doi: 10.1111/j.1369-7625.2010.00638.x

A relational perspective on autonomy for older adults residing in nursing homes

Susan Sherwin PhD FRSC* and Meghan Winsby MA†

*University Research Professor Emeritus, Department of Philosophy, Dalhousie University, Halifax, NS, Canada and †Doctoral Student, Department of Philosophy, University of Western Ontario, London, ON, Canada

Correspondence
Susan B. Sherwin PhD, FRSC
University Research Professor Emeritus
Department of Philosophy
6135 University Avenue
Dalhousie University
Halifax
NS B3H 4P9
Canada
E-mail: ssherwin@dal.ca

Present address: Meghan Winsby, 3137 McIver Rd., Westbank, BC V4T 1E7, Canada.

Accepted for publication
27 July 2010

Keywords: nursing homes, older adults, relational autonomy

Abstract

Aim To review critically the traditional concept of autonomy, propose an alternative relational interpretation of autonomy, and discuss how this would operate in identifying and addressing ethical issues that arise in the context of nursing home care for older adults.

Background Respect for patient autonomy has been the cornerstone of clinical bioethics for several decades. Important though this principle is, there is debate on how to interpret the core concept of autonomy. We review the appeal of the traditional approach to autonomy in health care and then identify some of the difficulties with this conception.

Methods We use philosophical methods to explain and discuss the traditional and relational conceptions of autonomy and we illuminate our discussion with examples of various contextual applications.

Conclusion We support the relational conception of autonomy as offering a richer, more contextualized understanding of autonomy which attends to the social, political and economic conditions that serve as background to an agent's deliberations. To illuminate these ideas, we discuss the situation of frail older adults who frequently find their autonomy limited not only by their medical conditions but also by cultural prejudices against the aged and by the conditions commonly found within the nursing homes in which many reside. We propose ways of improving the relational autonomy of this population.

Introduction

Respect for patient autonomy has been the cornerstone of clinical bioethics for several decades. Important though this principle is, there is debate on how to interpret the core concept of autonomy. In recent years, various theorists have proposed relational alternatives to the traditional view of autonomy.[1] 'Relational autonomy' refers to a cluster of approaches to autonomy, which emphasize (rather than ignore) the socially embedded nature of agents. In this article, we shall briefly review the traditional interpretation of autonomy in bioethics and explain how a relational approach offers a richer, more contextualized understanding. Where the traditional approach focuses on the capacity of the patient and on the clinician's

obligation to provide adequate information, a relational approach asks that we attend also to the social, political and economic conditions which serve as background to an agent's deliberations. We shall discuss the value of taking social context into account – particularly patterns of discrimination and inequality – as we evaluate some of the key background conditions against which choices are made, exploring how this alternative conception of autonomy can improve our understanding of caregiving responsibilities. To illuminate these ideas, we will discuss the situation of frail senior adults who reside in nursing homes and frequently find their autonomy limited not only by their medical conditions but also by cultural prejudices against older adults.

Traditional approach to autonomy

The ideal of respect for patient autonomy in clinical encounters is of central theoretical and practical concern to bioethicists, patients, clinicians and caregivers. The attraction of this ideal is readily understood and accepted in Western democracies where respect for personal autonomy figures centrally in social and political discourse in many domains: it is promoted in moral, legal and political spheres as key to ensuring that individuals live lives that are, to the greatest extent possible, of their own choosing (i.e. in accordance with their own interests, goals and life plans). As such, the familiar ideal of autonomy common to mainstream philosophical, legal and political theory is grounded in traditional liberal ideology. To be autonomous is to be a 'free, self-governing agent'.[2] (P.143) Autonomous agents make decisions that are uncoerced and that best express the outcomes of their own deliberative processes. The dominant cultural ideal of such agents envisions them as independent, rational, and self-interested persons.[2]

It is widely accepted that patients have a right to make significant decisions regarding their lives and bodies and hence, their health care. 'Autonomy' in clinical contexts is generally understood to refer to an individual patient's authority over decisions affecting his/her own healthcare and body, with the earlier 'doctor knows best' approach largely replaced by a patient authority view (at least within North America). While all patients are entitled to have their autonomous decision making respected, they must be sufficiently competent to make well-founded decisions that reflect their own values. Unfortunately, many older residents of nursing homes are afflicted by dementia or other conditions that have reduced their level of competency. In such cases, clinicians are expected to honour any clear instructions that were given when the patient was competent. Absent such direction, they must rely on the decisions of those who have legal authority to decide on the patient's behalf; ideally, such surrogates will be guided by appreciation of the patient's values.

The principal mechanism for respecting patient autonomy in clinical settings is a process of informed consent, where competent patients (or the surrogates of non-competent patients) express formal agreement with a proposed therapy after receiving clear information regarding all relevant information. Such decisions are to be made voluntarily, without external coercion or efforts to distract a patient from focus on his/her own welfare. Informed consent includes a right to informed refusal since respect for autonomy also entails respecting patients' wishes regarding medical non-interference. In practice, however, informed consent procedures are often reduced to the technicality of obtaining a signature on a generic form, sometimes with little attention to the decision maker's actual understanding or wishes. Properly executed, however, informed consent serves as a mechanism for protecting patient autonomy.

Personal autonomy runs into particular risk in the clinical setting, owing in large part to the increased dependence and vulnerability that frequently accompany illness. When ill, patients often experience greater dependency, and with it, a greater likelihood that they will have their interests and values overridden by others. For example, there is a significant risk of paternalism where clinicians are tempted to substitute their own judgment for that of a patient, particularly

when they feel that they have a better insight into that patient's medical needs than the patient himself/herself, and they seek to ensure the best medical outcome. Moreover, patients may feel constrained from insisting on their own wishes for fear that questioning or rejecting their doctors' advice may result in abandonment. In addition, some patients are susceptible to abuse or exploitation in the service of others' financial, academic or social interests. All of these problems are exacerbated for patients who reside in nursing homes, particularly when they are subject to stereotypical assumptions about the connection between old age and reduced competency.

While efforts to protect patient autonomy provide a means of avoiding some of the ways in which patients risk losing control over important decisions in their lives, there is often a significant gap between the ideal of independent, competent, fully informed, voluntary decision making and the actual conditions in which patients must choose, even when patients are living independently. For example, the ideal of autonomy assumes that patients are able to draw upon all the resources necessary, deliberate objectively, arrive at independent judgements and communicate their decisions effectively. Such a description does not fit the experience of many ill people who encounter a busy and complex health care system, consisting of overworked caregivers struggling to provide efficient but somewhat regimented care. Moreover, the traditional interpretation treats all patients as generic, or interchangeable. It ignores important differences among actual patients; each enters the decision-making process from unique circumstances that may place important, but easily overlooked limits on their choices. In addition, it focuses too heavily on evaluating the competency of the patient and not nearly enough on examining the range and nature of the options from which each patient must choose.

Relational autonomy

To meet some of these difficulties, we subscribe to an alternative conception of autonomy called 'relational autonomy'. It identifies a broader range of barriers to autonomous choice than is usually acknowledged in autonomy discussions. In particular, it considers the embodied social location and experience of patients relevant to assessments of autonomy. Rather than theorizing about abstract individuals, conceived of simply as rational deliberators, we recognize that persons are essentially social beings, whose distinct identities are developed and maintained within a complex web of social relations.[1] The particular social location of a given individual is influential in establishing his/her priorities, concerns, values and beliefs about himself/herself. Moreover, it often determines a person's opportunities to develop the necessary skills for exercising autonomy.[3]

Autonomy admits of degrees, such that a person can have more or less autonomy. Moreover, the ways in which autonomy can be limited are multiple: there are many different types of factors that can interfere with a person's ability to pursue maximal autonomy. On this interpretation, then, the duty to respect patient autonomy in some cases will include trying to help patients achieve as much autonomy as possible in the circumstances, and this requires consideration of the various dimensions that might be undermining their autonomy.

One serious type of threat to patient autonomy concerns the fact that the set of meaningful options available to patients is shaped by the circumstances of each one's social, political, economic and cultural situation; for example, patients without adequate health insurance will have far fewer accessible medical options than those living within a well-supported healthcare system. And patients who belong to minority cultures may encounter health care providers who are unwilling to allow the use of their traditional healing practices. We believe the received view of autonomy is mistaken insofar as it assumes that agents can step back from this social web and engage in a process of rational deliberation that is not importantly complicated by the details of their particular social circumstances.

Our relational approach is particularly concerned with questions of social justice. We think

it necessary to consider the impact of patterns of inequality and prejudice on the options and opportunities available to each person. Although respect for patient autonomy helps to ensure that efforts will be made to protect the rights and interests of even seriously disadvantaged patients, it is not a sufficient response to structural inequalities. To promote greater autonomy, it is also necessary to recognize and address the ways in which oppressive structures can undermine the autonomy of many patients. Within societies prone to discrimination against older adults, this is an important dimension to include in our reflections on obligations to older persons residing in nursing homes.

Relational theory rejects atomistic understandings of the self and insists that we be attentive to the ways in which membership in socially salient groups affects agents' experiences throughout life. It makes clear that the relational self is encouraged and maintained within a complex set of social relationships, and this set of relationships – both public and personal – will be differently enabling. Members of oppressed or stigmatized groups are more likely to be disadvantaged with respect to their degrees of social mobility, income-earning potential and even their quality of health care.[4] They frequently face group-specific constraints on the types of choices available to them, and the consequences attached to resisting prevailing patterns of practice reflect widespread undervaluing of the group as a whole. It is common for members of oppressed groups to find that the options they are to choose amongst are skewed towards practices that sustain their oppression. For example, women are encouraged to meet demanding standards of youth and beauty to the point that many face serious discrimination if they allow their hair to turn grey and their faces to display wrinkles. Jurisdictions that still permit mandatory retirement make it difficult for many older adults to earn an income that will keep them from poverty. This serves to increase the social isolation of many, and further reinforces stereotypes.

A further complication has to do with the fact that when members of oppressed groups internalize some of the social biases attached to their group, they often experience a reduced sense of self-worth and self-trust;[5] yet, self-trust is an essential component of exercising autonomy. Older adults, along with people living in poverty and members of racialized minorities, are constantly exposed to deeply entrenched stereotypes that deny their competence to manage their own lives well; some have a hard time believing there is no truth to these biases. When agents experience diminished self-trust, they are less likely to challenge the pervasive biases that structure the options made available to them or to question the system of rewards and punishments that encourage them to comply with dominant stereotypes.

When oppression structures the options available to members of disadvantaged groups and unjustly limits the opportunities to express autonomy, increasing a person's autonomy cannot be achieved merely through better education or increased competence. What is really required is a change in the background social conditions which conspire to perpetuate their oppression and thereby undermine their full autonomy. For agents to be autonomous, they must be able to resist the options that help to sustain their own oppression. To ensure that conditions are such that the exercise of a reasonably high degree of autonomy is possible, it is sometimes necessary to try to correct limitations inherent in the background conditions of each person's social location.

We want to draw attention to one more difference between relational autonomy and the more familiar traditional conception before turning to the implications of a relational approach to autonomy in clinical encounters involving older nursing home residents. Traditional accounts of autonomy implicitly favour an ideal of independence and view dependence or reliance on others as an impediment to autonomy. Negative attitudes towards dependence are problematic for at least three reasons: (i) they ignore the important fact that we are all interdependent and rely on one another in multiple ways, (ii) they serve to devalue efforts to care for others by denying the urgency and fre-

quency of such work, and (iii) they devalue persons who are clearly highly dependent, such as children and people with serious disabilities.[5] Relational theory seeks to make explicit the reality of multiple layers of interdependence and the importance of resisting tendencies to devalue people with special needs and those who care for them. The case of autonomy among older adults who reside in nursing homes is particularly challenging because many experience a real and steady loss of both independence and autonomy, and the institutional requirements of nursing homes make it difficult to fully address the broad spectrum of their individual circumstances, while biases against older persons are pervasive in many modern societies.

Relational autonomy and ageing

We shall focus more narrowly now on one particular group that is subject to systemic discrimination, namely older adults. Relational autonomy is explicitly concerned with protecting and promoting the autonomy of members of oppressed groups, and, hence, it is a valuable lens to use in our discussion. We believe that older adults (at least within mainstream North American society) are victims of ageism, a particular form of oppression. Monique M. Williams defines ageism as 'prejudice towards, stereotyping, or discrimination against persons solely on chronological age deemed to be "old"'.[6] (P.443) Certainly, older persons are frequently victims of pernicious stereotypes, negative attitudes, and outright abuse.[6] They are often overlooked, if not actively excluded, in the hiring market – until very recently, it was common to force people to retire at a designated age, no matter what their state of health and capacities. Furthermore, as Williams points out, prejudice with respect to age remains acceptable among young people. It finds expression in the media and in popular culture, and it influences the way the young interact with their elders.[6] In a culture that glorifies youth, ageing is often treated with fear and aversion. Relational autonomy directs us to consider the ways in which such biases limit and structure the options available to older adults and the ways in which they may be particularly vulnerable to reduced opportunities for exercising autonomy.

Among the stereotypes associated with growing old are loss of cognitive abilities like memory and the ability to learn new skills, physical decline, unattractiveness and general uselessness. Many seniors struggle with family members and health care providers to maintain their autonomy in health and other matters when well-meaning others seek to exercise paternalism. In the face of such systemic discrimination, it is particularly important to use a relational autonomy lens that is sensitive to the dangers of distorting stereotypes. This lens helps to reveal the frequency of unjustified paternalism towards competent seniors and provides grounds for developing strategies to protect the autonomy rights for vulnerable older patients.

The task is complicated, however, by the fact that there is some basis in truth for some of the stereotypes. Generally, old age does carry it with it some deterioration in physical abilities and, for far too many elderly persons, it also involves a significant decrease in cognitive capacities. Older citizens are at far higher risk than others of developing forms of dementia that undermine their competence, and, thereby, the degree of autonomy they can exercise.

Adapting to increased dependence after a long life of relative independence is challenging both for older persons and for those who care for them. These challenges are particularly acute for those who live in institutions, particularly nursing homes – that is, residential facilities that provide nursing and personal care to dependent residents. There are many types of care aimed at seniors unable to live independently. Some, such as assisted living, community support, and home care are aimed at helping seniors to live in private homes. There are also several types of facility-based residential options for seniors with greater needs, including hospitals and nursing homes – which provide round-the-clock support and professional nursing services.[7] Nursing homes accept residents who have lost significant physical and/or cognitive function. Hence, the

institutions are designed to try to compensate for lost capacities; this focus can leave residents vulnerable to mistaken presumptions about their individual level of competence and create little space for attending to remaining levels of autonomy. These threats to their autonomy occur not only in the realm of medical decision making but also in other aspects of their daily care.

The greater acceptance of institutionalization for older adults which has occurred over the last century has exacerbated our societal tendency to view them as 'major social problems, rather than as people who can provide a sense of wholeness or wisdom'.[8] (P.191) This pattern reinforces rather than challenges the pervasive ageism that plagues the care seniors receive.[8] Those who enter nursing homes inevitably face a significant reduction in the range of options available to them by virtue of the nature of institutionalized living itself.[9,10] Many nursing homes adhere to an institutional model of care, which focuses first and foremost on task completion – such as dressing, bathing, feeding – and documentation[7,11] Emphasis on the physical care of nursing home residents in a regimented, task-oriented facility fosters a structure that privileges efficiency over resident choice. The limited options with respect to personal space, for example, are particularly salient.[12] Often, only semi-private rooms are available to residents, where they are paired with a stranger without their explicit consent. Private rooms may be available, but only at additional cost to the resident.[13] It seems that in many nursing homes, those who enter surrender the opportunity to maintain privacy or personal control over many ordinary matters; residents are treated as having issued blanket consent to close physical contact with nursing professionals and other care workers. Daily activities like meals, social interaction, and bathing, are often structured in ways that leave little space for residents to make choices.

Although it is important to respect autonomy for seniors who retain competence, not every older adult is able or willing to take on responsibility for important decision making.[14] Patients who suffer from even moderate dementia are limited in their capacity to make choices that are in their best interests. For the many nursing home residents who are seriously compromised in their cognitive capacities, paternalistic treatment is not only warranted; it is often a necessary part of their overall care. Sometimes, caregivers must insist on matters of hygiene, medication, or nutrition despite vigorous refusal on the part of confused residents. Indeed, in many cases, there is a more serious risk of neglect of the residents' needs and a failure of paternalistic care than of someone overruling patients' expressed wishes. 'Respect for patient autonomy', when patients lack the capacity for consent, should never serve as an excuse for failure to identify and respond to the needs of a patient who cannot make explicit requests. The difficulty, then, is to find an appropriate balance that avoids deployment of either a generalized deferral or a catch-all paternalism when responding to residents' expressed wishes.

Unfortunately, many nursing homes are not well structured to manage this delicate balance. Many are modelled on medical facilities and presume that autonomy is relevant only if it meets idealized standards of informed consent. Cathy Butterworth (2005) discusses this and other difficulties with consent on the part of older persons in nursing homes. She points out that the issue of consent in the nursing home context is one which has been scarcely researched, and differs from consent in the medical context mainly because, as we have suggested, the process is *ongoing* and represents a 'stage in the continuum of involvement' between care giver and resident. She argues that consent cannot be viewed as a 'one-off' event, or even episodically. Instead, if it is to be meaningful, consent in the nursing home must be viewed as 'one aspect in a process of including service users in decisions about their care'.[14] (P.40) Consent forms are not in and of themselves adequate to issue consent to the various types of care administered in the nursing home setting.[14] When a single facility is responsible for delivering medical and nursing care, along with the necessities of daily living (help with feeding,

dressing, bathing, etc.), the norms of medical decision making can blend unnoticed into the other realms of life for residents.

In addition, the rhythms of running the institution and the practices that can become normalized create an environment where new residents may find that their opportunities to exercise autonomy become very limited very quickly, and often, more severely than their current abilities demand. Seniors enter these facilities because they have become unable to care for themselves, but the type and degree of impairment can vary widely. While many suffer dementia, others do not; even those diagnosed with a disease such as Alzheimer's disease that results in dementia may enter care at a time when they are still capable of making at least some types of choices for themselves. The fact that they are dependent on others for assistance with the tasks of day-to-day living, as well as nursing care and medical treatment, and that they may have difficulty making complex decisions runs the risk of being interpreted to mean that they are unable to make any types of decisions for themselves. However, expanding residents' roles in decision making can be a very difficult practical issue, as decisions about prescriptions, for example – one of the most common medical interventions faced by nursing home residents – can have significant repercussions for patients' wellbeing. Hughes and Goldie[15] examine the degree to which the residents in several Northern Ireland nursing homes participated in prescription decisions. For the most part, they found, residents deferred to prescription decisions made for them. While health care workers agreed that more resident involvement in these decisions would lead to greater autonomy among the elderly residents, they also held that 'control' of the prescription/administering process within the nursing home would be compromised. The stereotypes of declining mental faculties that plague all seniors are particularly strong with respect to those living in nursing homes.

Moreover, some seniors internalize the beliefs and attitudes towards old age that are pervasive within the larger culture. When older persons assume negative characterizations of ageing and dependency, and experience some decline in their own capacities, the result can be a diminished sense of self-worth and self-trust. The belief that one is not competent, or must rely heavily on others to make decisions on one's behalf, can become self-fulfilling.

Against this backdrop of real and presumed limits to decision-making ability among older nursing home residents, it is particularly urgent to ensure that staff members are attentive to the dangers of pervasive stereotypes. They must be vigilant in their commitment to be responsive to the desires of residents who wish to exercise a degree of autonomy and who maintain some capacity for doing so. For example, to ensure respect for the ways in which residents want to live the rest of their lives, staff should provide opportunities for residents to engage their decision-making skills where possible. Unfortunately, many nursing homes are designed to address physical needs without being sufficiently attentive to social dimensions. A focus on medical needs, together with an assumption that loss of independence means loss of all meaningful degrees of autonomy, results in limited opportunities for self expression. Such tendencies can be resisted if we adopt a relational autonomy lens that is sensitive to the harms of pervasive ageism and that appreciates the importance of fostering autonomy by creating opportunities to promote and exercise it. If we take a broader view of the nature of autonomy, we are more likely to reflect on the possibility of expanding opportunities for choice and improving the types of options available.

Nursing homes are charged with the responsibility for delivering the necessities of life for a wide range of patients with complex conditions and each facility must meet regulated norms for the services they provide. They must provide care within a budget that is often far less than what ideal care demands. Typically, they are short staffed and rely heavily on minimally trained workers. Heavy workloads, fatigue, lack of proper equipment and inadequate training are not uncommon, and can conspire to render the environment unsafe.[13] In the face of such pres-

sures, it is understandable that the institutional model of care, which is task-oriented and regimented toward efficiency, has remained prevalent among nursing facilities. Circumstances often make it difficult to customize arrangements in ways that encourage each resident to maintain and exercise as much autonomy as he/she can.

Fortunately, there are alternative models available that offer ways of breaking this destructive cycle. 'Resident centered' care models, such as *Eden Alternative*, and 'relationship centered' models such as *My Home Life* in the United Kingdom move away from the traditional medicalized, institutional method of care. They seek to open communication among all levels of staff and to set 'a standard of how to treat residents by treating staff with respect and dignity'.[16] (P.189) They actively try to foster communities within nursing homes where elderly residents 'experience dignity and respect, have a choice in everyday activities, have connections with the outside world by frequent interactions with the external community and develop meaningful relationships with other living things (including plants, animals, and humans)'.[16] Such respect-oriented care models may provide useful starting points for the redesign of programmes, which will be more sensitive to the autonomy interests of residents.[16]

Conclusion

To truly attend to the needs and interests of frail older persons who require the care associated with residency in nursing homes, we need to change the conceptual framework within which many facilities function and be more attentive to the need to correct the damage of oppressive ageism. A relational autonomy approach suggests that the problem does not lie primarily with specific caregivers or institutional managers, but rather with the cultural space occupied by nursing homes for older citizens. We need to challenge the multiple ways by which most parties begin with assumptions of absent, rather than diminished, capacities on the part of residents. We need to transform these types of institutions to foster degrees of relational autonomy even when more traditional versions of autonomy are no longer available.[17]

We recognize that demands to attend to patients' autonomy present very real difficulties in the clinical encounter of nursing home care. Such demands are especially challenging when autonomy among the elderly is often elusive, and the barriers to autonomous choice within nursing homes are many and complex. Less institutional models of care that are more sensitive to the social facts of nursing home residents probably require resources and staffing ratios that are difficult under current funding conditions. Nonetheless, we believe that the virtues of adopting a relational approach to enhancing the autonomy of older residents in nursing homes outweigh these difficulties. As far as possible, nursing homes should try to assist residents in maintaining control over matters of importance to them by fostering a facility culture marked by increased resident options and a care model that prioritizes the social well-being of elderly residents over completion of care regimens.

A relational autonomy lens helps us to appreciate the importance of making nursing homes responsive to the impact of the cultural devaluing of old age on seniors' self-image and self-trust and the orientation of their caregivers. It sheds light on the barriers to autonomous choice that stem from social, as well as cognitive, limitations. Through such reflection and action, we seek to support efforts to alter the structures common to many nursing homes and encourage opportunities to promote a degree of autonomy for residents wherever possible. A relational framework that is attentive to the role of biases and the importance of relationships can help facilitate required institutional transformations. It reminds us that the responsibility for promoting and protecting the autonomy of even the most vulnerable citizens extends beyond the duties of institutional caregivers and is shared by all of society.

References

1 MacKenzie C, Stoljar N (eds). *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the*

Social Self. New York and Oxford: Oxford University Press, 2000.
2 Christman J. Relational autonomy, liberal individualism, and the social constitution of selves. *Philosophical Studies*, 2004; **117:** 89–107.
3 Meyers DT. *Self, Society, and Personal Choice*. New York: Columbia University Press, 1989.
4 Young IM. *Justice and the Politics of Difference*. Princeton: Princeton University Press, 1990.
5 McLeod C, Sherwin S. Relational autonomy, self-trust, and health care. In: MacKenzie C, Stoljar N (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York and Oxford: Oxford University Press, 2000: 259–279.
6 Williams M. Invisible, unequal, and forgotten: health disparities in the elderly. *Notre Dame Journal of Law, Ethics, and Public Policy*, 2007; **21:** 442–478.
7 Canadian Healthcare Association. *Policy brief: New Directions For Facility-based Long-Term Care*. Ottawa: CHA Press, 2009.
8 Gale B. Advocacy for elderly autonomy: a challenge to community health nurses. *Journal of Community Health Nursing*, 1989; **6:** 191–197.
9 Kane RA, Caplan AL, Urv-Wong EK, Freeman IC, Aroskar MA, Finch M. Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. *Journal of the American Geriatrics Society*, 1997; **45:** 1086–1093.
10 Scott PA, Välimäki M, Leini-Kilpi H *et al*. Autonomy, privacy, and informed consent 3: elderly care perspective. *British Journal of Nursing*, 2003; **12:** 158–168.
11 Shawler C, Rowels GD, High DM. Analysis of key decision-making incidents in the life of a nursing home resident. *The Gerontologist*, 2001; **41:** 612–622.
12 Young IM. A room of one's own: old age, extended care and privacy. *Female Body Experience: ''Throwing Like a Girl'' and Other Essays*. Oxford: Oxford University Press, 2004: 155–178.
13 Armstrong P, Boscoe M, Clow B *et al*. *A Place to Call Home: Long-Term Care in Canada*. Halifax, Nova Scotia: Fernwood, 2009.
14 Butterworth C. Ongoing consent to care for older people in care homes. *Nursing Standard*, 2005; **19:** 40–45.
15 Hughes C, Goldie R. ''I Just Take What I Am Given'' Adherence and resident involvement in decision making on medicines in nursing homes for older people: a qualitative survey. *Drugs and Aging*, 2009; **26:** 505–517.
16 Thompson S, Parker Oliver D. A new model for long-term care: balancing palliative and restorative care delivery. *Journal of Housing for the Elderly*, 2008; **22:** 169–194.
17 Lanoix M. Triangulating care. *International Journal of Feminist Approaches to Bioethics*, 2010; **3:** 138–157.