INTRODUCTION

The Experience of Loss and the Range of Contestation

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Contesting Aging and Loss actively engages and contests the aura of inevitability and loss deeply associated with aging, particularly in Western societies. Upon critical reflection, many theories of aging and the practices associated with them—both in research and in clinical contexts—reveal more about the *conceptualization* of age by researchers, health-care providers, and policy makers than they do about the *everyday lives* of older people around the world. In these pages we find instead that aging is embedded in dense webs of experiences mediated by what are often increasingly extreme imbalances of power. It is the disparity in power that most often leads to losses—of self-determination, rights, and control over many aspects of an older person's life. The contributors to this volume do not avoid these sites of encounter, which occur both in the community but perhaps more frequently in institutions that use the experience of aging for ends that are contrived to meet their own requirements, often at the expense of the elderly. Elderly persons often interpret their experience very differently from those whose task is to assist them. The latter far too often seem to take their duties as a license to control older persons for purposes that have little to do with those older persons' own human requirements and desires. Extensive ethnographic interviews with older persons about what they think constitutes successful aging are one method by which to begin to understand the many adjustments that older persons make, adjustments that they regard as contributing integrally and positively to the quality of their lives. The chapters in this text take seriously the proposition that care

for an aging person is about the elderly — not simply about the caregiver, however important that person might be. So, throughout this volume, the voices of seniors can be heard in contexts where they all too often are ignored or have no say in the many decisions that define much of their lives.

To begin this exercise, the central cultural construction of age and its envelopment by a peculiarly linear notion of time is examined in Chapter One. Peter Stephenson shows that time and age have been intricately linked in ways that we are only beginning to appreciate, and that the central notions of loss and decline derive from the way in which time is regarded as “passing.” We are introduced to the idea that in much of Western society, our understanding of aging is deeply rooted in both a science and economy that value the idea that newness, or “novelty,” is the essence of living. In this view, time is both a linear process proceeding from start to end, and a thing that can be produced. Stephenson argues that this idea is so foundational that it generally escapes our notice because we simply assume it to be true that time can be “saved,” for example, or that it eventually always “runs out.” He argues that this is also attached to the idea that aging is irreversible, inevitable, and a decline that ends in severely compromised experiences of living. Much research on the biology of aging and the notion of time in physics contradicts the idea that both aging and time are universals of some kind; they are, instead, relative. Considerable differences in the ways in which both time and aging are experienced in non-industrial cultures, and described in the accounts throughout this volume, lend empirical (ethnographic) support to these alternative conceptualizations of aging. Stephenson’s chapter concludes with a critique of the ways in which linear time is used in clinical assessments of very normal elderly persons in order to assign some individuals to the category of those predisposed to developing dementia when they might actually just be more private and reflective, or simply choosing to actively resist testing. Stephenson (and later, in Chapter Eight, Janice Graham) shows us that by privileging the notions of what counts as social capital (novelty, active responsiveness, outgoing behaviour, executive functions), we have built clinical markers that recognize and value self-aggrandizement (selling oneself) from the cradle to the grave. Thus, novelty-seeking behaviour is privileged as healthy and normal, while quiet listening, observing and reflection, and active resistance are not. In this way we both “contest” some of the most basic assumptions about aging by suggesting that these are reflections of the society that has produced them, and not a bedrock part of the reality that surrounds us.

The concept of “successful aging” that has been advanced as a conceptual tool and an idealized goal for seniors has caused confusion and misunderstanding between health professionals and policy makers on the one side, and

many older people on the other. This stems from the dual use of the idea, which sees it used as both a means and an end, as an external measure and a personal goal. Margaret von Faber and Sjaak van der Geest conducted research among a group of older (85-plus) people in a mid-sized town in the Netherlands and discovered that these seniors rejected the idea that being “successfully old” meant that one was healthy and autonomous and able to live without the help of others. Physical strength and health, the seniors with whom they spoke argued, could hardly be called an achievement or be qualified as “success.” In Chapter Two, von Faber and van der Geest describe “successful aging” instead as an artful adjustment to changing circumstances that they understand very well. Older people who keep their good spirits in the face of the numerous losses that come their way are regarded as “successful.” Those who manage to keep their social network alive and continue to attract friends and relatives in spite of their own restricted mobility are widely regarded as living successfully. The secret of “success,” the Dutch elders reveal, lies in adjustment. Despite their own feelings of having successfully adjusted to serious challenges associated with aging, employing externally imposed objective definitions of what constitutes “successful aging” would have resulted in virtually none of their participants’ actually meeting the criteria. The older people described by von Faber and van der Geest illustrate their views by narrating experiences from their own lives. These are embedded in the chapter as case studies, where older people describe, in their own words, what success means in the face of the challenges that aging has brought to them.

The notion of “success” advanced by these very old individuals from the Netherlands is not unlike the adaptations that Robin Oakley describes being made by seniors living in the former reserve area of Namaqualand in South Africa in Chapter Three, or that are revealed in Chapter Four by Sam Migliore and Margaret Dorazio-Migliore in their description of Italian-Canadian seniors’ view of “the good old age” (*la buona vecchiaia*) as something to be managed in a spirited way. Both the Dutch and the Italian-Canadian seniors view “loss” as a much more multifaceted experience than either “successful” aging theory or popular notions of decline would suggest. For example, South African Nama elders’ longstanding resistance to colonially imposed constraints on their lives is densely embedded in kinship networks. The ways that elderly people have become empowered in Namaqualand hinge on the survival and use of traditional knowledge about their place in a rapidly changing world. Counteracting the impact of their own enforced migrant labour away from traditional lands, Namaqualand seniors today bring an intimate knowledge of land use, medicinal and healing knowledge, traditional practices, and kinship organization into a context where they have been guaranteed land access for housing

and grazing rights. Moreover, some aspects of the peasant-based gerontocracy—that is, rule by elders—continue into the present, with youth heeding the wishes of elders and putting them at the centre of the extended family. They bring these into play to resist the many losses—personal and collective—that they confronted during the long years of colonial oppression throughout the twentieth century. It is precisely because they retain (and have not “lost”) traditional knowledge that they are successful in contesting the many forces that make their lives difficult as they age.

These first chapters are all about making arrangements—adjustments—to deal with changed lives, and it is significant that it is the artful negotiation of problems that elderly people choose to see as defining their experience. The solution, not the problem, represents the way in which aging is experienced in a positive fashion. In Chapter Four, Migliore and Dorazio-Migliore aptly weave together the artful negotiation of social spaces in the context of change with traditional concepts. They describe the range of meanings people associate with the concept of *la buona vecchiaia* and its many implications for the quality of life of older Italian Canadians, who actively seek to promote well-being in their later years in order to manage life’s many setbacks. This form of management, like that exemplified by the Dutch seniors described in Chapter Two, is deeply embedded in social networks. And, like the activities of the Namaqualand seniors, it relies on traditional forms of knowledge and understanding. It is not grounded in a universe of novel ideas and practices, but rather situated within relevant traditional language, concepts, and practices.

In all three of these chapters we see older people in the Netherlands, South Africa, and Canada successfully navigating some difficult emotional and physical terrain, mainly without the assistance of others intervening on their behalf. These are descriptions of the many ways in which agency is manifested in the lives of older people, even where a superficial examination would appear to focus just upon various forms of loss. A linear model of “losses”—leading eventually to the loss of life that is so common to studies in biomedicine and some areas of gerontology—is soundly contested by the rich and varied experiences that people have throughout their lives, filled as they really are with ups and downs, and by the small triumphs that people experience in overcoming both trivial and major difficulties.

One of the great challenges associated with navigating old age is the lack of resources associated with declining incomes and the increased costs of looking after oneself and, perhaps, a partner or adult children whose lives have been compromised by disability of some kind. This strikes most at those older persons who are poor and isolated. Because, at least in the wealthiest countries, there are by far many more older women than older men, aging has often

been constructed by both researchers and policy makers as primarily a women's issue. Indeed, the older the cohort among the elderly, the higher the percentage of women it contains in these countries. In addition, elderly women are often relatively impoverished and powerless in societies dominated both by men and, especially, by the affluent members of their society (who are often one and the same). There are many studies in the feminist discourse on aging which substantiate the difficult problems that older women confront, but Cherry Russell, in Chapter Five, focuses on the social networks and isolation experienced by relatively powerless older men. She suggests that the emphasis on older and poor women, coupled with the view that older men are relatively privileged, has tended to obscure the plight of those men who are poor, and whose numbers are substantial, even if they represent a relatively smaller proportion of the elderly. In her case studies Russell highlights the plight of many men whose experiences have been shaped within the framework of Australia's class structure as defined by their labour in particular times and places. The insecurity of their work simultaneously exposed the men Russell describes to resources (accommodation, meals, and other men) and vulnerabilities (work-related injury, a high-risk male lifestyle, a culture of heavy drinking, and a general lack of "care") that have provided little support for securing permanence in their lives. Therefore, many of the men with whom Russell spoke have been increasingly vulnerable to the effects of economic and social change as they have aged. She concludes that "a political economy of well-being, rather than a paradigm of aging as biomedical loss, is the more fruitful model to guide research and policy" (p. 100). The principal loss that many elderly people experience is an economic one associated with their marginalization as members of a society accorded little respect because they no longer are regarded as "productive." Russell's chapter brings the forces of power and marginalization into sharp relief by allowing us to hear the voices of older, disenfranchised Australian men.

When illness strikes the lives of older persons, they enter a world of institutions and practices that often seems to make their lives more difficult, rather than affording them some measure of relief. When seniors are hospitalized for acute illnesses and medical procedures, they confront a system that seems to conspire against them while promising help. In Chapter Six, Christina Holmes and Peter Stephenson feature excerpts from interviews with people hospitalized in Victoria, British Columbia, which reveal the many ways in which seniors often struggle to maintain their dignity in the context of even relatively brief hospital stays. Importantly, the journeys to, within, and home from hospital can be perilous in ways that service providers do not appear to understand. Older adults have a risk of increased health complications when they are hospitalized,

including very serious infections that in turn lead to prolonged stays (elevating risk even more), overall poorer health and suffering after discharge, and even death. Holmes and Stephenson point out that the high mortality rates of seniors in acute-care hospitals are not simply a result of declining health. While their admission into hospital may be the result of an accident, a minor procedure or a set of diagnostic tests, exposure to various diseases in hospital renders older patients extremely vulnerable to the risk of infection. The image of loss associated with seniors entering acute-care hospitals for long stays, and possibly dying there, sometimes has less to do with their medical condition than with the condition of the hospital to which they are admitted. In several dialogues reported in this chapter, the patients themselves attribute the health-care system's decline to decreases in the number of workers and a lowered standard of care. How seniors experience and view acute-care hospitalization therefore has profound implications for better hospital practice and public health in general. The voices of the seniors in Chapter Six echo and affirm Russell's call in Chapter Five for a greater focus on policy rooted in an understanding of what constitutes well-being within a framework of imbalances of power.

What happens when people become increasingly isolated in their own restricted worlds resulting from pathological processes such as Alzheimer's disease? The fundamental paradigm of loss *in extremis*, as it is represented in contemporary psychology and the shared attributes of definitions of dementia, is described in detail in the chapters by Pia Kontos (Chapter Seven) and Janice Graham (Chapter Eight). Social scientists and health-science scholars are now beginning to challenge the loss of self that has been so widely associated with the cognitive deficiencies lying at the core of dementia. The body, however, has not been incorporated into the discourse about diverse representations of the nature of the self and explorations of the experience of having Alzheimer's disease. In Chapter Seven, Kontos articulates a challenge to the discourse of presumed loss of selfhood in Alzheimer's disease, one that captures the ways in which selfhood is embodied and reproduced non-discursively through our corporeal actions. With a keen eye for the details of human involvement and meaning-embedded activities, Kontos draws upon the raw data from participant-observation in her ethnographic exploration of selfhood amongst a group of cognitively impaired residents of an Alzheimer's support unit. We become witness to people following deeply habituated, symbolically meaningful practices expressed as polite greetings or responses, as preferences for coffee and certain foods, or as poignant acts of consolation. Kontos takes the reader on a journey that tracks insights from the phenomenology of Merleau-Ponty and Bourdieu's theory of habitus and the everlasting imprints of socialization, to empirically rich ethnographic evidence, to argue

that selfhood is embodied and thereby persists despite advancing Alzheimer's disease. For Kontos, incorporating the body into a rethinking of personhood in dementia is not merely a philosophical exercise, but one that has important implications for health-care policy and improving dementia-care practice. Using drama as a novel method of translating her ethnographic research for front-line dementia-care practitioners, Kontos explores with health-care practitioners in focus-group discussions the breadth and importance of nonverbal communication for self-expression by persons with severe cognitive impairment. Data from self-administered post-performance surveys and the focus-group discussions themselves indicate both the effectiveness of drama as a knowledge-translation strategy, and the important potential implications of practitioners' integrating an understanding of bodily expressions of selfhood into their clinical practice. The picture of Alzheimer's disease, so commonly framed by despair and the idea that a person is lost, is instead movingly described by Kontos in embodied practices — weaving, singing, knitting — sustained by individuals who need not always be seen in despair. If we regard emotional and embodied intelligence as part of personhood, as Stephenson argues in Chapter One, then many attributes of a person survive far longer than simple measures of cognitive loss conventionally allow us to believe. This is, as Kontos demonstrates with closely observed ethnographic examples, sustained in the networks of older persons, whose links to one another often persist and are derived from times and places far apart from their current residence. This even includes, for example, shared and extremely negative experiences as Jews in concentration camps in Europe during World War II.

Similar to the portraits of cognitively normal adults in our earlier chapters, emotionally charged meaning in old age is not always “heart warming” or laden with positive experiences; it can even include the unspeakable. Personhood is not defined by being able to perform nonsensical cognitive tasks such as repeating one's phone number backwards (which is really used as a measure in some tests). It is embodied life—in all its fullness. This reminds us most crucially that to contest loss is not to dismiss it, or to deny it as an experience. Rather, it means confronting, questioning, adapting, negotiating, incorporating, and at times surmounting it in ways that confer meaning onto life. Engaging all these skills is not necessarily an easy task, and it can be made much more difficult in the face of some of the most powerful global institutions, including the pharmaceutical industry and its profit-driven promotion of endless treatments to alleviate one or another aspect of aging.

With this in mind, in Chapter Eight Graham grapples with the corporate manipulations that attend Alzheimer's disease, demonstrating (ironically) how “soft” social science along with clinical research have actually been appropriated

by the pharmaceutical industry to promote certain drugs that may or may not actually help people to resist the disease in its early stages. Graham takes a close look at the uncomfortable and ambiguous relationship between caring for and treating people with dementia. Caring about and for people with symptoms of dementia is a category not often recognized as “therapeutic” — it is far more often treated as custodial work. A medical diagnosis, however, places an individual into an illness or sickness category that thereby allows him or her to receive medical attention, which is seen as clinical treatment. With the broad introduction of anti-dementia drugs in the late 1990s, medical attention in the form of promises of biotechnical intervention via pharmaceutical treatment has become even further removed from care. Writing a prescription is different from caring about and for a person whose compassionate, reciprocated, and meaningful relationships with others have been built over a lifetime. The hope for symptomatic therapies is driven by the desire to maintain and eventually perhaps even restore biological connections (neuro-paths) to these past relationships (social-paths). While waiting for this magic pill to arrive, however, there has been a growing recognition among physicians that social and functional activities provide the foundation for a particular quality of life. Clinical attention has moved to acknowledge an interactional person involved with others in everyday activities, rather than the lone disembodied patient. In her chapter, Graham examines this shift in medical diagnostic attention, yet she takes a decidedly cautious stance in welcoming what might be considered a favourable trend in the clinical turn toward patient-centred, individualized assessment, diagnosis, and treatment. Some clinical researchers have turned from the paradigm of loss in their clinical practice and are instead extolling the virtues of Alzheimer’s therapies as improving quality of life. Any small measure from a constellation of behavioural changes that could be defined as a slowing of “loss” is defined as positive in an assemblage of multi-factorial measures now employed by the pharmaceutical industry. In many of the studies, no attention is actually paid to whether this outcome is a product of the activity of the drug or of other (social) practices — essentially, all the caregiving that is construed as custodial work, rather than as a kind of therapeutic activity. Changes that emerge from an increase in the quality of life associated with predominantly social forces are being systematically ignored as explanations. They are used instead as measures of the success of the drug. In this way, changes in behaviour are always attributed to drug regimes, and never to the increased presence, for example, of a caregiver, or to a richer social life associated with community-based care: field trips, or embodied experiences such as dancing, singing, and knitting groups, as described by Kontos in Chapter Seven. As a medical anthropologist

keenly aware of how engaged and deeply committed researchers in the past have naively become shills promoting industry interests (such as powdered-milk substitutes in calorie-deprived populations who had no access to clean water), Graham asks whose welfare and whose interests are really being served.

In the most general terms, psychological theories of various pathologies of aging can be seen, as Stephenson points out in Chapter One, as magnifications of processes that are normative — that is, widely held conventions about “normal” aging. In other words, from this perspective those with dementia are seen as old, only more so. Ultimately those who suffer from such an old-age-associated dementia confront being seen as non-entities, having lost their sense of self, both to themselves and to others. Despite the continuation of an embodied self described in detail by Kontos in Chapter Seven and expanded upon by Graham in Chapter Eight, the person with Alzheimer’s disease is often denied personhood. This denial can come in everyday interaction or by systemic means and derives partly from the way in which a person is constructed in research. Seniors in particular can be all too easily exploited by others, including some in the pharmaceutical industry whose measures of successful treatment as “lessening losses” can best be described as simply phony.

All of the chapters in *Contesting Aging and Loss* are devoted to deepening our collective understanding of the many ways in which loss is contested in the everyday lives of older persons in social contexts around the world: from Australia to the Netherlands, from South Africa to Canada, and among both people who are relatively privileged and those who are poor, and among those who are variously traditional and modern. The larger forces that impinge on their lives — multinational corporations, colonial relocations, dangerous work lives, and institutions of total care — increasingly confront us all in the contemporary era of globalization. The concluding chapter by Graham reviews the various chapters of the text, drawing them together into a forceful policy statement about just what it means to contest loss in these manifold contexts. That people who are old and often vulnerable still manage to contest and resist these forces is more than a hopeful sign; perhaps in the most basic way it is a defining part of the human condition. However pervasive the human experience of loss may be, it is not uncontested, either in lives lived, or in the text in hand. In this sense, simply reading and studying about the subject may be a small act of resistance itself. In that spirit we offer this text to the student and professional alike, both of whom not only may be engaged in preparation for work of some kind with seniors, but whose own lives may ultimately come to embody a similar experience. We also — both as researchers and in far more personal terms — offer it as a form of thanks to all the seniors in our lives, for being the exemplars they truly are.

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