

Review

## Aging, Informed Consent and Autonomy: Ethical Issues and Challenges Surrounding Research and Long-Term Care

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### Abstract

The history surrounding the notion of 'informed consent' is provided in the interest of setting a framework for the emergence of an ethics of aged care. Informed consent negligence is seen as a breach of duty involving potential litigation through the legal concept of 'failure to warn'. Respect for the autonomy of older persons is highlighted as a cornerstone of care by medical professionals and family members. There remains the challenge, however, of caring for older people who do not have full decision-making capacity. Research involving older people creates a range of ethical issues that warrants the use of best practice principles that respect the autonomy, integrity, dignity and safety of older participants. The use of restraints as part of aged care is demonstrated to have implications for infringements of human rights. While promoting the importance between communication and ethics of care, a case is made for the adoption of a person-centred approach that acknowledges both the autonomy and personhood of older people. In relation to the quality of aged care and safety, the message for all caregivers is to ensure that all decisions large or small incorporate a genuine mix of ethical reflection, avoidance of unnecessary risks and prudent judgement that leads to the most beneficial course of action.



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## Keywords

Beneficence; culture centric; end-of-life decision making; free agency; non-maleficence; paternalism

## 1. Introduction

In terms of aged care, the concept of long-term care includes a broad range of health care support services that are required by older people with chronic illness or disability over a relatively long period of time. Obson and Bogenschneider [1] indicate that long-term care involves support for people suffering from a range of debilitating medical problems that include arthritis, paraplegia, dementia related disorders, traumatic brain injuries and chronic mental illness. In the present situation, the definition of long-term care has been aligned with the approach taken by the *World Report on Ageing and Health* – “The activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity” [2]. Long-term care can range from aging in place (growing old at home), residential facilities, assisted living nursing homes, continuing care retirement communities and other residential facilities. It is important to understand that the majority of older people are not destined to need long-term care. However, with increasing age, the prevalence of long-term care increases dramatically [3].

Future planning initiatives for the provision of long-term care for the aged must involve consideration of a complex array of dynamic factors involving economic restructuring and resource allocation, changing family patterns, migration trends and resultant ethnic composition and policy developments, all of which along with other domains of social life can be expected to impact the shaping of the long-term aged care system [3-5]. Deloitte Access Economics [6] in a report on the future workforce and skills requirements in the Australian aged care sector indicate that with “advances in medicine and patient care mean that continuous training and skills development are necessary in the aged care workforce” (p. 33). Historically, it is interesting to reflect on the work of Goffman [7] in his work on ‘Asylums’ and his sociological concept of “The Total Institution” described as “a place of residence and events where a large number of like-situated individuals, cut from the wider society for an appreciable period of time, together lead an enclosed formally administered round of life” (p. xiii). Such living arrangements were eventually challenged due to major infringements on inmate autonomy and human rights abuses. The important question to ask is-How far have we improved with respect to quality of life outcomes for older people residing in long-term care facilities or those in receipt of home based care? Goodman [8] in her critique of the Goffman essays offers the following perspective which must surely challenge current approaches to aged care practices “Asylums may have been demolished and the care of vulnerable adults transferred to community settings. However, we may wish to reflect upon the degree to which the social processes of total institutions also lie in ruins, to be replaced by respect, dignity, autonomy and beneficence” (p. 81). For Bolig et al. [9] the nursing home setting presents a complex array of ethical issues involving insufficient resources, resident autonomy, use of restraints and decision making regarding end-of-life care.

It is one thing to advocate ethical care of the aged but this must necessarily be balanced with the reality that long-term care operates in a social, economic, political and medical framework. Equally important is to understand that “good caregiving is not possible without good social policies, adequate economic resources, and competent doctors and nurses who see caregiving as a vocation” [10]. According to Elliot [11] the four key principles that inform ethical health care in the context of Western philosophy are “autonomy, beneficence, nonmaleficence and justice” (p. 326). This essay is particularly focused on giving critical attention to the relationship between ‘good health practice’ and informed consent, autonomy and paternalism. In particular, there exists the theoretical and practical challenges surrounding the provision of an ethics of care approach as part of a humanistic model for culture change in aged care that promotes genuine opportunities for choice, voice and decision making by older people. The failure to listen to older people involved in accessing health care services has been shown to impact on their well-being [12].

The important consideration for health professionals and family caregivers is to fully appreciate that applied ethics for older people is about how they wish to be treated and the extent to which they are allowed to make their own decisions. It is also important to recognize and appreciate that for all health practitioners their professional work constitutes an *existential* process in which their respective work based worlds and consequent actions and practices are often impacted by a complex mix of ethical and moral challenges. The task of engaging professional practice with the spirit of applied ethics is well formulated in the following statement by The President’s Council on Bioethics [10]:

*To think about ethics is to think about the goals we pursue for ourselves and others (the good); about the actions we do (the right); and about the sort of people we hope to be (our character). Each of these aspects of ethics is important, and each makes its claim upon us. (p. 100)*

## **2. Understanding Informed Consent**

The historical development of informed consent can be traced back to the Nuremberg Code which was created following World War 2 and resulted from the inhuman experiments conducted during the time of Nazi Germany [13]. Later the Belmont Report [14] advanced the ethical standards including the rules and regulations associated with obtaining a legally based informed consent which first requires that the patient / research participant receives the correct information while at the same time is able to understand the information before providing his / her informed consent concerning biomedical and behavioral research. Van Norman [15] explains that in fact it was France and then the US that predated Nuremberg in setting “legal precedents enforcing patients’ rights” (p. 38). The Australian based Victorian Charter of Human Rights and Responsibilities Act 2006 [16] states that informed consent in relation to medical treatment “must be voluntary and the person concerned must have been given sufficient information for an informed decision to be made. This would include information such as the nature of the person’s condition and the treatment options available, including explanations of possible risks, side effects and benefits of the treatment” [17]. While the informed consent process is a very important approach for protecting human subjects involved in research or medical treatment the rules and regulations are not always followed according to the legal informed consent process [18]. Escobedo et al. [19] argue that neglecting the importance to behave ethically at all times when

engaging participants in research or performing medical interventions represents a failure of professional responsibility to promote “the rights of participants’ as autonomous beings to ensure that they are treated with justice, beneficence and respect” (p. 7). Nijhawan et al. [20] point out that in relation to clinically based studies that “Conventionally informed consent is thought to be in terms of the documents signed and dated by participants, setting forth the purpose, benefits, risks and other study information necessary to allow the participants to make an informed and voluntary decision to participate in a clinical study” (p. 134). The preceding researchers also draw attention to the need for clinicians to regularly assess consent capacity in each older patient due to the likelihood of fluctuations in his / her overall health status.

It is well to remember that informed consent is related to the legal concept of “*failure to warn*” [18, 21]. According to the Consumers Health Forum of Australia [17] “Informed consent is a key concept in the provision of health care which has ethical, legal and practical dimensions” (p. 1). Most importantly, researchers and health care professionals need to fully understand and appreciate the relationship between informed consent and communication as applied to the provision of direct health care and / or involvement in research which does not at the time involve a health intervention treatment. In other words, researchers and health care personnel need to give due consideration to the *what*, and *why*, and *when* and *how* and *where* and *who* of information given to older individuals participating in either research projects or those older people who are confronted with the need for medical treatment ranging from minor to major interventions. LaRusso [22] makes the telling point that communication is a complex mix of the verbal and the nonverbal which includes “the factors of *time, space, form and action*” (p. 5). From an ethical perspective, informed consent forms an essential component of the moral right of individuals to autonomy over their own bodies and is based upon the principle of free agency [23]. In essence, the concept of consent is based upon the principle of patient autonomy which is the cornerstone of basic human rights [24]. The Victorian Healthcare Association [25] supports the preceding stance with the following argument “When the principle of autonomy is used as the basis for informed consent, consent is required because it helps clients right to self-determination” (p. 2).

O’Neill [26] claims that while it is an illusion to expect wholly specific consent from a patient, the point must be understood that the purpose of consent procedures “is to limit deception and coercion, they should be designed to give patients and others control over the amount of information they receive and opportunities to rescind consent already given” (p. 4). It is not difficult to understand that when an older person or their caregiver is receiving information on an impending medical intervention that they may experience high levels of anxiety and confusion “due to being kept so busy gathering or being exposed to information they have no time left to think about it, play with it, make valuable associations between and among the various bits stored away” [22]. For LaRusso, there are far too many instances of people having insufficient ‘*soaking time*’ or that required to convert information into an acceptable level of understanding “is a missing ingredient in the schedules of bad teachers, bad lovers and bad communicators in general” (p. 9). The preceding viewpoint applies equally to health care professionals who often short-change patients on essential information due to busy work based schedules or in some cases through outright indifference to patient needs [27]. The consequences emanating from non-adherence to the ethical requirement for informed consent can result in a range of problems whereby “At an individual level, poor informed consent processes can result in consumers

undergoing unnecessary treatment and incurring a preventable harm” [17]. Failure by an older patient to comprehend information from a clinician can result in the signing of a consent form even though the individual may not fully understand the benefits, harm, and risks related to the proposed treatment. Graham and Brookey [28] in their paper “Do Patients Understand?” make the following salient point:

*Individuals with limited health literacy are at risk for error and poor health outcomes. They have trouble understanding medication instructions, appointment reminder forms, informed consent, discharge instructions, and health education materials. This leads to lack of adherence to medication regimens; missed primary care appointments, laboratory tests, and referral appointments; and lack of proper health self-management. (p. 67)*

The ethical value of informed consent is that it lends support to the maintenance of individual autonomy by including the following features: 1) The individual is competent to make a personal decision on the information provided 2) The individual has received adequate and relevant information 3) The individual gives every indication that he / she understands the information and feels quite comfortable to ask questions for clarification and 4) The individual makes his / her final decision voluntarily [29, 30]. Christensen et al. [29] provide a measure of understanding in relation to the challenges associated with seeking ‘informed consent’ in the older population:

*Ensuring that the process of informed consent occurs adequately for all the individuals it is important but difficult for clinicians and researchers alike. How informed someone becomes through “informed” consent depends on several issues, such as how well the information is presented, whether the recipient is hampered by mental or sensory impairments, the emotional tone of the situation, and the rapport with the examiner. (p. 353)*

It has to be accepted that there are a number of circumstances where a person may be unable to provide informed consent that includes situations requiring immediate emergency treatments, the case of a patient with cognitive decline resulting from Alzheimer’s disease, drugs, depression, stroke and major mental illness. Informed consent also supports the philosophical concept of consumer directed care (person-centred care) which allows the older patient to play a major decision-making role in contrast to the traditional doctor led model. Consumer directed care in Australia provides the opportunity for advance care planning where an individual can make decisions about his / her future by putting things in place in order that his / her choices will be known and acted upon if his / her decision making-capacity is ever compromised by a serious accident, major illness or memory loss through dementia related problems [31]. Advance care planning offers a range of benefits that promote a) the opportunity for an older person to think, discuss and document his / her wishes / preferences / choices in relation to end-of-life decision making b) initial and ongoing conversations between an older person / patient, their families and health professionals c) planning ahead for potential deterioration in future health status and d) formalization of advance care planning when a person is still in good health [32]. Bollig, Gjengedal and Rosland [33] proffer the view that advance care planning “should be offered to all cognitively able nursing home residents” (p. 456). Carr and Luth [34] provide a valuable exposé on contemporary issues and future directives surrounding advance care planning.

Wicclair [35] reporting on the issue of decision making capacity provides the following perspective on the function of competency: “That function is just and foremost to sort persons into two classes 1) those whose voluntary decisions ... must be respected by others and accepted as binding and 2) those whose decisions even uncoerced will be set aside and for whom others will

act as surrogate decision-makers” (p. 102). An Australian publication by Queensland Health [36] *Guide to Informed Decision-Making in Healthcare* states “Performed well, the informed decision-making process builds trust, prevents harm and reduces surprise and distress if complications or adverse events occur” (p. 1). The best model of informed consent is one that is process oriented as explained by Lidz, Appelbaum and Meisel [37] “The process model, ... tries to integrate informing the patient into the continuing dialogue between the physician and the patient that is a routine part of diagnosis and treatment” (p. 1385). First and foremost, informed consent is primarily the practical and ethical application of respect for persons undergoing medical and /or health related interventions. All health care professional might well heed the following note of concern offered by LaRusso [22]:

*Very often, too often, the communicator contradicts or compromises the act of sharing by offering it in an atmosphere which carries an impression of carelessness, friction, insincerity and indifference, which the listener correctly reads as a true representation of the speaker’s thought and feelings.* (p. 13)

### **3. A View on Autonomy**

Autonomy relies on the informed consent process, and is at risk, if the information provided for decision making is vague or limited because the ‘doctor knows best’. Welford [38] informs us the word autonomy can be traced back to the Greek language ‘*autonomia*’ which means living by one’s rules and when fully translated means ‘self-rule’. Koppelman [30] adds to the preceding perspective by suggesting that “Autonomous decisions are decisions that reflect the self who makes them” (p. 65). Perhaps it is worthwhile to capture the traditional ideals of autonomy as expressed by Agich [39] as inclusive of “independence and self-determination, the ability to rational and free decisions, and an ability to accurately assess what constitutes the individuals own best interest” (p. 1). Kingsley and Johnson [40] proffer the view that when community health care workers are confronted with the dilemmas of elder abuse that efforts to resolve each particular case should be considered under the conceptual headings of autonomy, no harm and justice. Grosse [41] suggests that autonomy can be under threat by illness which has more likelihood of occurring for older people requiring long-term care. While Grosse does not specify the type of illnesses that undermine autonomy he does indicate that doctors often believe that a patient’s independence and freedom can be compromised by the effects of disease. Grosse also argues that when we talk of autonomy that we need to realize that “there will be periods of “situational dependency” such as bereavement, unemployment, illness, or hospitalization” (p. 7). Hesse [42] provides a balanced perspective on the continuum of dependency versus independence “A developmental perspective helps us face the reality that dependence is an essential characteristic of humanness” (p. 2045). The concept of autonomy as ‘*independence*’ is somewhat paradoxical and seemingly unrealistic in terms of practical application when dealing with those older people in long-term care who display cognitive decline and levels of frailty that require increasing assistance with activities of daily living [43]. Concern for the autonomy of older people might well reflect upon the following viewpoint expressed by Machielse and Hortulanus [44]:

*For future generations of older adults, a good balance between independence and connectedness is crucial: only then can they fully enjoy freedom, and at the same time feel safe and protected in the face of limitations and adversity.* (p. 135)

In reality, autonomy is best understood as a dynamic mix of independence, interdependence and dependence with each factor waxing and waning over the lifecycle. Just as new born babies are totally dependent at birth, so too will dependency dominate for some severely disabled persons including increasing numbers of long-lived older people requiring long-term care. Schermer [45] argues that there will be those older people who “trust their physicians to make the right decision because they are more confident in the physician than they have in themselves” (p. 176). Hesse [42] in her critique of Agich’s 1993 text *Autonomy and Long-Term Care* emphasizes how Agich “proposes that a positive concept of autonomy remain the primary ethical value in long-term care, but he believes it must be grounded in the world of the patient, not the ivory tower of the thinker” (p. 2045).

There is a danger that when attempting to understand the notion of autonomy that we remain culture centric. Elliot [11] in her paper *Health Care Ethics: Cultural Relativity of Autonomy* raises challenges concerning cultural competence where health professionals need to understand the health beliefs, values and practices of cultures different from their own [4, 5, 46, 47]. Today the study of the meanings and practice of individual autonomy must go beyond the traditional view held in English speaking countries. Cultural psychology helps us understand that some cultures do not necessarily give priority to individual autonomy. Respect for cultural diversity allows for the creation of a distinction between individualism and collectivism regarding the notion of autonomy. Dell’Osso [48] a strong advocate for cultural sensitivity in modern day healthcare argues “many different cultures like to be informed and demand involvement from their support system, which usually is family and friends to help dictate a better care plan for the patient” (p. 22). Stewart et al. [49] illustrated this point of view nearly two decades ago “For some cultures, involving the patient’s family in treatment decisions is the norm; clinicians may need to take into account their patients’ views on this topic” (p. 319). Kara [50] demonstrates that in the case of Turkey that versions of autonomy and individual informed consent currently exist in accordance with the level and involvement of emotional family togetherness with respect to decision making on healthcare matters [51]. The need for cultural sensitivity in patient care is made quite clear by Dell’Osso [48] “Culture expresses and interprets conditions of health and illness differently. Therefore, if patients request for involvement of their family in assisting them in healthcare decisions as their cultural norm, providers should be respectful of this, and carry out professional decisions with keeping them in mind (p. 22).

Schermer [45] in her book *The Different Faces of Autonomy* provides valuable insights on a) the concept of autonomy and the principle of respect for individual autonomy b) philosophical and ethical perspectives on autonomy c) empirical research surrounding hospital practice and d) medical decision making and e) the physician-patient relationship. Schermer [45] argues that to hold fast to a single comprehensive definition of autonomy is not the real purpose of ethical understanding and analyses. For Schermer “Autonomy is best understood as an umbrella notion that can cover different aspects” (p. 180). Schermer shows that in recent times there has emerged an ‘ethics of care’ within the debate surrounding autonomy leading to the introduction of “two important aspects of the human condition –interconnectedness and vulnerability” (p. 9). In other words, for Schermer, the notion of substantive autonomy ignores the reality that people at some time or another are not entirely “self-sufficient but also vulnerable and needy” (p. 9). While Schermer is a staunch advocate for fostering respect for patient autonomy in hospital practice, she nevertheless contends “The main issue in discussions about autonomy as a character ideal seems

to be the tension between substantive independence, and the dependence on and connection with others” (p. 10). Rodriguez-Osorio and Dominguez-Cherit [52] reporting on a review of the literature on medical decision making, show that while there exists a strong emphasis on respecting patient autonomy [53] there are some experts who simply do not hold steadfastly to this principle [54, 55]. In particular, the preceding review highlights that ‘*moral pluralism*’ is particularly prevalent in multicultural societies. The message for health professionals is that when dealing with older people, it is more important that they are at all times respected and treated with dignity as well as being provided fair and realistic opportunities to make their own decisions. Stirrat and Gill [56] provide a challenge to the dominant notion of individual autonomy in bioethics by suggesting that based upon accumulated experiences relating to ethics in medical practice that a “review of the operational definition of patient autonomy is required for the twenty first century” (p. 127). Perhaps there is some practical wisdom in an earlier perspective offered by Agich [39]:

*Rather than agree for a core or essential definition of autonomy, it would be best to acknowledge that the meaning of autonomy is irremediably context dependent.* (p. 6)

#### **4. The Threat of Paternalism on Informed Consent and Autonomy**

Older adults are the subject of a range of damaging stereotypes and assumptions such as ‘older people have declining capacities and are generally incapable of making decisions that protect their overall well-being’. This assumption provides an easy application of paternalistic actions from health professionals and family caregivers. Unfortunately, paternalistic actions often occur from well-meaning caregivers who fail to recognize that they are removing the opportunity for patients to make their own choices [45]. Paternalism when examined in a medical, nursing or family context can be explained as a caregiver undertaking ‘benevolent decision making’ in another person’s best interests. Moral philosophers tend to agree that a competent person’s decisions should never be overridden even for what is often justified as being for a person’s own good [57]. According to Rodriguez-Osorio and Dominguez-Cherit [52] “Paternalism comes from the Latin *pater*, meaning to act like a father, or to treat another person like a child” (p. 709). The intentional or unintentional overriding of a person’s competently made decisions are a direct infringement on autonomy with implications for self-esteem, self-respect and wellbeing. Rodriguez-Osorio and Dominguez-Cherit argue that paternalism can significantly jeopardize the level of informed decision making which can lead to a situation whereby a shared approach to decision making can be ethically compromised. It is to be noted that Smebye, Kirkevold and Engedal [58] argue that in the case of caring for a person with advanced dementia that paternalism can be justified within an ethics of care drawing upon the principles of beneficence and non-maleficence. Schermer [45] identifies the dilemma facing medical professionals in relation to paternalistic intervention “In ethical theory, the tension between respect for the right to self-government and respect for or promotion of well-being is conceptualised as the problem of paternalism” (p. 14).

Of course, in situations where a patient’s decision-making capacities are seriously compromised, paternalistic intervention is warranted, particularly in situations relating to hygiene, nutrition and medication. When caring for an older patient it is best to adopt what is a respectful and ethical approach, simply *ask* the patient what they would like to happen in terms of meeting their preferred needs and wishes whether large or small. Heidenreich et al. [59] speak of the need to acknowledge the patient as a susceptible human being and therefore make every effort to respect

the patient's autonomy by application of the concept '*relational autonomy*' which fosters a genuine attempt to solicit an understanding of his/her needs and wishes at the time. Davidson [60] provides an important ethical perspective on the primary essence of geriatric patient care which "lies in the capacity of an interdisciplinary team to view the aged patient as a dynamic, whole individual; to view him or her as a physical, psychological, spiritual and social being" (p. 182). According to Buchanan [61] paternalistic intervention in the area of public health involves a different ethical focus in contrast to what is required in clinical medicine "Whereas medicine focuses on individual health, public health is concerned with the health of the entire population. Thus, in contrast to the fiduciary duty to the individual patient found in clinical medicine, public health ethics is founded on societal responsibility to protect and promote the health of the population as a whole" (p. 15).

## **5. Involving Older People in Research: Ethical Considerations**

Population aging is leading to increasing demand for more evidence based research into the vast array of aging issues which can be very useful for informing policy and practice outcomes. The point must be made that aging research is not limited solely to frailty, disability, poor health and aged care. Today there is a call for both multidisciplinary and interdisciplinary research on aging issues that involve such areas as economic development, environment and climate change, health promotion and health literacy, intergenerational relationships and solidarity, planning and development, tourism, housing, transport, leisure and recreation, elder abuse, family caregivers, older drivers, older workers and technology. Irrespective of the area chosen for research involving older human subjects the message should be that all research should be conducted using ethical approaches that include a) strict adherence to the requirement to only do good, and the duty to avoid harm b) ensuring that research is confidential and that the research participant's privacy is always respected c) ensuring without exception that informed consent has been obtained from everybody participating in a research project and d) identification of individuals and / or social groups that are deemed vulnerable or at risk with subsequent steps taken to protect their interests and overall well-being. A specialist research ethics guidance paper on research involving older people by the University of Sheffield [62] provides the following best practice principles relating to either the representation or exclusion of older people:

- Studies of the adult population that exclude older people only for convenience sake are unscientific and unethical.
- Research that seeks to establish the circumstances, preferences and views of older people by asking carers or surrogates is bad science and unethical.
- Research that seeks to represent the circumstances, attributes and opinions of *all* older people should address the group's wide age range; this may require age-stratified sampling or other approaches to ensure a sufficient sample of the oldest groups. (p. 1)

Any effort to build a robust and ethical research culture on aging must first ensure the establishment of an ethics committee including guidelines on confidentiality and informed consent. Researchers should from the outset establish protocols that protect and safeguard the privacy, confidentiality, autonomy and integrity of all research participants. Safeguarding information obtained from a research participant is a key part of the research process and is an essential component in the relationship of trust and respect between researcher and participant.

The publication of research findings should not include enough information that a participant can be identified. Failure to honor the principle of confidentiality can result in a range of negative consequences that may impact the health and well-being of the older research participant including close family members. While researchers may promise to uphold the principle of confidentiality to an older participant this may for example present an ethical dilemma when during the course of a research project the older person reports experience with institutional abuse. Thus, researchers must address the ethical issues that arise when withholding information could leave an older person in serious jeopardy [63, 64]. Staff working in aged care facilities wishing to undertake patient based research usually do so in partnership with a university where an ethics committee is a mandatory component of all research undertakings. However, institutions other than universities may establish their own ethics committees which must adhere to standard guidelines and regulations. Terminology is an important consideration in research and along with particular forms of jargon needs to be avoided [65]. Equally important is the need to avoid assumptions such as all older people are generally frail, disabled and showing signs of decline in cognitive capacity. It is critically important that clear communication between researchers and older people including any community or institutional groups is essential in order to ensure that research outcomes are achieved professionally and ethically across all stages of research.

Experience shows that areas of aged research that present high level ethical challenges in relation to obtaining informed consent are more likely to occur in situations where older people are a) dependent on informal and /or formal caregivers and b) known to have diminished cognitive capacity. The preceding situations challenge researchers to find ways to obtain the trust and sustained cooperation of informal family caregivers or formal caregivers who have medical, nursing and social care responsibilities [62]. Under the ethical principle of justice there exists a duty to publish and share research findings with all relevant parties that assisted with the initial and ongoing research process including all research participants. As a consequence, on completion of research there remains the ethical challenges relating to a) the translation and dissemination of findings to all those who took part either directly or indirectly and b) the translation of research findings into practice and policy [66-68]. While not part of a standard approach for the translation of research findings there is the ethical challenge of translating research findings into an appropriate summary format for general public understanding and comprehension [69, 70].

## **6. Aged Care: The Ethical Challenge of Dementia**

While it must be understood that people with Alzheimer's disease have been able to make decisions for themselves prior to the onset of the disease, the progressive nature of dementia gradually diminishes the capacity of those inflicted to make some or all decisions on their own. The progressive decline in capacity to make decisions presents major problems associated with autonomy as well as achieving proper informed consent. It is important to recognize, however, that while not all nursing home residents suffer from Alzheimer's disease or other dementia related disorders they may suffer from cognitive impairment due to a range of debilitating health conditions that include frailty and multi-morbidity [71]. In terms of dementia care Kane [72] argues that genuine efforts are required by caregivers whether formal or informal to give due consideration to "what constitutes a reasonable quality of life for people with dementia." and the

all too frequent urge “to protect, to regiment, and to sequester such individuals” (p. 303). The issue for caregivers of older people with dementia is to understand that there still exists a basic need for self-determination. “The challenge therefore is to relate to a person *who used to be there* to the person *who is there*” [73, 74]. Higgs and Gilleard [75] in their text *Ageing, Dementia and the Social Mind* are strong advocates for fostering the belief that personhood remains in dementia and that it should be respected and supported in both theory and practice. Ray [76] an advocate for social justice outcomes for “at risk” older people argues that health service practitioners should “promote the commitment that older people with high support needs have the right to personhood and citizenship being upheld, supported and defended” (p. 149). Sabat and Harré [77] in an examination of the self in people with Alzheimer’s disease indicate “The primary cause of the loss of self is the ways in which others view and treat the Alzheimer’s sufferer” (p. 443). Kitwood and Bredin [78] argued that dementia care required attention to the psychological task of protecting the sufferer’s personhood. Sabat [79] in his book *The Experience of Alzheimer’s Disease* signals quite clearly “In some ways, this book represents a paradigm shift in that the person is seen as the *subject* of study rather than as the *object* of study” (p. ix). Caddell and Clare [80] reporting on their work with people with Alzheimer’s disease showed that “participants were in a state of flux, experiencing both continuity and change in their sense of identity simultaneously” (p. 379). Recent work on deep brain stimulation on people with early-onset Alzheimer’s disease is indicating that while further research is recommended there exists potential for positive effects on identity [81]. Siegel, Barrett and Bhati [82] argue that investigators undertaking deep brain stimulation experiments on people with Alzheimer’s disease must face up to the ethical challenges with “particular attention to elements of subject enrollment and informed consent” (p. 429). For Viaña, Bittlinger and Gilbert [83] future trials on deep brain stimulation for people with Alzheimer’s disease should ensure that “patients will not experience avoidable forms of harm should they be enrolled in these experimental trials” (p. 289).

Robison [84] outlines a valuable range of creative interventions to assist with the varied circumstances faced by people with dementia and their respective caregivers. In particular, the work by Fredriksen-Goldsen, Jen, Bryan and Goldsen [85] on the marginalized and growing segment of the older population is particularly important for its focus on the risks factors associated with lesbian, gay, bisexual and transgender (LGBT) older adults. In terms of the possibility of an individual entering an aged care facility in the future the choice may be to select what Brownie [86] describes as *The Eden Alternative* which “is a model for culture change in aged care that aims to enrich the lives of all whom live and work in residential aged care facilities” (p. 63). Brownie highlights that the guiding philosophy for the preceding model of aged care aims to provide an environment that both empowers and respects the right of older people to “fulfill their right to construct and pursue meaningful lives” (p. 63). Culture change in residential care facilities requires leadership committed to improving the quality of life for aged care residents [87]. According to White-Chu et al. [88] “The process of culture change in long-term care involves a shift in philosophy and practice toward resident-directed, consumer-driven health promotion and quality of life. Fundamental to this shift is a focus on the importance of the relationship between the resident and direct care staff” (p. 309).

With increasing pressure in Australia from governments both state and federal to provide innovative models of residential aged care *The Eden Alternative* represents an innovative approach that endeavors to support individual autonomy and decision-making ability. Needless to

say, the preceding care model will require new educational approaches and resource allocation that prepares staff at all levels of operation to adopt an ethics of care that is based on the principles of person-centred care that respects individual autonomy [87, 89-92]. It is to be noted that the concept of 'person-centred care' is used interchangeably with 'patient-centred care' [93, 94]. Mills and Asbridge [95] in their work on the current place of person-centredness in health and social care services provide the following viewpoint on the situation:

*Indeed, despite the inexorable rise of the patient as a sovereign consumer of health and social care services, with all of the powers and privileges such a status technically affords, the ability of patients to act as prime movers of patient-centered change within care systems has remained largely underexplored, if not, by default, disallowed. (p. 1)*

Koppelman [30] draws attention to the relationship between human dignity and autonomy and in the case of people with Alzheimer's disease provides an important mandate for caregivers to not only focus on the whole person but to also understand "If a surrogate is to make decisions that are in the spirit of the patient's autonomy, the surrogate must determine the self in the absence of that self's capacity for self-determination" (p. 66). The approach proposed by Koppelman requires that surrogate decision making requires efforts to combine understandings of the patient's previous self or the '*then self*' with the existing or '*now self*'. For Koppelman "By focusing on the whole self we at least strive to do justice – even if our, as of now limited capacity may cause us to fall short" (p. 82). The challenge to work with the whole person will require a genuine effort to understand the patient's life story. The aged of the future will no doubt be more in tune with what they would like to occur with respect to their future needs which in turn can help to provide loved ones with how they would like decisions to be made on their behalf should they lose their capacity making ability. There is no perfect formula or personality profile for those taking on the difficult and onerous role of caregiver for a person with Alzheimer's disease. In light of the uniqueness of each caregiver situation and circumstances it is well to reflect upon the following perspective offered by The President's Council on Bioethics [10]:

*It is precisely because caregivers are not saints that we need to ensure that certain moral boundaries are firmly in place and that the necessary freedom to act exists within a social world where certain kinds of actions are unthinkable because they are ethically out of bounds. And it is precisely because of the heartache that accompanies seeing those we love, suffer the ravages of dementia that we need to guide compassion with ethical reason, so that our compassion does not unwittingly lead us astray. (p. 99)*

## 7. The Use of Restraints: A Key Ethical Issue

The use of restraints to control difficult or troublesome patients in aged care facilities warrants attention. A person-centred focus offers a restraint free approach leading to a way of thinking and behaving that preserves the human rights of a person. Unfortunately, all too often, the use of restraints of one kind or another becomes a response of first choice rather than a last resort [96]. The three common forms of restraint used on older people are 1) **Physical restraints**- designed to restrict or control movement and /or behavior 2) **Chemical restraints**- involves the use of medication(s) to calm, modify and control behavior and 3) **Environmental restraints**-applied to change, restrict or modify a person's immediate surroundings in order to confine movement to a limited spatial setting. Weiner, Tabak and Bergman [97] suggest that more often than not, the use

of restraints, are for the benefit of the caregiver and institution rather than for the patient's benefit. Wang and Moyle [98] report that there is no scientific evidence that shows that the use of physical restraints protects a nursing home resident against harm or injury. Cotter [99] in terms of using physical type restraints concludes "Physical restraints should be eliminated as an intervention in older adults with dementia because they are also very likely to cause acute functional decline, incontinence, pressure ulcers and regressive behaviors in a short period of time" (p. 80). Scheepmans et al. [100] provide insights on the use of restraints on older people receiving home based care with implications for the development of support interventions to help informal caregivers to reduce the use of restraints in home care settings.

The use of any restraint must always be a last resort after exhausting all reasonable alternative management options. The inappropriate use of a restraint has legal implications, and as a consequence, it is always wise to consult with the resident or their legal representative and / or primary family caregiver and should take place as soon as possible prior to the application of a restraint [101]. According to the Australian Department of Health and Ageing [102] the use of restraints represents an infringement on human rights and for clarity purposes offer the following definition of a restraint free environment:

*A restraint free environment means no words, devices or actions will interfere with a resident's ability to make a decision or restrict their free movement...The use of restraint confronts a resident's rights and dignity and, in some cases, may subject the resident to an increased risk of physical harm. (p. 41)*

## 8. Conclusions

In light of the preceding discussions surrounding older people and informed consent, it might be useful to consider whether or not the following statement by Sugarman, McCrory and Hubal [103] presents a major ethical challenge for modern day societies "Although there is broad agreement about the need for informed consent, there is also some uncertainty about how-or whether-we achieve meaningful consent in practice" (p. 517). In the interest of protecting the rights of older persons there must be serious efforts undertaken to develop and implement modern day policies and procedures to ensure quality assurance outcomes in relation to gaining informed consent from members of the older population. While policy formulation of the right kind is an important first step nothing really changes unless it is fully embraced in practice. In particular, clearly defined standards including regular audits of relevant healthcare institutions should become mandatory in order to protect the autonomy, dignity and rights of older people.

An area of special ethical and moral concern within the context of aging and long-term care is associated with end-of- life decision making. Over two decades ago Kears [104] proclaimed that there was a silence about death and dying in gerontological circles. A case can be made that even today there exists a lack of serious conversations about the place of ethical thinking and practice in relation to death and dying. Surely, the spate of gerontological literature on aging well in contemporary society should also promote a humane focus on dying well [105-108]. According to Carrese and Rhodes [109] end-of-life decision making involves a complex mix of psycho-social issues, unforeseen ramifications and a heightened potential for negative consequences for the dying person, family members and medical personnel [110]. Chochinov [111] offers a framework for exploring how 'dignity-conserving care' can assist a patient to die with dignity. Recent research

by Bollig et al. [9] and Bollig [71] highlights the ethical challenges surrounding decision-making and end of life care in nursing homes. Cartwright [112] argues “Health professionals need to understand the fears and concerns of their patients, their preferred place to die and to respect patient autonomy” (p. 57). Cartwright also identifies the need to activate changes in the professional preparation of health professionals associated with management of pain and end-of-life decision making:

*There is an urgent need for increased and improved training of health professionals in pain management and palliative care, and for the development of practical, ethical policies and guidelines with respect to withdrawing / withholding life sustaining treatment.* (p. 57)

The time has arrived where strong collective advocacy efforts need to be initiated to formally articulate specific human rights for older people such as autonomy, independence and ethics of care that in turn are used to define the duties and responsibilities of families, governments, researchers, and health professionals involved in the care and provision of medically related services for the aged. Pearce et al. [113] highlight the shortfall in appropriately trained clinicians to deal with the increasing numbers of older people requiring surgical interventions later in life. This preceding challenge has obvious ethical and moral implications requiring attention and resolution by the medical profession and allied health care professionals. The ethics of medical and health care apply to all age groups, and as such, medical and nursing education systems have a moral and ethical responsibility to address any expected shortfall in the availability of appropriately trained personnel to care specifically for older people. The Institute of Medicine [114] in the United States of America in the publication *‘Retooling for an Aging America’* draw attention to the need to initiate new strategies and education programs to build the future health care workforce to provide for the expected increase in the number older people seeking medical care and treatment. The moral and ethical health care challenge for the future is aptly expressed by Wyman, Shiovitz-Ezra and Bengel [115] “As the “third age” has been extended through longer average lifespans, so too are older persons living with more chronic and acute health problems and relying on care through the health system to maintain functioning and prolong life” (p. 194). Arai et al. [116] provide valuable insight into the provision of ethical aged care in Japan which has planning and resource implications for societies worldwide. Stone and Harahan [117] offer the following four principles in support of effective and ethical approaches for improving the long-term care workforce serving older people:

(1) Conventional rules of supply and demand and traditional sources of labor cannot be counted on to resolve future workforce shortages.

(2) To compete for and properly develop workers, long-term care must be recognized as a distinct sector within the larger health care sector.

(3) Workforce roles and responsibilities must be responsive to a new array of service delivery models and to the increasingly complex and diverse needs of clients.

(4) The competencies that are needed to work in the long-term care field must be defined and put into practice before careers in long-term care can be widely recognized as worthy, and workers accorded a status equal to that of their peers employed in acute and primary care (p. 109).

In the care of older people, it is well for caregivers (*Informal and formal*) to reflect upon the following advice offered by Weston [118] “We need to know that what we see as good actually is good in that the client gains without undue stress, (autonomy and justice)” (p. 240). The real danger for caregivers is that what they see as being good for their needs is not necessarily so for

the care recipient. Dohmen [119] offers a clear perspective on the notion of care ethics “The main point of care ethics is not *what* you are living for, but with *whom* and for *whom*. It is an ethics of responsibility” (p. 39). With the preceding thoughts in mind the aim should be to undertake the task to continually recognize, respect, enhance and protect the autonomy and dignity of older people who may for whatever reason require our assistance in research projects and / or be a care recipient of acute or long-term care. Francis Peabody [120] in an address to medical students at Harvard University provided a clear and unequivocal statement on patient care:

*The good physician knows his patients through and through, and his knowledge is bought dearly. Time, sympathy, and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine. One of the essential qualities of the clinician is interest in humanity, for the secret of the care of patient is caring for the patient.* (p. 48)

Both now and in the future, it will be incumbent upon all of us to reflect upon the gravity of the challenges that are part and parcel of caregiving for those older members of society who have become vulnerable by the passage of time. In so doing, it seems reasonable that each of us in the confines of our own existential space attempt to address the question “What are the basic ethical principles of caregiving”? It is suggested that a good starting point might well commence with a focus on the following perspective offered by The President’s Council on Bioethics [10]:

*Caregiving always takes shape in the particular-involving distinctive individual patients and caregivers, in unique and often complicated circumstances-and there can be no single principle or invariable formula for discerning the best care possible in each and every case. In decisions large and small, loving prudence is required to discern the most beneficial course of action.* (p. 210)

## Author Contributions

The author wrote and revised the manuscript.

## Competing Interests

The author has declared that no competing interests exist.

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