---	---	7	---	---	11	---	---

4.5 Observational results: emerging themes

The following are some of the most common themes relating to preference for active involvement in decision-making, as identified in the qualitative analysis of recorded respondent comments. The frequencies of the items in these notes are recorded in order to determine whether categories reflects general themes or an occasional response.

Norm of Independence in Care

One theme emerged based on comments such as "I don't expect much"; "I'm reasonable"; "I'm not a nuisance" or "I'm fair" (n = 12). One resident also suggested that "I would like more involvement but don't NEED much." The underlying idea within these comments is that residents *should* do all they can to make things easy on the staff, including doing what the nurses say without argument, and not being dependent on them for care. This social norm also emerged in responses to one of the scale items: specifically, whether it is a resident's duty to sit back and let the staff take over. Residents who agreed with this statement (58%) often added that they felt residents should do what they can to care for themselves, hence making things easier on the staff. This aversion to care "dependency" might reflect a social norm emphasizing independent care for self: responses to the above questions may be affected by the perceived social desirability of independent living. Several respondents (as an estimate, about 5) proudly declared that they did not need a lot of hands-on care, and that they were independent. This independence was almost always discussed in relation to activities of daily living, however, rather than decision-making. This is congruent with findings by Wahl (1991),

indicating a strong tendency towards independence in ADLs among elderly persons. Additionally, in qualitative interviews by Reed and Stanley (2000: 174), "some older people expressed their concern to avoid being a burden to others."

The fact that some residents expressed a preference for independence in ADLs as appropriate highlights the crucial issue of the definition of care in this research. While specific numbers were not recorded, it did seem evident in conversations with residents that many residents accepted the need for care as something done to self by staff; very few acknowledged that "care" included decision-making. A serendipitous finding that emerged in this thesis is that the definition of care, as intended in the survey, was not how many residents conceptualized it. Similarly, there were different interpretations of "decisions." For instance, some residents think about daily decision-making in terms of choices about what to do, rather than about what is done to oneself. The distinction between decisions about what to do in a given day (activities) and decisions about what gets done to the resident (care) is an important one. In response to the statement "there are enough choices for me here," residents tended to indicate that they had a lot of control regarding things to do in a given day, but less control about what gets done to them in terms of care. This is an interesting finding in relation to the definition of care. Since activities that residents do during the day can affect their health (and the need for traditional 'care' services), if care is defined broadly as "anything done to enhance health," then involving residents in their care planning should include BOTH their involvement in decisions about what activities they wish to participate in ('care,' broadly defined), and in decisions about what gets done to them (traditional 'care'). Considering the similarities and differences between the concepts of the desire for resident

involvement in activities and the desire for involvement in decision-making about care is an avenue for future research.

Preferences as Irrelevant

While residents expressed strongly independent views about activities of daily living in the facility, they often expressed less independent views about decision-making. Asking about preferred levels of involvement in decision-making often had little relevance for respondents. For instance, two responses to this query included: "It's not a question of what I would prefer, but I'm happy"; and "I'm here, under their care, so what I want does not matter." Another serendipitous finding was that respondents had an especially hard time distinguishing between the involvement they thought they should expect, and what they wanted (numbers were not recorded). In these cases, preferences were almost inextricable from the "should" (Benbassat et al., 1998; Sutherland et al., 1989; Smith et al., 1984).

A similarly interesting (yet unexpected) finding was that respondents had problems distinguishing between possible levels of involvement and actual levels of involvement. When asked about the amount of involvement they felt they realistically could have, 42% of those interviewed cited responses that were grouped under the category of "that's the way it is here." Also, over one-quarter of respondents interpreted this question not in terms of restrictions within the institution, but in terms of their own capacities (i.e. "I don't need care, therefore I don't need much involvement"). There were those, however (29%), who identified the realities of life in the facility as determining the amount of involvement they could have.

Desirability of Outcomes

Preferences for involvement were often confused with preferences for the outcome of the decision. For instance, it is an impressionistic estimate that many respondents, when asked "who should decide" about a decision (for instance, whether they should move rooms), tended to answer directly based on their preference for the outcome (i.e. their desire to move). At least one resident confirmed this observation with her comment, "I should have the privilege of deciding, especially if I like the room." Whether respondents wanted to move was important in determining how much control they desired over the decision. However, this pattern does indicate a preference to have an independent say in the decision from the outset. Ultimately, this observation points to the importance of the "personal relevance" of the care decision being made in affecting preferences for involvement.

Control is, of course, strongly tied to preferred outcomes. In fact, Reid, Haas and Hawkings (1977) developed a measure of locus of control that included a rating of the desirability of the outcomes. Additional conceptual work is needed to look at how "involvement" and "control" overlap. For instance, does "involvement" necessarily mean "getting your own way?" In this thesis, the desire for involvement was discussed in terms of preference for active, goal-oriented, primary control in decision-making (actual decisional control) and the responses tended to reflect the amount of desired control over a decision (i.e., who should make the decision/have the final say). Some people, however, might also prefer to simply "have their say" and achieve another kind of control in this manner. For these individuals, involvement might require only that they are consulted and listened to, no matter what the degree of control over the outcome of the decision.

Because of the conceptual overlap between involvement and control over the outcome, a lack of expressed preference for involvement may reflect a lack of interest in the outcome. For some, their room is a priority. Others dislike, or are ambivalent about their room. Interest in the outcome is potentially related to a wide variety of factors, just as is interest in being involved. Alternative factors influencing interest in the outcome might include depression, or personality characteristics, or personal priorities. Acquiesence, however, might also be fostered in an institutional environment, and lead to an expressed lack of interest in what is done to oneself. Additionally, a lack of interest in an outcome may reflect a belief that involvement really will not make a difference. The complexity of decision-making participation preferences is evident when one tries to disentangle these factors.

Reactive Structure of Involvement

While the purpose of this research was to consider whether residents wanted up-front involvement in care decisions, another noteworthy observation was that the residents had a keen sense of how things currently worked in the facility. This was reflected in observations such as: "They're good, if things come up"; "If you have a concern, they're pretty good at carrying on with it"; "You're responsible for speaking up"; "They never ASK"; "There are not any decisions to make"; "If you need something, they are responsive"; and "If I complain, they take notice" (n = 14). Reactive, not proactive, involvement is the norm.

Residents who felt their problems were addressed in this system appeared happy, which raises the question of whether proactive involvement is really necessary. One resident noted: "They can make the decisions as long as I'm happy." Satisfaction with

involvement was almost always confounded with satisfaction with the actual outcome, as will be discussed in further detail later. For instance, this might mean that if residents are kept happy through an effective complaints system, they would not desire greater control, or would not need to be offered a more proactive form of involvement.

As one way of addressing this question, after the data were collected, the researcher went through each of the interviews and coded the respondent either as "disgruntled" (1) or "not disgruntled" (0). A resident was categorized as "disgruntled" if comments indicated that they were particularly unhappy with a decision that had been made; or a lack of action on their concerns; if they expressed that they would like more involvement, or were otherwise upset by how the facility was run. Twenty-four percent of the residents emerged as "disgruntled" in some way, and in bivariate correlations, this emerged as significantly positively related to the desire for active involvement ($p<.05$ for both the dichotomous and continuous dependent variables), as well as to confidence ($p<.05$). This analysis suggests that residents who are dissatisfied or otherwise disgruntled with the facility and/or staff are more likely to want active involvement in decision-making. Interestingly, they are also more confident, although this may simply reflect the fact that more confident residents would be more likely to express their dissatisfaction.

But what does this system of complaints and reactive involvement mean for non-confident residents? One respondent had concerns but did not feel comfortable going to resident council because she felt she was "not the same person" after her stroke, had trouble remembering words, and did not feel confident to attend. Another respondent felt she had "gotten into trouble" one day for voicing her opinion, while another said she felt

she lacked confidence when she first entered the facility, and another said that too many complaints result in the staff paying less attention.

One of the difficulties with a complaints system of involvement, as noted by other authors, is that it often ignores structural barriers to change (Beardwood et al, 1999). In LTC facilities, restrictions and policies can limit the potential for resident-initiated change. If complaints are made but nothing is done because of policies and regulations, residents may become increasingly frustrated at not being able to change the policies and regulations. A good complaints system would not deflect attention from real, underlying structural issues in providing care (Nettleton & Harding, 1994). For instance, an effective complaints system might involve taking individual complaints and discussing them with a resident council, identifying policy or regulatory barriers where they exist, and providing some means of joint action on change in policy or regulation.

Reasonable Complaining

Generally, respondents seemed confident about speaking up. For instance, fully 60% felt confident about commenting about the care they receive, based on responses to a single-item measure in the survey. However, there may be problems with how "being reasonable in complaining," or complaining in reasonable ways, is defined. One common theme among resident comments was that "whining" is inappropriate; that "good" complainers complain constructively, in serious and reasonable situations, only "when necessary," and to the "appropriate authorities." "Bad" complainers question too much, complain about things that can't be changed, or complain to other residents (n= 9). This is another avenue that is worthy of exploration in future research.

At least a few residents (n=4) commented that they would like to be given active involvement and/or control: "If a question arose and they asked, I'd give my opinion, but this does not seem to be how it is now"; "People shouldn't be demanding but they should have something to say, they should be asked"; "I should get a chance to be asked my opinion, If they don't agree and can explain it to me, okay. But I should still be allowed to have a say."

Disillusionment with the Complaints System

In contrast to residents who emphasized the efficiency of staff in resolving complaints and concerns, other residents had lost faith in the complaints system. They lacked positive outcome expectations, or the belief that involvement within a reactive, complaints-based system, would make a difference (n=17). Their comments include the following: "If I know something, I keep my mouth shut. . . it only causes trouble and probably won't change things anyways"; "You are responsible for speaking up – but they won't listen, they'll do what they want"; "Nobody listens, wouldn't make a difference"; "The staff might listen, but wouldn't do it anyways"; and, "If you have a say, nothing happens." Some people also thought the resident council would also not change anything. Additional comments reflecting this theme include the following: "They listen, to a point"; "One nurse listens, but nothing happens"; "Challenging things does not do any good." One resident said the reason for this lack of responsiveness is that the staff are "short-staffed and absentminded." This theme was also expressed in relation to food. Some residents (an estimated 10%, though specific numbers were not recorded) complained about the food itself, the lack of control over the food, and the lack of action on complaints to staff or administration about food. While there are obvious problems

trying to satisfy large numbers of residents with divergent tastes, at least two residents were actually refusing to eat the food and losing weight as a result!

Trust in Experts

In the vignettes, those who wanted their doctor to decide often cited a lasting, strong relationship of trust with their physician. Many saw doctors and nurses as specialized experts: "It's really their job to decide"; "They are trained for this"; "The [residents] here are not capable; they [staff] are paid to know their job"; "They are bound to be better decisions than mine" (items = 10). Trust was a crucial issue in terms of whether a resident wanted to involve the staff in decisions; one resident felt she could decide, but wouldn't want much involvement because she felt the staff were capable and had her trust.

Additionally, certain residents expressed keen awareness of the staff hierarchy in the facility, from care aides to nursing staff to administration. They often felt differently towards different elements of the hierarchy, particularly towards staff and administration. For instance, at least one respondent made the distinction that residents should complain "to the appropriate authority" (i.e., management) in order to get action taken on their concerns. One limitation of the questionnaire is that all of these groups are combined as "staff." Pre-constructed response categories did not allow for separate distinctions between "management," "care aides," and "nurses."

Awareness and Acceptance of Structural Restrictions

As in past qualitative research on long-term care facility residents, there seemed to be an awareness of restrictions on involvement and control among many of those interviewed. For instance, respondents commented that, "The staff are doing their best under the circumstances," and "It's too much to expect them to come before the decision is made, there is just not enough staff". The administration and the way the home must be structured limits flexibility and independence; this is often acknowledged as a necessary requirement. Some respondents acknowledged the attempts of certain sincere, sympathetic staff, yet were aware of the limitations of the structure and policies of the facility. Many of the respondents (n=18) seemed to accept restrictions and routines as necessary, and accept that "they are running the show," and that "you've got to fit in the picture" of how things are done. This theme relates to the concept of secondary control, which also seemed to be expressed by residents: "be strong enough to ignore the little things and to do some things about the things you can change." Some residents expressed the view that there is a strong necessity for the individual to adjust to the environment, because there is no other choice. The conditions cannot be changed. In a study by Reed and Stanley (2000), this phenomenon was labeled "stoicism." For example, 26% of respondents strongly agreed, and 57% somewhat agreed, that: "the best advice to a new resident is to just roll with the punches." Additionally, one resident commented that she was "getting used to" having someone tell her what to do.

4.6 Institutional Totality – results of the facility contact questionnaire.

One element of the data collection process involved the completion of short questionnaires about institutional choice and flexibility that were self-administered by

facility contacts (administrators, directors of care, etc). The questionnaire is included in Appendix D.

Attempts were made to code the answers to the questions on the facility questionnaire to create an overall summary measure representing institutional totality. However, a number of the questions did not work well in practice. For instance, in many cases, there was little or no variation between answers from different facilities. Only one facility had any shared rooms; all of the six facilities used a sign-out sheet for cognitively intact residents leaving the facility on a daily basis; all of the facilities had a resident council, the mandate of this council primarily related to raising concerns and making suggestions or recommendations. Scores on a scale measuring the degree of choice or flexibility permitted in 7 substantive areas ranged from 56 to 67 out of 70, with an average of 60. The information from these questions lacked utility for distinguishing between facilities in terms of institutional totality (i.e. they lacked sufficient variability).

Other questions did not work well in practice. For instance, answers to the question "does your facility have in place a standardized, objective system for reprimanding and rewarding residents" included "Not applicable"; "Not sure what you mean"; and "That sounds like a Pavlovian system!" In addition, a question about what types of personal property residents could bring with them to the facility varied depending on the amount of detail included – when just considering furniture items, there was little variation – residents could bring between 0 and 3 pieces of furniture, depending on the facility – the average was 2 (usually a chair and a small table).

Additionally, some survey questions may have been less useful for a practical understanding of institutional totality, as answers may have been affected by the rhetoric of the "official position" or policy of facilities.

Due to limitations of several of the questions mentioned above, this survey measure was not used as an indicator of institutional totality. Interesting findings, however, were evident. Already mentioned is the fact that facility contacts felt that, on average, 93% of their residents were voluntarily admitted to the facility (this varied between 70 and 100%). While all of the facility contacts reported the existence of a resident council, the function of the councils related primarily to making suggestions, complaints or recommendations. Only at two of the facilities did the mandate of the council appear to include providing a means for residents "to initiate forms of action" as well as make suggestions. Bivariate results reported earlier suggest that residents residing at these facilities tend to be both more disgruntled and tend not to prefer joint decision-making.

Facility contacts tended to report very high levels of choice offered to residents across a variety of decisions (scores on a seven item scale reflecting the degree to which the facility is able to permit flexibility in seven areas ranged from 56 to 67 out of 70, with an average of 60 (higher scores indicating more choice/flexibility is allowed). Interestingly, three facilities reported that assistance while bathing/showering was not a requirement if the individual was able to have a bath/shower, while three facilities reported that assistance was a requirement. While "living wills" were not always a policy at facilities, most facility contacts reported requiring some form of advance directive from cognitively intact residents upon admission.

It should be noted that the problems with the measure of institutional totality used in this thesis research should not deter other researchers from employing this concept. The concept is conceptually meaningful and would prove useful for those seeking to understand the adaptation of individuals to LTC environments and for evaluating quality

of care in these environments. Future attempts to measure institutional totality should consider other measures than those included in this questionnaire, as well as other forms of collecting the data (observation, facility records, patient, family and staff surveys).

For the purpose of this thesis, however, given the limitations mentioned above, facility size (measured as the number of beds in the facility) was included as a proxy for institutional totality. Facility size ranged from 70 to 279 for the six facilities, with an average of 129.72 (SD 72.79). Results for facility size did not reveal any significant results in the bivariate or multivariate analyses, with the exception that it predicted the desire for joint involvement in the third vignette (room transfer), in the second and third models ($p<.05$ in the negative direction). That is, residents who lived in facilities of smaller size tended to want joint involvement in this particular decision about a room transfer within the facility.

In conclusion, the respondents tended to be female, have several chronic conditions; most (43%) felt it was their decision to enter the LTC facility, and most (88%) had someone available to help them in decision-making. Twenty-one percent of respondents preferred that someone else make the decision or that it be jointly made in all four vignettes. Twenty-two percent wanted themselves to have full control in at least one vignette, 29% in two, 22% in three, and only 6% preferred full, independent control in four out of four of the vignettes presented. Bivariate and multivariate analyses indicate that respondents with higher expressed confidence, and to a lesser extent, those with higher levels of formal education and more chronic conditions, tend to prefer more active involvement and control in decision-making. Outcome expectations predicted the desire for joint decision-making. Observational and qualitative findings highlight the following:

the difficulty in getting respondents to say what they prefer; the importance of the desire for control of the outcome of the decision; the current reactive system of involvement; and residents' acceptance of structural restrictions (short staffing, lack of resources, demands of caring for a group) as necessary.

CHAPTER 5: DISCUSSION AND CONCLUSIONS

This research was initiated to examine whether some LTC facility residents desire to be relieved of control of decisions, and whether this is related to cognitive-adaptive factors relevant to institutionalization. The intersections between dependency, compliance and empowerment in decision-making, within a highly constraining social and organizational context (the LTC facility), were the phenomena under study. By gaining an enhanced understanding of factors influencing the desire for participation in decision-making, the purpose of this research was to contribute knowledge useful in creating interventions that are both ethical and effective in engaging residents and encouraging participation. Ultimately, this research addresses the interaction between LTC facility residents and the facility environment. The variables selected for analysis address existing theoretical and research literature on decision-making preferences, institutional life, adjustment and coping processes, and individual and group-specific experiences.

5.1 Preferences for involvement in decision-making

Other researchers have identified heterogeneity in resident or patient preferences for involvement in decision-making. Findings for other studies vary dramatically (between 9 to 78%) depending on methodological and conceptual differences, and area of focus (Benbassat et al., 1998). Across the four vignettes, an average of 27% of respondents desire to "give away" all or most of the control over decision-making. This is similar to findings reported by Blanchard and colleagues (1988), who report that 31% of cancer patients did not wish to participate in therapeutic decisions, and Wetle and her

colleagues (1988), who report that 38% of LTC facility residents did not want to be involved in DNR decisions.

For the four vignettes presented in this thesis, those who desired either that others make the decision OR that they have less-than-equal say in a joint decision-making process represented between 11% and 50% of respondents, depending on the specific vignette. This confirms the need to use situation-specific measures of involvement preferences, and to consider specific situational influences on desired involvement in decisions (Allshouse, 1993; Benbassat et al., 1998; Hack et al., 1994). It also confirms the multidimensional nature of decision-making preferences. The nature of the decision affects the desire to be involved. For example, patients tend to prefer more involvement in less technical decisions and in more personally relevant decisions (Biley, 1992; Deber et al, 1996; Guadagnoli & Ward, 1998; Thompson et al., 1993).

Contrary to the assertion of Kapp (1981), many residents (43%) preferred full, independent decision-making (this ranged between 29% and 65% depending on the vignette). Ultimately, however, there is a problem of the practical relevance of this finding. Existing rules and regulations within LTC facilities constrain the ability of individuals to make certain decisions on their own. The problem of the relevance of autonomous decision-making within LTC facilities reflects a discrepancy between the rhetoric of control and empowerment and its reality within the existing context. One conceptual implication that should be considered here is whether the conceptualization of decision-making involvement, in LTC facilities, should include the power to make any changes. Interestingly, only two of six resident councils for the six LTC facilities participating in this thesis research had, in their mandate, the goal of "initiating action."

This is an example of the gap between the rhetoric and reality of empowerment of LTC facility residents.

5.2 Predicting preferences for involvement: common predictors

Common predictors of both the desire for full, independent involvement (the sum of four dichotomous measures) and the desire for active involvement (the sum of four scale measures) were education, the number of chronic conditions, and confidence. Predictors of the desire for full, independent involvement only explained 16% of the variance in the dependent variable, yet explained 25% of the variance in desired active involvement. Additionally, for individual vignettes, the predictors only explained between 11 % and 16% of the variance. These findings suggest that summary measures based on ordinal measures of preferred active involvement across the four vignettes were more useful (in terms of explained variance by the independent and control variables) than measures reflecting the total number out of four vignettes for which individuals desired full, independent control (based on dichotomous measures for the four vignettes). More variance was also explained within each of the four vignettes when the scale measure of desired active involvement was used, as opposed to the dichotomous measure of desired full, independent involvement. The key conclusion in this regard, then, is that phenomena can be better explained with a multi-item measure. Note, however, that even the scale measures of desired involvement leave a large proportion of decision-making preferences "unexplained."

5.2a Education

The finding that higher levels of education are associated with the desire to be involved in decisions confirms earlier research results (Benbassat et al., 1998; Cassileth et al., 1980; Sensky & Catalan, 1992; Strull et al., 1984; Thompson et al, 1993). It was thought that residents' levels of formal education might affect their perception of a worthy contribution and relevant expertise: "well-educated patients were more likely to have more illness-related knowledge or, at least, have the ability to determine the kind and amount of information they needed to make informed, rational decisions" (Hack et al., 1994: 287; Ashworth et al., 1992;). It has also been suggested that self-efficacy and perceived control are lower, and exposure to psychosocial risk factors is greater among those with lower educational levels, and/or that education might act as a proxy for socio-economic status, which is associated with these factors.

However, education was not a significant predictor of outcome expectations, confidence, beliefs in the appropriateness of active involvement, or secondary control strategies in regression analyses of these variables. Because education remained statistically significant with the addition of confidence into the regression model, this suggests an education effect that is independent of confidence. Education, beyond instilling confidence, might represent a kind of "learned effective agency" or human capital (Mirowsky & Ross, 1998). That is, education teaches a wide range of generally applicable skills and abilities, including communication, decision-making, logic, and analysis, that enhance self-efficacy for decision-making (related to, but conceptually separate from confidence). Additionally, education can be seen as more directly enhancing effort and motivation for a variety of tasks (Kohn & Slomczynski, 1993, cited in Mirowsky & Ross, 1998).

In terms of policy implications, the effect of education suggests that given increased levels of education among future cohorts of LTC facility residents, increasing proportions of cognitively intact residents (admissions of these residents, however, will decrease) may seek participation in decision-making (Haber, 1994).

5.2b Chronic conditions

It might be expected that those with a greater number of chronic illnesses might desire less decision-making involvement, due to the drain on physical and emotional resources involved, and the stress, uncertainty, loss and anxiety created by illness. Previous research in acute-care supports this hypothesis, suggesting that an enhanced need for trust is involved in these situations (Benbassat et al., 1998; Biley, 1992; Catalan et al., 1994; Ende et al., 1989; Donaldson et al., 1991; Lupton, 1997; Waterworth & Luker, 1990). It has also been suggested that LTC facility residents may try to match their involvement in decisions with their perceived physical abilities, which decline further as a result of increasing dependency (Marmoll-Jirovec & Maxwell, 1993).

The findings generated in this thesis would indicate that those with more chronic conditions have a greater desire for active involvement and control in decision-making, suggesting that the experience of acute illness is quite different than that of chronic illness. An observational study of hospital patients by Lidz and his colleagues (1983) also found that patients with chronic diseases tend to be more active than patients with acute conditions.

This finding, while contrary to what some of the literature might suggest, indicates the resilience of those living with chronic illness. Elderly individuals with chronic conditions likely have more experience with the health care system, and a greater

awareness of their bodies and their particular chronic illnesses (i.e. knowing what treatments work and which do not), which may motivate them to be more involved. This is congruent with findings from Hibbard and Weeks (1987), who found that elderly individuals with greater experience of the health care system were more likely to pursue active "consumer" behaviours. Haug (1994) also posited that those with extensive and/or adverse experience in the health care system want greater involvement in their care decisions.

As the eligibility criteria for those entering LTC facilities become even more restricted to those with the poorest physical health, those institutionalized elderly who can still make decisions will have more and more chronic conditions and frailty, and it is reassuring that simply having more chronic conditions will not negatively affect these residents' desire to be actively involved in decision-making. One caveat, however, is that the results here might reflect a systematic response bias, whereby those residents who also have high levels of chronic illness, but are less resilient, or who have increased illness severity (rather than number of conditions), may be those who refused to do the survey, citing tiredness or illness. It may be that a measure of illness severity may reveal results more reflective of the original hypothesis – these results may only be reflective of the "resilient ill."

5.2c Confidence

If a LTC facility resident places little confidence in his or her ability to contribute meaningfully, he or she may feel uncomfortable with decision-making responsibility or active involvement. As a result, residents may express lower levels of desired control in care and medical decisions, preferring to place more trust in the opinions of staff and/or

family members. The finding that confidence predicts the desire for involvement in decision-making seems to confirm this interpretation. In fact, confidence was the strongest predictor of preference for active involvement and preference for full and independent involvement in the full models.

The fact that 29% of respondents cited something about themselves as affecting how much involvement they thought they could have reflects how assessed personal abilities might affect expectations for (and perhaps expressed desire for) active involvement. Additionally, residents' assessments of their own abilities to participate may be affected by their acceptance of the sick role and their beliefs about the knowledge required to make a decision (which may be why the desire to be involved in the vignette about medications is relatively low compared with the other vignettes).

The role that institutionalization might play in affecting confidence was not confirmed in this research, however. It was speculated that the lack of privacy, individualized care and opportunities for self-determination, and the power and status differentials involved in many LTC facilities might promote a loss of feelings of confidence and self-esteem among residents, and related changes in self-views (Foldes, 1990; Wetle, 1991; Nystrom and Segesten, 1994; Ashworth et al., 1992). In addition, socialization into a passive resident role and the internalization of resident stereotypes might also lower residents' beliefs in their abilities to participate. The measures of institutionalization used in this research (length of stay, facility size) might have been inadequate to account for any effect that the environment might have on resident confidence or the desire for active involvement.

While analyses of the structured interview data suggest that those with low confidence may be less likely to express interest in participating in decisions, it also

reveals a statistically significant bivariate association between confidence and the belief in the appropriateness of active involvement ($r=.21$, $p<.05$). This association also emerged in logistic regression analyses of the impact of independent variables, including the "appropriateness of active involvement," on confidence as a dependent variable ($OR=3.04$, $p=.04$). While causation cannot be determined, it is possible that belief in the appropriateness of active involvement might affect one's confidence to be involved in decision-making. Interestingly, it should also be noted that those residents who reported having made the decision to enter the facility on their own tended to *disagree* with the statement that active involvement in decisions is appropriate.

Qualitative findings suggest that less confident residents may be disadvantaged within the current system of reactive involvement or complaints. For instance, at least one resident insisted: "What I want does not matter." In a complaints system, residents must be confident enough to speak up about their care, rather than make decisions up-front.

However, a similar problem may affect non-confident residents who are offered the chance to be involved in decision-making about their care. It has been suggested that "nurses' efforts to engage the patient in her own care can easily be a source of bewilderment and may even be taken by an individual who doubts her worthiness to contribute as evidence of the nurse's lack of care" (Ashworth et al., 1992: 1436). While interventions could be designed that encourage participation, there is a risk that they might overwhelm residents who would rather not participate. A better strategy might be to encourage confidence, rather than participation per se. In this thesis, the association of the belief in the appropriateness of active involvement with confidence suggests that confidence might be enhanced by setting examples to promote the belief that involvement is appropriate resident behaviour. The resident council is a good example in this respect,

and was noted as important by many residents. Additionally, Wetle (1991: 286) has suggested that enhancing autonomy in "everyday" or micro decisions about care may increase a resident's "sense of confidence and mastery necessary to advocate for involvement in the 'macro' issues."

Designing interventions that address confidence rather than participation may not only be more effective, but might better respect individual autonomy. There is a fine line between the reluctance to participate, the desire to please, and forced autonomy. For instance, inauthentic autonomy (Collopy, 1988) would emerge when residents participate in making decisions in order to comply with staff wishes that they participate, yet who feel uncomfortable with a collaborative role. Encouragement to participate in decision-making, when applied in a context where the "resident role" of pleasing care providers is operating, has an amplified effect. In other words, social desirability may be the real reason some individuals consent to participate in care planning sessions, and providers of care should be aware of this ethically problematic "red flag". The process of involving residents who are not confident about their participation and do not desire involvement may in some cases even harm the emotional or psychological health of residents, and damage chances for meaningful participation.

5.3 Predicting preferences for involvement: vignette-specific predictors

While education, chronic conditions and confidence were common predictors in the overall model for both the desire for full, independent control and desired active involvement, this thesis also examined predictors of these dependent variables for each of the four vignettes. Vignette A represented the decision about bedtimes. Compared with the other vignettes, the greatest percentage (65%) of respondents preferred full,

independent control in this decision. This highlights the importance of "everyday" decisions for individual autonomy. Predictors were confidence and secondary control. Secondary control was also a significant predictor of preference for active involvement. In both analyses, those who did NOT feel that it was important to be on the staff's good side were more likely to want active involvement.

It is possible that a social norm that involves pleasing care providers operates in the LTC context, and this might affect expressed desires for active involvement. This kind of "social desirability" effect would inhibit the expression of independence in decision-making (in contrast to qualitative data suggesting that independence in ADLs is seen as desirable). The belief in the appropriateness of active involvement was also significant in the regression on the desire for active involvement for the decision about bedtimes. The independent variable representing the belief in the appropriateness of active involvement was a single-item measure: "residents are entitled to their opinion, in ANY matter." Those residents who believed they were entitled to their opinion were more likely to want active involvement. Confidence emerged as the strongest predictor of desired involvement in the decision about bedtimes. Because this vignette reflected one of the least "technical", most common, "everyday" decision, this finding might suggest that confidence is one of the most important determinants of desired involvement in everyday decisions (which some have argued are most important for autonomy). Following from this suggestion, findings from this vignette might also suggest the potentially inhibiting effect of the "desire to please the staff" on resident desires for involvement and autonomy.

Vignette B represented the decision between two medications with differing effects on quality of life. Exactly half of the respondents wanted to defer to others for this

decision. This relatively large proportion preferring to "give away" control would be expected, given the technical nature of this decision. Confidence and the number of chronic conditions were significant predictors of both the desire for full, independent involvement, and the desire for active involvement, for this vignette. While the effect of chronic conditions, as discussed earlier, may be due to the fact that those with more extensive experience with chronic conditions and the health care system might feel more confident being involved in this decision, it is interesting that chronic conditions have an effect independent of confidence for this vignette. Having chronic conditions might affect motivation to be involved, regardless of confidence. This may reflect some kind of motivation to avoid the adverse health effects of poor treatment decisions. It may also be that individuals with more extensive experience with the health care system want more involvement because they perceive the decision made in this vignette as being less technical than those who do not have many health conditions or experience with the health care system.

Confidence was a stronger predictor for the medications vignette than chronic conditions. Considering that changes in medications, while more technical than decisions about bedtimes, are commonly occurring and more "everyday" decisions, this highlights the importance of confidence in "everyday" decisions (especially since confidence did not emerge as a significant predictor in either of the two vignettes discussed next, which represent two "big ticket" decisions).

Vignette C represented the decision about a room transfer. There were no significant predictors of preference for full, independent involvement, and the only predictor for preference for active involvement was education. The association between education and the desire for active involvement is interesting considering the lack of a

predictive effect of confidence for this vignette. The role of education for this vignette might be found in its association with perceived control (not measured in this thesis), or socio-economic status; or with motivation or self-efficacy for decision-making generally (which might be more important for these "big ticket" decisions). Of the four vignettes, respondents expressed the greatest overall desire for joint-decision making (59%) for this decision about room transfers, which may be due to the fact that this vignette was worded in such a way as to imply the facility is included from the outset (i.e. the facility initiates the idea of moving the resident).

Vignette D represented a decision made, in advance, about what medical procedures a resident does or does not want towards the end of his/her life. The least proportion of residents (11%) desired none or little control in this decision. This may highlight the importance of this particular "big ticket" decision for LTC facility residents. Those who felt that the facility was not responsive to their concerns preferred more active involvement in this decision. This is interesting, because it would have been expected that those who thought their participation would make a difference would want more involvement. It is also interesting considering that this vignette is probably the least "context-specific," in the sense that it pertains least to life in the facility (which the items for the outcome expectations scale are focused on). The positive association between depression and the desire for independent involvement in this decision is also noteworthy, and indicates that those with depression were more likely to want full involvement in planning for end-of-life treatment decisions.

In this vignette, education and the number of chronic conditions predicted the scale measure of the desire for active involvement, and outcome expectations were also a significant predictor (again in a negative direction). Education's effect, as noted in the

discussion of the previous vignette, might be more important for "big ticket" decisions. The effect of chronic conditions for this vignette (independent of confidence) may be in the effect of extensive previous experience with the health care system (these individuals might view this decision as less technical than those with fewer chronic conditions, or might have a greater interest in the outcome of the decision).

The effect of outcome expectations, however, is less clear, but might involve individual resident's perceptions of trust in the facility staff and administration (for instance, those who feel that their participation would make a difference in staff response might desire to be less involved in this decision because they would also place their trust in staff or administration to be responsive to their needs and wishes in an advance directive decision). However, staff or administration comprised only 3% of respondents' answers to "who should be involved" in the decision about advance directives. In the bivariate analysis reported in the previous chapter, residents coded as "disgruntled" (based on their comments) wanted more active (i.e. independent) involvement in decisions. More disgruntled residents, who do not feel the facility is responsive to their concerns, may simply be more likely to desire active involvement – this is supported by one resident's comment, "they can decide as long as I'm happy."

Considering the four vignettes overall, it appears that confidence is an important factor particularly in affecting preference to be involved in more common, "everyday" decisions; education may be a more important factor affecting the preference to be involved in rarer, "big ticket" decisions. Having chronic conditions (and perhaps related experience with the health care system) might affect how decisions are perceived (i.e. whether they appear as "technical" or not) and/or the importance given to the outcome.

5.4 Additional findings: discussion

The qualitative data seemed to indicate the presence of beliefs reflective of the concept of secondary control – at least some portion of residents seemed aware of the necessity of restrictions and routines, and a common way of coping was acceptance of and adaptation to the LTC environment: "you've got to fit in to the picture." The single-item measure of secondary control ("it is important for my well-being to be on the staff's good side") was a significant predictor in two of the four vignettes (bed-times and advance directives), but not in the regression on the summary forms of the dependent variables (both the desire for full, independent involvement, and the desire for active involvement). Better measures of the concept of secondary control are needed that are appropriate with elderly populations and that more adequately capture the range of meaning of the concept. This might also involve measuring secondary control in relation to other coping strategies, in order to look at a range of coping strategies and their associations with confidence and desired involvement (Jalowiec, 1989; Shaw, 1992).

This thesis also suggested that the context of the LTC facility would affect cognitive-adaptive variables and subsequent preferences for involvement. The institutional context was addressed through variables measuring length of stay and facility size. The lack of statistically significant findings in relation to these variables (with the exception of facility size, which is negatively associated with the desire for joint decision-making for the vignette about room transfers) is of note. Perhaps confidence about participation is something learned before residents enter a LTC facility. Personal experiences, the experience of aging in an ageist society, and previous hospitalization experiences might all contribute to one's confidence in decision-making participation. For instance, beliefs about appropriate behaviour or confidence speaking up might stem

from pre-institutional experiences related to the context of health care. Additionally, it may be that there is something more symbolic than objective about institutionalization that has an effect. For instance, it may simply be entry into the facility that instigates a symbolic change in self-perception (this could be measured more appropriately by longitudinal research designs).

The thematic observations reported in this thesis do seem to indicate some importance of the context of the LTC facility. For instance, the lack of choices offered "up front" in LTC facilities might work to lower desire for participation in empowering activities, at least in the sense that many residents expressed high levels of satisfaction with the current system of reactive involvement or complaints. It could be that the variables used to study the institutional effect were inadequate to detect any relationship. Additionally, the possibility remains that the strength of differences in accumulated life experiences among residents outweighs any commonalities in their everyday experience of a lack of control within a total institution (i.e. that life history takes precedence over environment). However, based on the differences in predictors and in overall levels of desired involvement across the four vignettes, situational (if not contextual) factors affect resident desires for participation, indicating that the desire for involvement is not a stable phenomenon. Lastly, it remains that the lack of an apparent affect of facility size and length of stay could be due to a lack of sufficient variability across the institutions included within this study.

ANOVA procedures and independent sample t-tests comparing preferred involvement among groups based on the institutional totality indicators (i.e. those living in facilities which report allowing more flexibility) and based on size of facility produced few statistically significant findings. One exception was that those who resided in

facilities with a more active resident council mandate appear to be both more "disgruntled" (based on coding of comments) and less likely to prefer joint decision-making. It may be either that residents who are more disgruntled may push for more a more active resident council mandate; it might also be, however, that in these facilities, a more pronounced discrepancy between the reality of participation (as in the council mandate) and reality might occur that fuels disgruntlement. Additionally, findings indicate that more disgruntled residents tend to prefer active involvement, and multivariate findings indicate that those who felt the facility is more responsive to their concerns prefer joint decision-making. These findings suggest some link between context and preferences for participation that remains to be fully explored.

Regarding the decision to enter the LTC facility, 43% of residents believed it had been their decision entirely; 25% felt it had been a joint decision with family or doctors; and 32% felt the decision had been made by others. This finding is interesting, given that administrators and contacts at the six facilities, in a short self-administered questionnaire, had reported that approximately 93% of residents were "voluntary admits." There is a possibility that a resident's perception of who made the decision to enter the LTC facility, or their memory of the decision, may be inaccurate – for the purposes of this thesis, however, it may be the perception that matters most in terms of resident adjustment. Additionally, length of stay is associated with entry decision in a bivariate analysis, indicating that with increasing length of stay, residents are more likely to report that the decision to enter the LTC facility was their own decision. This could be due to failing memory over time elapsed from entry in to the facility; or a cognitive adjustment strategy that involves accepting the decision and/or changing one's perception to believe one had actually made the decision. It could also reflect changing selection factors in LTC

facilities whereby despite the assertions of facility contacts, more and more individuals in recent years may not make an independent decision to enter a LTC facility. Lastly, this finding could be attributed to differences in the definition and perception of "voluntary" admission between staff and residents (with staff perceptions of the concept including anyone who eventually consented to or complied with the move, however the decision may have been negotiated). Interestingly, believing that one has made the decision to enter the LTC facility on one's own was associated with decreased odds of believing that active involvement is appropriate. This might relate to findings presented elsewhere in this thesis that suggest that disgruntled residents are more likely to want involvement.

5.5 Predicting preferences for involvement in joint decision-making

Results for the third form of the dependent variable revealed that only outcome expectations predict preference for joint decision-making. Those who felt that the facility was responsive to their concerns were more likely to prefer joint decision-making. This can be compared to the results for the fourth vignette (advance directives) which indicated that those who felt that the facility was NOT responsive were more likely to desire active involvement in the fourth vignette (advance directives). More disgruntled residents, who do not feel the facility is responsive to their concerns, are more likely to desire active involvement – as supported by one resident's comment, "they can decide as long as I'm happy." This link between resident perceptions of life in the facility and their desire for autonomy has interesting policy implications. LTC facilities might be advised, for instance, under a system of complaints and 'reactive' involvement, to do their best to address resident concerns, not only to prevent residents from becoming disgruntled with

life in the facility, but also to keep residents content with "negotiated" or joint decision-making (this may highlight the importance of trust in facility staff and administration).

In separate logistic analyses with preferred joint decision-making as the dependent variable for each vignette, a predictor emerged only for vignette C (room transfer). Specifically, facility size emerged as significant (in a negative direction) in the second model, and remained significant with the addition of the cognitive-adaptive variables. This indicates that in larger facilities, residents are less likely to desire joint decision-making for this vignette. The vast majority (92%) of those who wanted only one person to make this decision (the opposite of joint decision-making) wanted this person to be him/herself. Rooms in larger facilities may be a greater variety of shapes and sizes, leading residents to perceive that other rooms would be better (or worse) than the one they are currently living in (thus having a more vested interest in the outcome of the decision, and wanting themselves to make the decision). The issue of room transfer might also be of greater relevance for the everyday lives of residents in larger facilities.

The fact the same predictors (education, chronic conditions and confidence) explained up to 25% of preference for active involvement, but only 4% of preference for joint decision-making, suggests that these are two very different concepts that should be distinguished, and that different predictors of preference for joint decision-making should be examined. Based on the findings from this thesis, outcome expectations and facility size are two predictors that may be more important in further research looking at the desire for joint decision-making among LTC facility residents.

Lastly, one of the key findings based on a thematic analysis of the respondent comments is that the current system of involvement in decision-making in LTC facilities is a reactive one based on complaints, rather than a proactive one of involving residents

"up-front" in decisions. Important considerations for future research are not only, as mentioned above, the concern that non-confident residents will have their concerns go un-addressed; but also, whether current complaints systems in LTC facilities adequately address structural barriers to change, or whether they raise "false expectations," which may in turn increase the numbers of "disgruntled" residents who don't feel the facility is responsive to their concerns; lastly, future research should also consider the definition of a "reasonable" complaint.

5.6 Summary of key conclusions

The main conclusions of this study include the following:

1. A large proportion of residents desire full, independent decision-making involvement. The practical relevance of this finding, however, is important to consider. Qualitative results reveal, however, that many residents accept the routines and regulations in LTC facilities as necessary.
2. Residents with more formal education tend to desire active involvement, and education seems particularly important in preferred involvement in "big ticket" decisions. Education may provide a learned effective agency or enhance motivation for involvement.
3. Residents with more chronic conditions tend to desire active involvement. These residents may have more experience with the health care system and knowledge of their own chronic conditions that motivate them to be involved. They may also feel decisions have greater consequences for them.

4. Residents with greater confidence tend to desire active involvement, particularly in more common, "everyday" decisions. Confidence is also related to the belief in the appropriateness of active involvement.
5. The system of resident involvement in decision-making in LTC facilities is one in which residents are expected to "speak up" or complain if something concerns them.
6. Outcome expectations and happiness with life in the facility appear relevant to decision-making preferences. Those who believe that the facility is responsive to their concerns are more likely to desire a joint-decision making situation; disgruntled residents are more likely to want full, independent control.
7. The desire for joint decision-making is distinct from the desire for active involvement in decision-making and has different predictors that remain to be explored.
8. A large amount (75%) of the variance in desired involvement remains unexplained.
9. Those seeking to empower LTC facility residents might try to provide "several options for ways in which a resident might choose to participate" (Wetle et al, 1988: 37). They should also be aware of situations where individuals may be "reluctant collaborators" in decision-making, of the potential for coercion to participate and coercion to comply with facility viewpoints in the decision itself, and of situations in which involvement may be stressful or uncomfortable for residents (Waterworth & Luker, 1990; Wetle, 1991).
10. This work highlights the need to look at how individuals adapt to their institutional environments, and what effect, if any, the management or structure of

the institutional environment might have on expectations, beliefs and assumptions related to care in a LTC facility.

11. This thesis also points to the need to consider whether the definition of decision-making should include the power to effect change. This seems particularly important, conceptually, given findings that indicate that the concept of preference for involvement is closely related to the importance of the decision and the value or priority placed on the outcome. However, while decision-making from a conceptual standpoint might include the power to effect changes, from a practical standpoint, it is easy to see how the relevance of the concept of active involvement in decision-making in a LTC facility setting is jeopardized, given the number of various "interested parties" in decisions made in this context.
12. Involvement in decision-making is not only one means to achieve primary, goal-oriented control, but it is also one means to achieve autonomy. This thesis also highlights the need to revisit the conceptualization of the concept of preference/desire for involvement. The importance of the decision and the nature of the decision, and the value placed on the outcome, are important conceptual factors to be explored in further work. The value placed on the outcome is particularly important in light of the fact that this can be affected by coping strategies which may involve minimizing priority given to control or autonomy (i.e. "what I want does not matter"); it may also be affected by socialization and assumptions about appropriate involvement.

5.7 Limitations

Measuring what people want is a complex and difficult task. Measures of the desire for decision-making responsibility may yield more positive responses than measures of actual behaviour, as Beisecker (1988) argues in research on patient consumerism. In other words, "people are often poor predictors of their own behaviour, so that statements of intent often lack validity when compared with subsequent events" (Oppenheim, 1966, p73). Similarly, it is difficult for people to distinguish their desires or expectations from what they have, what they think is possible, or what they should have.

The results may only be applicable to residents who would want to be involved, as these individuals were likely to be those who would also consent to answer the survey (selection bias in those who agreed to participate). There was also a selection bias in the sampling procedure that means that the implications of this research are also not generalizeable to non-profit institutions, nor to the increasing population of LTC facility residents who experience dementia. That is, the implications of this research extend only to residents cognitively capable of making decisions in a LTC facility environment, individuals whose numbers are declining in LTC facilities over time.

The development of self-constructed scales and their poor reliability was a problem for the analysis of results. Poor reliability of the scale measures led to the use of single item measures, which have their limitations: for instance, the item representing secondary control may be too narrow for the concept (and thus not capture its full range), and the item representing the belief in the appropriateness of active involvement's single item may be too broad or general. Single-item measures are also more affected by slight differences in the asking of the question, including its form, content, and emphasis (Oppenheim, 1966; Turner & Martin, 1984).

Measurement problems are also related to an agreement bias (aquiescence, a tendency to assent: Oppenheim, 1966) evident when interviewing residents. One example of this is that when the interviewer was reading the lead-in describing the format of the agree-disagree questions, at least two respondents stated, "I pretty much agree!" even before any of the question items were read to them. The tendency to "agree" may have affected many of the scale items. Additionally, social desirability (tendency to express socially desirable attitudes) is also a concern – for instance, the vast majority of respondents did not want to say anything bad about staff, and some were even offended by questions which were interpreted as representing staff evaluation (specific numbers were not recorded). It is recommended that future research utilize a social desirability measure.

Another limitation of the research undertaken here is it's cross-sectional nature. While a longitudinal design was not feasible given time and other constraints, conclusions drawn from cross-sectional data will be tenuous. Longitudinal data based on interviews with residents before and after entry into a LTC facility could more conclusively determine the extent to which socialization into a resident role and other factors are actually the result of institutionalization, and the extent to which they are personality factors that individuals bring with them to the facility. This kind of research would be a useful extension of the analyses presented in this thesis.

The small sample size is also a concern, and may increase the probability of Type II error, or the error of not detecting a statistically significant difference when one does exist.

Another limitation of the data is related to the data collection process. Comprehension is a big concern when interviewing older adults. Most of the residents

were not accustomed to Likert scales and agree-disagree response categories. This was also noted by Dykstra (1990: 33), "many of the older respondents were unfamiliar with questions using pre-structured answer categories." For some, it was necessary to phrase the item as a direct "yes-no" question, as this was often the only way to communicate the nature of the question. Even among those residents who did grasp the agree-disagree concept, extension to "somewhat" and "strongly" distinctions was too difficult (not a strong enough distinction). An unfolding technique was attempted whereby interviewers asked agree or disagree, followed by the strongly-somewhat distinction, but even this tended to confuse and frustrate respondents. Usually the distinction was tried, but if it was not succeeding, interviewers were instructed to interpret statements like "it depends"; "to an extent"; "not necessarily"; "in some matters" as "somewhat" responses. In fact, residents often added many of these kinds of qualifiers to their answers, preferring to think in terms of concrete examples rather than general statements. Additionally, the distinction between "strongly consider preferences" and "provide input" in the joint decision-making process was often too slight and confusing for residents. As a result, the two categories were combined into one for the purposes of analysis. Ultimately, it is uncertain whether these kinds of difficulties reflect a general problem when interviewing frail older adults, or whether they reflect limitations in the construction of the items (Oppenheim, 1966).

The thematic analysis was not a planned part of the data collection process, and data used for this analysis are thus not "pure text." The data consisted of comments recorded by interviewers during the course of the interview and observations noted by the researcher. These were selectively, not systematically, recorded and may be subject to

bias. The findings generated as a result of the thematic analysis must be interpreted with caution.

Future research might employ more adequate (i.e. valid, variable) institutional measures, as well as better (i.e. more reliable, comprehensive) measures of the cognitive-adaptive factors. It might also consider how preference for decision-making involvement differs based on other engagement measures in LTC facilities, including whether someone attends resident council; social interaction/friends in facility; and the attendance of social and recreational events offered by the facility. This thesis suggests that the motivation for involvement in care activities (independence in ADLs) is high in LTC facilities; it would also be interesting to examine how motivation for involvement in other aspects of facility life relate to motivation for involvement in decision-making about care.

Other avenues for exploration include the current system of complaints and the reality of resident "involvement" in such a system (i.e. what is a good vs bad complaint?); the meaning of compliance and the resident role for residents and staff; and the process by which individuals come to accept that adjustment requires "toeing the line". Also interesting for future research is how perceptions of dependence in ADLs and perceptions of independence in making decisions are similar or different among the institutionalized elderly.

Alternate research designs that would also be appropriate to the study of these phenomena include a between-group comparison of differences between community dwelling and institutionalized elderly; or a longitudinal study that considers beliefs before institutionalization and how these change over time. Qualitative interviews and/or the use of additional open-ended questions would also be useful for determining the reality of

resident involvement in LTC facilities, their perceptions of this involvement and its implications for their autonomy, and the role that institutionalization might play in affecting confidence in being involved.

5.8 Conclusion

The principles of health promotion, health reform, empowerment and quality of care all support the involvement of individuals in health care decision-making, as patients or as residents of care facilities. Patient care conferences and resident councils are examples of means for involving cognitively intact residents of LTC facilities in decision-making. Other ways might include more frequent interviews of selected staff, with residents, more frequent contact between administration and residents; and informal soliciting of opinions by staff (shift in practice), which would need to be accompanied by integrating choice as a part of daily routine, as much as possible.

This thesis research with 100 residents of LTC facilities in Victoria, B.C. was initiated to examine predictors of the desire to be involved, and the degree and form of preferred involvement in four different care and medical decisions. Socio-demographic and illness factors, as well as factors representing institutionalization and expectations and beliefs related to life in an institutional environment were considered in measurement and analysis.

While measurement issues related to institutional totality made this research less useful for understanding the role of institutional totality in explaining desired involvement, the importance of the institutional context is evidenced in qualitative findings that accompanied the administration of the interviews, as well as some bivariate findings. The concept of institutional totality is a meaningful concept that remains to be

fully explored in research in LTC facilities. Future research should employ more useful measures of institutionalization and the institutional context in considering the effects of the context on residents of LTC facilities.

Whereas the current involvement of residents in LTC facility decision-making is reactive (in the form of an informal complaints system), this thesis indicates that a large proportion of residents do prefer full, independent decision-making involvement (particularly if they are disgruntled with how the facility responds to concerns). Residents with higher levels of formal education, a greater number of chronic conditions, and more confidence (in particular) tended to desire more active involvement in decision-making. The most obvious implication of this is that future cohorts of cognitively intact individuals entering LTC facilities, or similar residential facilities, may desire greater levels of involvement, as they will have both higher levels of formal education (cohort effect) and greater numbers of chronic conditions (i.e. selection criteria will favour frailer residents).

However, predictors of the desire to be actively involved differ from the predictors of the desire to be jointly involved in decision-making. Additionally, predictors of the desire to be involved in "everyday" decisions may differ from predictors of the desire to be involved in "big ticket" decisions (confidence having more effect in the former, education having more effect in the latter).

Policies and programs designed to enhance autonomy could focus less on promoting involvement in decision-making, and more on promoting the confidence needed to want to participate in everyday decisions. There should also be opportunities to participate in these kinds of decisions, as well as "big ticket" decisions, but these should be more than token consultations, otherwise, residents' faith in the responsiveness of the

facility to their concerns could be damaged. This thesis highlights the importance of more research in the area of decision-making participation preferences, particularly research that recognizes the complexity of the issue.

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APPENDIX A
Letter to request permission for research

August 2001

Centre on Aging
University of Victoria
P.O. Box 1700 STN CSC
Victoria, B.C. V8W 2Y2

Administrator
Facility
Address

Dear Mr/Ms Administrator:

I am a graduate student at the University of Victoria in the Department of Sociology. As part of my requirements for my graduate programme, I am conducting research on the decision-making preferences of long-term care facility residents, a topic about which we know little. This research is being co-funded by the B.C. Health Research Foundation and the Canadian Health Services Research Foundation.

I am writing to request permission to interview approximately 15-20 residents of YOUR FACILITY regarding their desires for active participation in care decisions. Although we all have a concern that residents maintain their autonomy to the extent possible, we know little about how to facilitate this among the frail population that you serve. This research will help inform the development of policies and programs designed to enhance the quality of care services provided to LTC facility residents.

Your cooperation in this research would entail having a staff nurse or administrator compile a list of all residents who are mentally competent to participate in this study. This may take 20 minutes to complete. I would randomly select residents from this list, and approach them for their informed consent to be interviewed. Myself and a close friend (whom I have hired) will be conducting the interviews. My friend (NAME) has signed an oath of confidentiality and has been trained by me prior to conducting interviews.

Resident participation will be strictly voluntary, and all information received will be handled in such a way as to ensure confidentiality and anonymity for residents and

facility alike. This research has been reviewed and approved by the UVIC Committee on Research Involving Human Subjects.

Yours is one of several facilities in which I hope to conduct research and the information obtained from residents in your facility will be analysed together with that from residents in all facilities, together. I will not be conducting any analysis in which your LTCF can be identified. In reporting the results of my research, names and specific locations of facilities will not be identified.

I have experience volunteering in LTC facilities and completed a Gerontology diploma program at Simon Fraser University. This research will fulfill part of the requirements for my Masters degree in Sociology at the University of Victoria, and has been approved by my supervisory committee. The chair of my supervisory committee is Dr. Neena Chappell (721-####).

I am available to answer any questions or discuss any concerns that you may have (office: 721-####; home: ###-####). I will share the results of my research findings with your facility and any residents who wish to review the report.

I hope to conduct interviews in MONTH. I will be contacting you in the next week to discuss this request, and at your convenience we could schedule a time to meet. Please find attached a copy of the questionnaire, the informed consent form, and the ethics approval certificate for your perusal. I would also wish to know whether your facility will accept the judgement of the University of Victoria's ethical review committee concerning this research, or whether review by your own board or similar authority is required. Thank you very much for your consideration.

Sincerely,

Laura M. Funk

APPENDIX B
Interview Schedule

Interview #_____ Date (yy/mo/dy) 01/___/___

INTERVIEWER:
1 Laura 2 Esther 3 Carola 4 Hanna

1. (interviewer to complete): Gender of Respondent
Female..... 0
Male 1

2. (interviewer to complete): Size of Facility (# beds in facility) _____

3. . (interviewer to complete): Size of Unit (# beds on floor) _____
_____

4. What year were you born? _____.

5. ***(card)*** How far did you get in school?

Some elementary school..... 0
Elementary school completion (grade 7)..... 1
Some junior secondary school..... 2
Junior secondary completion (grade 10) 3
Some senior secondary school 4
Senior secondary completion (grade 12/13)..... 5
Trade school 6
Some college or university..... 7
College diploma(s) or university degree(s) completed..... 8

6. Who made the decision about your move to a long-term care facility? For instance, did you yourself make it, your family, both of you, or someone else?
_____
_____.

7. How long have you lived in this home? _____ years, _____months.

8. Did you live in any other facilities before this one?

No..... 0 *(go to #11)*
Yes ..... 1 *(go to #9)*

9. IF YES to above: what was the name of that facility? _____.

10. How long did you live there? _____years_____months

11. Would you say you have a family member or close friend available to help you make decisions?

No..... 0
Yes..... 1 (specify relationship: _____)

12. I am going to read some statements, and based on your experience and feelings, please tell me whether you agree or disagree with them. (THEN ASK: SOMEWHAT OR STRONGLY?)

a) A resident's opinion is taken seriously here.
SD ____ (0) DS____ (1) AS____ (2) SA____(3)

b) My well-being in this facility is under staff control.
SD ____ (3) DS____ (2) AS____ (1) SA____(0)

c) My participation in decisions here makes a difference.
SD ____ (0) DS____ (1) AS____ (2) SA____(3)

d) It does not really matter what I think, staff will just go ahead and do what they want.
SD ____ (3) DS____ (2) AS____ (1) SA____(0)

e) My involvement in decisions often lacks meaning.
SD ____ (3) DS____ (2) AS____ (1) SA____(0)

f) There are enough choices and alternatives for me here.
SD ____ (0) DS____ (1) AS____ (2) SA____(3)

13. ***(card)*** Residents are sometimes asked for their say in decisions about their care and medical treatment. How much involvement could you really have/is reasonable/realistic to expect to have in these decisions here?

No involvement at all 0
A little involvement..... 1
Moderate involvement..... 2
A lot of involvement 3

14. Why?

_____
_____
_____.

15. Is *this level* of involvement what you would prefer? Why or why not?

_____

_____

_____.

I am going to describe four imaginary situations that you might encounter here. I will ask you who you think **should** make the decision, **if** it happened to you.

Vignette A: For instance, suppose you were interested in going to bed late in the evening, although most people go to bed early.

16. Has this happened to you/Are you a "night owl" yourself?

No ..... 0 *(go to #18)*
Yes 1

17. a) How was the decision made?

_____

_____

_____.

b) Would you have liked more or less involvement? If yes, explain.

_____

_____.

18. If NO: Who do you want to decide what time you go to bed? *IF they mention just one individual* – Would you want anyone else involved in the decision?
If YES: So, who do you want to make the decision *(confirm if that's how they would want it made again)*?
(circle more than one if appropriate)

Myself 0
A staff member 1
My doctor 2
A family member 3
A friend 4
Other (*specify:*_____) 5

If more than one are mentioned:
19. ***(card-joint decision)*** Specifically, how should the decision be made? Do you want the final say? Do you want *(mentioned other)* to have the final say? Or do you want equal say?

I should decide, and others provide input..... 1
I should decide but strongly consider
the preferences of others..... 2
There should be equal say in the decision..... 3
Others should decide but strongly consider
my preference..... 4
Others should decide, I should provide input..... 5

Vignette B. Now, suppose you are in pain, there are two kinds of medications you can take. One medication would make you very sleepy, but work better for your pain. The other medication would keep you alert, but would not work as well for the pain.

20. Has anything similar to this happened to you?

No..... 0 *(go to #24)*
Yes..... 1

21. a) How was the decision made? In what way were you involved?

_____
_____
_____.

b) Would you have liked more or less involvement? If yes, explain.

_____
_____.

22. If NO: Who do you want to decide which medication you take? *IF they mention just one individual* – Would you want anyone else involved in the decision?
If YES: So, who do you want to make the decision *(confirm if that's how they would want it made again)*?
(circle more than one if appropriate)

Myself..... 0
A staff member..... 1
My doctor..... 2
A family member..... 3
A friend..... 4
Other (*specify:*_____)..... 5

If more than one are mentioned:
23. ***(card-joint decision)*** Specifically, how should the decision be made? Do you want the final say? Do you want *(mentioned other)* to have the final say? Or do you want equal say?

I should decide, others should provide input 1
I should decide but strongly consider
the preferences of others 2
There should be equal say in the decision 3
Others should decide but strongly consider
my preference 4
Others should decide, I should provide input 5

Vignette C. Suppose you were told that the staff wanted to move you to another room in this same facility.

24. Has this happened to you?

No ..... 0 *(go to #30)*
Yes 1

25. a) How was the decision made? In what way were you involved?

_____
_____
_____.

b) Would you have liked more or less involvement? If yes, explain.

_____
_____.

26. If NO: Who do you want to make the decision about whether you should move?
IF they mention just one individual – Would you want anyone else involved in the decision?
If YES: So, who do you want to make the decision *(confirm if that's how they would want it made again)*?
(circle more than one if appropriate)

Myself 0
A staff member 1
My doctor 2
A family member 3
A friend 4
Other (*specify:*_____) 5

If more than one are mentioned:
27. ***(card-joint decision)*** Specifically, how should the decision be made? Do you want the final say? Do you want *(mentioned other)* to have the final say? Or do you want equal say?

I should decide, others should provide input 1
I should decide but strongly consider
the preferences of others 2
There should be equal say in the decision 3
Others should decide but strongly consider
my preference 4
Others should decide, I should provide input 5

Vignette D. You may have heard about arrangements that people can make, in advance, about what medical procedures they do or do not want at the end of their life.

28. Have you dealt with these issues/ were you asked to make a decision at this point about what medical procedures you want at the end of your life?

No ..... 0 *(go to #36)*
Yes 1

29. a) How was the decision made? In what way were you involved?

_____
_____
_____.

b) Would you have liked more or less involvement? If yes, explain.

_____
_____.

30. If NO: Who would you want the decision about what medical procedures you will receive in the last days of your life, if the decision were made today? *IF they mention just one individual* – Would you want anyone else involved in the decision?
If YES: So, who do you want to make the decision *(confirm if that's how they would want it made again)*?
(circle more than one if appropriate)

Myself 0
A staff member 1
My doctor 2
A family member 3
A friend 4
Other (*specify:*_____) 5

If more than one are mentioned:

31. ***(card-joint decision)*** Specifically, how should the decision be made? Do you want the final say? Do you want *(mentioned other)* to have the final say? Or do you want equal say?

I should decide, others should provide input..... 1
I should decide but strongly consider
the preferences of others..... 2
There should be equal say in the decision..... 3
Others should decide but strongly consider
my preference..... 4
Others should decide, I should provide input..... 5

32. ***(card).*** Now I have some agree and disagree questions again.

a) It is appropriate for residents to challenge the way things are run here.
SD ____ (3) DS____ (2) AS____ (1) SA____(0)

b) A good resident does not often complain.
SD ____ (0) DS____ (1) AS____ (2) SA____(3)

c) Residents should try to make things easy on the staff.
SD ____ (0) DS____ (1) AS____ (2) SA____(3)

d) Residents are entitled to their opinion, in <u>any</u> matter.
SD ____ (3) DS____ (2) AS____ (1) SA____(0)

e) It is a resident's duty to sit back and let the staff take over.
SD ____ (0) DS____ (1) AS____ (2) SA____(3)

33. ***(card) Now I am going to ask you about your health.*** For your age, would you say, in general, your health is:

Excellent for my age..... 4
Good for my age..... 3
Fair for my age..... 2
Poor for my age..... 1
Very poor for my age..... 0

34. Now, I will read a list of health problems that people often have, and for each one, I just need to know if you have had it in the last year.

	NO (0)	YES (1)
High blood pressure	0	1
Hardening of the arteries, heart attack or other heart problems	0	1
Stroke, or effects of stroke	0	1
Arthritis or rheumatism	0	1
Paralysis or paraplegia (confined to bed/wheelchair)	0	1
Parkinson's disease	0	1
Other neurological problems (e.g. epilepsy, MS)	0	1
Eye trouble not relieved by glasses (cataracts, glaucoma, retinal degeneration)	0	1
Ear trouble (including hearing loss)	0	1
Dental problems (teeth need care, dentures don't fit)	0	1
Chest/lung problems (asthma, pneumonia, TB, emphysema, bronchitis, breathing problems)	0	1
Troubles with your stomach or digestive system (ulcers, gastric or peptic)	0	1
Kidney trouble (or bladder problems)	0	1
Bowel problems (i.e. colostomy)	0	1
Diabetes	0	1
Trouble with your feet or ankles	0	1
Varicose veins	0	1

Depression 0 1

Trouble with your nerves
(incl. anxiety, emotional problems) 0 1

Skin problems (specify: _____) 0 1

Osteoporosis, sometimes called
fragile or soft bones 0 1

Cancer (specify: _____) 0 1

Significant memory loss (including Alzheimer's Disease) 0 1

Leg problems 0 1

Shingles 0 1

Bursitis/tendonitis 0 1

Allergies/sinus problems 0 1

Amputation of legs/arms 0 1

Back problems 0 1

Chronic pain 0 1

Thyroid problems 0 1

Hip problems 0 1

Other (specify) 0 1

35.

a) Are you able to eat without help?

1	2	3	4	5
without help	some help, DEVICE only	some help, PERSON only	some help, DEVICE + PERSON	unable to do it

b) Are you able to dress and undress without help?

1	2	3	4	5
without help	some help, DEVICE only	some help, PERSON only	some help, DEVICE + PERSON	unable to do it

c) Can you get about the facility without help?

1	2	3	4	5
without help	some help, DEVICE only	some help, PERSON only	some help, DEVICE + PERSON	unable to do it

d) Can you get in and out of bed without help?

1	2	3	4	5
without help	some help, DEVICE only	some help, PERSON only	some help, DEVICE + PERSON	unable to do it

e) Are you able to use the toilet without help?

1	2	3	4	5
without help	some help, DEVICE only	some help, PERSON only	some help, DEVICE + PERSON	unable to do it

f) Are you able to take a bath or shower without help?

1	2	3	4	5
without help	some help, DEVICE only	some help, PERSON only	some help, DEVICE + PERSON	unable to do it

36. Do you think your health affects your desire to be involved in decisions about your care here? If yes – why/how?

_____

_____

_____.

37. ***(card)*** My last set of questions are those agree or disagree ones again, like before.

a) The best advice to a new resident is to just "roll with the punches."
SD ____ (0) DS_____ (1) AS_____ (2) SA_____(3)

b) It is important for my well-being to be on the staff's "good side."
SD ____ (0) DS_____ (1) AS_____ (2) SA_____(3)

c) I would take some small risks to my safety to remain independent.
SD ____ (3) DS_____ (2) AS_____ (1) SA_____(0)

d) Staff should be flexible to my specific desires.
SD ____ (3) DS_____ (2) AS_____ (1) SA_____(0)

e) Strict routines are necessary here.
SD ____ (0) DS_____ (1) AS_____ (2) SA_____(3)

f) Having control is more important to me these days than before.
SD ____ (3) DS_____ (2) AS_____ (1) SA_____(0)

38.

a) I know what is best for me.

SD ____ (0) DS____ (1) AS____ (2) SA____(3)

b) I cannot make decisions about my own care.

SD ____ (3) DS____ (2) AS____ (1) SA____(0)

c) My opinion about my care is as important as what the staff thinks.

SD ____ (0) DS____ (1) AS____ (2) SA____(3)

d) I lack the ability to make decisions about medical problems.

SD ____ (3) DS____ (2) AS____ (1) SA____(0)

e) My input into care and medical decisions would be valuable.

SD ____ (0) DS____ (1) AS____ (2) SA____(3)

f) I lack the confidence to comment about the care I receive.

SD ____ (3) DS____ (2) AS____ (1) SA____(0)

APPENDIX C
Informed Consent Form

You are invited to participate in a study called "Autonomy and Long-Term Care Facility Residents" that is conducted by Laura Funk, a graduate student in Sociology at the University of Victoria. You may contact her if you have further questions (721-####, or ###-####).

This is part of Laura's requirements for a Master of Arts in Sociology, and is conducted under the supervision of Dr. Neena Chappell, Director of the Centre for Aging at the University of Victoria. You may contact Dr. Chappell at 721-####.

Laura is studying resident preferences for being actively involved in decisions. This helps us learn more about how to give residents the autonomy they might desire.

You are being asked to participate in this study because you were chosen by chance from a list of potential participants that Laura got from the administrator and nursing staff. You were on this list because of your ability to answer the questions, if you wish to.

If you agree to voluntarily participate in this research, this will involve responding to questions in a survey I have developed. This takes about an hour of your time, and can take place in the privacy of your room. The questions are about who you think should make decisions; your feelings about living here; and your health. No one, including this facility, will know your answers.

There are no known or anticipated risks to you by participating. The potential benefits of your participation include the opportunity to contribute to the understanding of resident autonomy and decision-making and helping to improve the quality of care in LTC facilities in a way that respects resident preferences.

Your participation must be completely voluntary. You are free NOT to participate. If you do decide to participate, you may still change your mind and withdraw at any time without explanation and without consequences to pre-existing entitlements to care or services. If you do withdraw from the study your data will not be used in my analysis - it will be destroyed. You may also decline to answer any particular questions that I ask.

To protect your identity, no names or identifying labels will appear on the response sheet, and this consent form can not be matched with the response sheet. Your name will NOT be published. Several facilities are participating in this research, so you will not be able to be identified through your facility. All information will be entered into

a general pool of responses to be analyzed for all facilities. This facility will not be identified.

To protect your data, your responses will be kept secure and password-protected on my personal computer. Only I will have access to them for research purposes. I will shred the hard copies after two years (they will be stored in a locked area until that time). After five years, I will delete the data stored on my computer.

I will provide copies of a short summary of my research to this facility's administration, and they will be available for you to read. I will also submit my report to my granting agency, and to scholarly journals and conferences. You will not be identified in any reports.

In addition to being able to contact myself or my supervisor at the above numbers, you may check the ethical approval of this study, or raise any concerns, by contacting the Associate Vice President Research at the University of Victoria (###-####).

Your signature below indicates that you understand the conditions of participation in this study and that you have had the opportunity to discuss any concerns with Laura Funk.

_____ _____

Participant Signature Date

_____ _____

Researcher Signature Date

A COPY OF THIS CONSENT FORM WILL BE LEFT WITH YOU, AND A COPY WILL BE TAKEN BY THE RESEARCHER.

APPENDIX D
Facility Contact Questionnaire

December 2001

Dear _____,

I would like to take this opportunity to thank you for all your help in my M.A. research that I conducted at FACILITY this fall. Yourself and the residents of this facility have provided enormous assistance in my study on autonomy among cognitively intact residents of LTCFs.

I will be analyzing my results starting this month, and will provide you with more detailed feedback about the research in a form that I hope will prove meaningful for your facility.

The attached brief questionnaire is a supplement for my research and may be completed at your convenience. It should take about ten-fifteen minutes of your time. Once again, I'd like to thank you for your help.

Sincerely,

Laura M. Funk
####@uvic.ca
###-####

Facility Questionnaire

LTCFs face a difficult task of providing efficient and effective care to residents with high levels of disability and chronic illness, as well as attempting to ensure that this care is not only safe, but that the resident's right to autonomy is also protected. The following questions concern general facility policies and structure, as well as the extent to which you feel your facility is able to permit flexibility for residents.

1. a) # private rooms in your facility: _____
   b) # shared rooms in your facility: _____

2. Approximate/average number of group scheduled activities each week (including meals): _____

3. At this time, what percentage of your residents, by your estimate, would you consider to be voluntary admits?_____
   Involuntary admits? _____

4. Please briefly describe approximately how much/what types of personal property are new residents permitted to bring with them from their previous place of residence, into their rooms.

_____

_____

_____

5. Does your facility have in place a standardized, objective system for reprimanding and rewarding residents? Or are reprimands and rewards given on an individual basis? Please briefly describe.

_____

_____

_____

6. Please describe your facility's rules regarding residents leaving/returning to the facility the facility on a daily basis:

_____

_____

_____

7. Is there a resident council at your facility? Please describe its mandate and function.

_____

_____

_____

8. Approx. how many nurses AND aides are present each day in your facility?_____ Each evening? _____

9. To what extent is your facility able to permit flexibility in the following areas, for **cognitively intact residents**.

a) Choices about daily living, such as timing of activities, bathing, food choices, access to telephone, snacks, spending money

1 2 3 4 5 6 7 8 9 10

(no choice in any of these areas) (full choice in all areas)

b) Decisions about physical environment (room arrangement, use of furniture, personal belongings, radio or tv)

1 2 3 4 5 6 7 8 9 10

(no choice in any of these areas) (full choice in all areas)

c) Decisions about the social environment (room assignment, choice of roommate, where to sit at meals, social activities)

1 2 3 4 5 6 7 8 9 10

(no choice in any of these areas) (full choice in all areas)

d) Treatment and health care decisions (medication, restraints, physical therapy, surgery, diet, wheelchair, geri-chair)

1 2 3 4 5 6 7 8 9 10

(no choice in any of these areas) (full choice in all areas)

e) Major financial decisions

1 2 3 4 5 6 7 8 9 10

(no choice in any of these areas) (full choice in all areas)

f) Transfer decisions (to hospital, within home, to another home)

1 2 3 4 5 6 7 8 9 10

(no choice in any of these areas) (full choice in all areas)

g) Crisis or life-death decisions (i.e. living wills, advance directives)

1 2 3 4 5 6 7 8 9 10

(no choice in any of these areas) (full choice in all areas)

What is your facility policy on the following:
Use of walkers: i.e. is everyone required to use them?

_____

Bathing/washing: i.e. is everyone required to have assistance while bathing?

_____

Living wills – are all entering residents required to have one?

_____

The time at which residents go to bed – how is this determined?

_____

Room transfers – how is this decision made, by whom? What if resident does not wish to move?

_____

APPENDIX E
Vignette-Specific Regression Analyses

Regression of Independent and Control Variables on the Desire for Full, Independent Involvement in Decision-Making

Regression of Independent and Control Variables on the Desired Level of Active Involvement in Decision-Making

Regression of Independent and Control Variables on the Desire for Joint Decision-Making

Other regressions:

TABLE 18

Impact of independent and control variables on the desire for full, independent involvement in decision-making Vignette A (Bed-times)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.02	0.98	ns	-0.02	0.98	ns	-0.01	0.99	ns
Gender	-0.06	0.93	ns	0.06	1.06	ns	0.14	1.15	ns
Education	0.15	1.16	ns	0.15	1.16	ns	0.15	1.17	ns
Chronic conditions	0.03	1.03	ns	0.03	1.03	ns	0.00	1.00	ns
Length of stay				0.40	1.49	ns	-0.04	0.96	ns
Entry decision				0.23	0.63	ns	0.48	1.62	ns
Facility size				-0.01	1.00	ns	-0.01	1.00	ns
Outcome							-0.05	0.95	ns
Confidence							1.18	3.25	<0.05
Secondary Control							-1.69	0.18	<0.05
Appropriateness							0.91	2.50	ns
a	1.23	---	ns	1.75	---	ns	2.12	---	ns
R^2 (Cox and Snell)	0.03	---	---	0.07	---	---	0.19	---	---
Model x^2	2.83	---	ns	6.87	---	ns	20.52	---	<0.05
df	3	---	---	7	---	---	11	---	---

TABLE 19

Impact of independent and control variables on the desire for full, independent involvement in decision-making Vignette B (Medications)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.02	0.99	ns	-0.02	0.98	ns	-0.02	0.98	ns
Gender	-0.34	0.72	ns	-0.18	0.84	ns	0.16	1.17	ns
Education	0.15	1.16	ns	0.17	1.18	ns	0.15	1.16	ns
Chronic conditions	0.11	1.12	ns	0.13	1.14	ns	0.15	1.16	<0.05
Length of stay				1.07	2.92	=.05	0.81	2.24	ns
Entry decision				-0.15	0.86	ns	-0.24	0.79	ns
Facility size				-0.01	1.00	ns	-0.00	1.00	ns
Outcome							0.06	1.06	ns
Confidence							1.31	3.69	<0.05
Secondary Control							-0.81	0.44	ns
Appropriateness							-0.14	0.87	ns
a	-1.18	---	ns	-1.71	---	ns	-2.92	---	ns
R^{2} (Cox and Snell)	0.05	---	---	0.12	---	---	0.18	---	---
Model x^{2}	4.96	---	ns	12.11	---	ns	18.70	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 20

Impact of independent and control variables on the desire for full, independent involvement in decision-making
Vignette C (Room transfer)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.00	1.00	ns	-0.02	0.99	ns	-0.02	0.99	ns
Gender	-0.42	0.65	ns	-0.41	0.66	ns	-0.53	0.59	ns
Education	0.22	1.24	ns	0.19	1.21	ns	0.19	1.20	ns
Chronic conditions	0.12	1.12	ns	0.12	1.13	ns	0.11	1.12	ns
Length of stay				0.46	1.58	ns	0.44	1.55	ns
Entry decision				0.51	1.66	ns	0.49	1.62	ns
Facility size				0.01	1.01	ns	0.01	1.01	ns
Outcome							-0.09	0.92	ns
Confidence							0.74	2.10	ns
Secondary Control							0.02	1.02	ns
Appropriateness							0.15	1.17	ns
a	-2.49	---	ns	-3.01	---	ns	-2.06	---	ns
R^2 (Cox and Snell)	0.07	---	---	0.11	---	---	0.14	---	---
Model x^2	6.75	---	ns	11.44	---	ns	14.93	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 21

Impact of independent and control variables on the desire for full, independent involvement in decision-making Vignette D (Advance directives)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	0.00	1.00	ns	-0.00	1.00	ns	-0.01	0.99	ns
Gender	0.60	1.83	ns	0.58	1.79	ns	0.76	2.15	ns
Education	0.12	1.13	ns	0.11	1.12	ns	0.14	1.15	ns
Chronic conditions	0.09	1.09	ns	0.10	1.10	ns	0.12	1.13	ns
Length of stay				0.46	1.59	ns	0.67	1.95	ns
Entry decision				-0.01	0.99	ns	-0.17	0.84	ns
Facility size				0.00	1.00	ns	0.00	1.00	ns
Outcome							-0.24	0.79	<0.01
Confidence							0.59	1.81	ns
Secondary Control							-0.14	0.87	ns
Appropriateness							-0.61	0.55	ns
a	-1.78	---	ns	-2.30	---	ns	2.24	---	ns
R^2 (Cox and Snell)	0.04	---	---	0.06	---	---	0.16	---	---
Model x^2	4.22	---	ns	5.95	---	ns	16.66	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 22

Impact of independent and control variables on the desire for active involvement in decision-making Vignette A (Bed-times)

Variable	B	Beta	p	B	Beta	p	B	Beta	p
Age	-0.02	-0.10	ns	-0.02	-0.11	ns	-0.01	-0.07	ns
Gender	-0.03	-0.01	ns	0.05	0.01	ns	0.08	0.02	ns
Education	0.13	0.20	ns	0.12	0.19	ns	0.11	0.17	ns
Chronic conditions	0.06	0.16	ns	0.05	0.15	ns	0.04	0.10	ns
Length of stay				0.06	0.02	ns	-0.23	-0.08	ns
Entry decision				0.26	0.10	ns	0.39	0.14	ns
Facility size				-0.00	-0.11	ns	-0.00	-0.10	ns
Outcome							-0.01	-0.03	ns
Confidence							0.50	0.19	ns
Secondary Control							-0.75	-0.22	<0.05
Appropriateness							0.67	0.21	=0.05
a	4.60	---	<0.05	4.89	---	<0.05	4.73	---	<0.05
$R^{2\ (adjusted)}$	0.04	---	---	0.03	---	---	0.12	---	---
F	1.86	---	ns	1.39	---	ns	2.15	---	<0.05
df	4	---	---	7	---	---	11	---	---

TABLE 23

Impact of independent and control variables on the desire for active involvement in decision-making Vignette B (Medications)

Variable	B	Beta	p	B	Beta	p	B	Beta	p
Age	-0.02	-0.08	ns	-0.02	-0.12	ns	-0.02	-0.08	ns
Gender	-0.06	-0.02	ns	0.01	0.00	ns	0.24	0.06	ns
Education	0.10	0.13	ns	0.09	0.11	ns	0.08	0.11	ns
Chronic conditions	0.08	0.19	ns	0.09	0.21	ns	0.10	0.24	<0.05
Length of stay				0.76	0.23	<0.05	0.51	0.16	ns
Entry decision				0.02	0.01	ns	-0.10	-0.03	ns
Facility size				-0.00	-0.04	ns	0.00	0.01	ns
Outcome							0.09	0.16	ns
Confidence							1.10	0.35	=0.001
Secondary Control							-0.45	-0.12	ns
Appropriateness							-0.16	-0.04	ns
a	3.36	---	ns	3.14	---	ns	0.91	---	ns
$R^{2\ (adjusted)}$	0.01	---	---	0.04	---	---	0.14	---	---
F	1.29	---	ns	1.55	---	ns	2.36	---	<0.05
df	4	---	---	7	---	---	11	---	---

TABLE 24

Impact of independent and control variables on the desire for active involvement in decision-making Vignette C (Room transfer)

Variable	B	Beta	p	B	Beta	p	B	Beta	p
Age	-0.01	-0.04	ns	-0.00	-0.05	ns	-0.00	-0.03	ns
Gender	-0.66	-0.19	ns	-0.60	-0.17	ns	-0.61	-0.18	ns
Education	0.17	0.27	<0.05	0.16	0.25	<0.05	0.15	0.23	<0.05
Chronic conditions	0.05	0.15	ns	0.05	0.12	ns	0.04	0.10	ns
Length of stay				-0.00	0.02	ns	-0.24	-0.09	ns
Entry decision				0.32	0.12	ns	0.38	0.14	ns
Facility size				-0.00	-0.07	ns	-0.00	-0.06	ns
Outcome							-0.02	-0.05	ns
Confidence							0.53	0.20	ns
Secondary Control							-0.23	-0.07	ns
Appropriateness							0.55	0.17	ns
a	3.15	---	ns	3.43	---	<0.05	3.25	---	ns
$R^{2\ (adjusted)}$	0.08	---	---	0.07	---	---	0.11	---	---
F	3.05	---	<0.05	1.95	---	ns	2.03	---	<0.05
df	4	---	---	7	---	---	11	---	---

TABLE 25

Impact of independent and control variables on the desire for active involvement in decision-making Vignette D (Advance directives)

Variable	B	Beta	p	B	Beta	p	B	Beta	p
Age	0.00	0.02	ns	-0.00	-0.00	ns	-0.02	-0.01	ns
Gender	0.36	0.13	ns	0.36	0.13	ns	0.38	0.14	ns
Education	0.11	0.21	<0.05	0.10	0.20	ns	0.10	0.20	=0.05
Chronic conditions	0.06	0.22	<0.05	0.07	0.23	<0.05	0.07	0.21	<0.05
Length of stay				0.27	0.12	ns	0.28	0.12	ns
Entry decision				0.03	0.01	ns	0.03	0.01	ns
Facility size				0.00	0.08	ns	0.00	0.09	ns
Outcome							-0.12	-0.30	<0.01
Confidence							0.41	0.19	ns
Secondary Control							-0.38	-0.14	ns
Appropriateness							-0.11	-0.04	ns
a	2.84	---	<0.05	2.60	---	ns	4.80	---	<0.01
$R^{2\ (adjusted)}$	0.05	---	---	0.04	---	---	0.16	---	---
F	2.36	---	ns	1.59	---	ns	2.65	---	<0.01
df	4	---	---	7	---	---	11	---	---

TABLE 26

Impact of independent and control variables on the desire for joint involvement in decision-making
Vignette A (Bed-times)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.01	0.99	ns	-0.00	1.00	ns	-0.01	1.00	ns
Gender	-0.25	0.65	ns	-0.37	0.69	ns	-0.40	0.67	ns
Education	-0.07	0.93	ns	-0.06	0.94	ns	-0.07	0.94	ns
Chronic conditions	0.04	1.04	ns	0.04	1.04	ns	0.06	1.06	ns
Length of stay				-0.48	0.62	ns	-0.32	0.73	ns
Entry decision				-0.11	0.89	ns	-0.17	0.84	ns
Facility size				0.00	1.00	ns	0.00	1.00	ns
Outcome							0.12	1.13	ns
Confidence							-0.91	0.40	ns
Secondary Control							1.03	2.80	ns
Appropriateness							-0.26	0.77	ns
a	-0.27	---	ns	-0.62	---	ns	-2.93	---	ns
R^2 (Cox and Snell)	0.01	---	---	0.05	---	---	0.12	---	---
Model x^2	1.18	---	ns	4.84	---	ns	12.03	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 27

Impact of independent and control variables on the desire for joint involvement in decision-making Vignette B (Medications)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	0.04	1.04	ns	0.04	1.04	ns	0.04	1.04	ns
Gender	0.91	2.48	ns	0.94	2.55	ns	0.84	2.31	ns
Education	-0.00	1.00	ns	-0.02	0.98	ns	-0.02	0.98	ns
Chronic conditions	-0.01	0.99	ns	-0.03	0.97	ns	-0.04	0.96	ns
Length of stay				-0.41	0.66	ns	-0.55	0.58	ns
Entry decision				0.60	1.82	ns	0.67	1.96	ns
Facility size				0.00	1.00	ns	0.00	1.00	ns
Outcome							0.07	1.08	ns
Confidence							-0.19	0.82	ns
Secondary Control							0.48	1.61	ns
Appropriateness							0.75	2.11	ns
a	-3.08	---	ns	-2.84	---	ns	-5.10	---	ns
R^2 (Cox and Snell)	0.04	---	---	0.07	---	---	0.11	---	---
Model x^2	3.80	---	ns	6.86	---	ns	10.81	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 28

Impact of independent and control variables on the desire for joint involvement in decision-making Vignette C (Room transfer)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.01	0.99	ns	0.00	1.00	ns	0.01	1.01	ns
Gender	0.25	1.29	ns	0.36	1.43	ns	0.58	1.79	ns
Education	-0.11	0.90	ns	-0.11	0.90	ns	-0.10	0.90	ns
Chronic conditions	-0.10	0.91	ns	-0.11	0.89	ns	-0.12	0.89	ns
Length of stay				-0.64	0.53	ns	-0.93	0.39	ns
Entry decision				-0.06	0.94	ns	0.06	1.06	ns
Facility size				-0.01	0.99	<0.05	-0.01	0.99	<0.05
Outcome							0.15	1.16	ns
Confidence							-0.21	0.81	ns
Secondary Control							-0.61	0.55	ns
Appropriateness							0.26	1.30	ns
a	2.06	---	ns	3.16	---	ns	0.88	---	ns
R^2 (Cox and Snell)	0.04	---	---	0.10	---	---	0.14	---	---
Model x^2	3.90	---	ns	10.17	---	ns	14.97	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 29

Impact of independent and control variables on the desire for joint involvement in decision-making Vignette D (Advance directives)

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.01	1.00	ns	-0.00	1.00	ns	0.01	1.01	ns
Gender	-0.39	0.68	ns	-0.40	0.67	ns	-0.51	0.60	ns
Education	-0.09	0.91	ns	-0.09	0.92	ns	-0.10	0.91	ns
Chronic conditions	-0.07	0.93	ns	-0.08	0.93	ns	-0.10	0.91	ns
Length of stay				-0.03	0.73	ns	-0.54	0.58	ns
Entry decision				-0.06	0.94	ns	0.14	1.15	ns
Facility size				-0.00	1.00	ns	-0.00	1.00	ns
Outcome							0.15	1.17	ns
Confidence							-0.48	0.62	ns
Secondary Control							-0.16	0.86	ns
Appropriateness							0.82	2.26	ns
a	1.53	---	ns	1.73	---	ns	-1.31	---	ns
R^2 (Cox and Snell)	0.03	---	---	0.03	---	---	0.10	---	---
Model x^2	2.56	---	ns	3.15	---	ns	10.18	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 30

Impact of independent and control variables on Outcome Expectations

Variable	B	Beta	p	B	Beta	p	B	Beta	p
Age	-0.03	-0.08	ns	-0.04	-0.10	ns	-0.03	-0.10	ns
Gender	-0.77	-0.11	ns	-0.66	-0.09	ns	-0.86	-0.12	ns
Education	0.00	0.00	ns	-0.00	-0.01	ns	-0.00	-0.01	ns
Chronic conditions	-0.05	-0.07	ns	-5.03	-0.07	ns	-0.07	-0.09	ns
Length of stay				0.72	0.13	ns	0.66	0.12	ns
Entry decision				0.23	0.04	ns	0.43	0.08	ns
Facility size				-0.00	-0.05	ns	-0.00	-0.07	ns
Confidence							-0.66	-0.12	ns
Secondary Control							0.15	0.02	ns
Appropriateness							0.94	0.14	ns
a	19.53	---	<0.001	19.46	---	<0.001	19.15	---	ns
$R^{2\ (adjusted)}$	-0.03	---	---	-0.04	---	---	-0.04	---	---
F	0.41	---	ns	0.54	---	ns	0.61	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 31

Impact of independent and control variables on Secondary Control

Variable	B	OR	p	B	OR	p	B	OR	p
Age	0.01	1.01	ns	0.01	1.01	ns	0.02	1.02	ns
Gender	0.85	2.33	ns	0.87	2.38	ns	0.87	2.37	ns
Education	0.02	1.02	ns	0.01	1.01	ns	0.00	1.00	ns
Chronic conditions	0.01	1.01	ns	-0.02	0.98	ns	-0.03	0.98	ns
Length of stay				-0.92	0.40	ns	-1.09	0.34	ns
Entry decision				0.92	2.50	ns	0.94	2.56	ns
Facility size				0.00	1.00	ns	0.00	1.00	ns
Outcome							0.02	1.02	ns
Confidence							0.32	1.38	ns
Appropriateness							0.44	1.55	ns
a	-0.05	---	ns	0.86	---	ns	-0.32	---	ns
R^2 (Cox and Snell)	0.01	---	---	0.06	---	---	0.07	---	---
Model x^2	1.31	---	ns	6.02	---	ns	7.04	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 32

Impact of independent and control variables on Confidence

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.01	0.99	ns	-0.02	0.98	ns	-0.02	0.98	ns
Gender	-0.50	0.61	ns	-0.36	0.70	ns	-0.64	0.53	ns
Education	0.06	1.07	ns	0.05	1.05	ns	0.04	1.04	ns
Chronic conditions	-0.00	1.00	ns	-0.01	0.99	ns	-0.04	0.97	ns
Length of stay				0.61	1.83	ns	0.55	1.73	ns
Entry decision				0.55	1.74	ns	0.73	2.08	ns
Facility size				-0.00	1.00	ns	-0.00	1.00	ns
Outcome							-0.09	0.92	ns
Secondary Control Appropriateness							0.35	1.41	ns
							1.11	3.04	<0.05
a	1.09	---	ns	1.40	---	ns	2.12	---	ns
R^2 (Cox and Snell)	0.01	---	---	0.07	---	---	0.12	---	---
Model x^2	1.23	---	ns	6.53	---	ns	12.06	---	ns
df	4	---	---	7	---	---	11	---	---

TABLE 33

Impact of independent and control variables on Perceived Appropriateness of Active Involvement

Variable	B	OR	p	B	OR	p	B	OR	p
Age	-0.03	0.98	ns	-0.03	0.97	ns	-0.03	0.98	ns
Gender	1.02	2.77	ns	0.99	2.69	ns	1.08	2.95	ns
Education	0.03	1.03	ns	0.03	1.03	ns	-0.00	1.00	ns
Chronic conditions	0.08	1.08	ns	0.13	1.13	ns	0.14	1.15	ns
Length of stay				1.20	3.31	<0.05	1.04	2.83	ns
Entry decision				-0.89	0.41	ns	-1.17	0.31	<0.05
Facility size				0.00	1.00	ns	0.00	1.00	ns
Outcome							0.11	1.12	ns
Confidence							1.09	2.96	ns
Secondary Control							0.34	1.40	ns
a	2.52	---	ns	1.18	---	ns	-1.59	---	ns
R^2 (Cox and Snell)	0.04	---	---	0.09	---	---	0.15	---	---
Model x^2	3.76	---	ns	9.61	---	ns	15.24	---	ns
df	4	---	---	7	---	---	11	---	---

VITA

Surname: Funk | Given Names: Laura Megan

Place of Birth: Surrey, British Columbia, Canada

Educational Institutions Attended:

University of British Columbia	1992 to 1994/1995 to 1997
University of Glasgow	1994 to 1995 (exchange year)
Simon Fraser University	1998 to 1999
University of Victoria	1999 to 2002

Degrees Awarded:

B.A. (Honours)	University of British Columbia	1997
Post Baccalaureate Diploma	Simon Fraser University	2000

Honours and Awards:

B.C. Health Research Foundation/Canadian Health Services Research Foundation studentship award	2000 to 2001
Robert M. Hagedorn Graduate Scholarship	2001
University of Victoria President's Scholarship	2000
University of Victoria Graduate Fellowship	1999 to 2000
Al Eisenring Gerontology Award (SFU)	1998
Kiyoharu and Kiyoaki Momose Scholarship (UBC)	1997
University of British Columbia Scholarship	1996
Joseph Anthony Beirne Memorial Scholarship (external)	1992, 1993
Hugh M. Brock Education Abroad Scholarship (UBC)	1995
TE and ME Ladner Memorial Scholarship (UBC)	1992
Outstanding Student Initiative (UBC)	1992
Samuel Patrick Cromie Pacific Press Credit Union Scholarship (external)	1992

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