

## Introduction

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## **INTRODUCTION**

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orldwide, the aging population is growing by leaps and bounds, affecting all regions and most countries (WHO 2006a; Weinberger 2007). These changing demographics generate a greater need for long-term care, whether provided in homes or institutional settings such as assisted living facilities and nursing homes. The majority of those in need will dwell in developing countries. Most will be women.

The current state of the dependent elderly and of long-term care systems around the world is, by all accounts, precarious and in urgent need of attention. While there are important differences in these systems and among populations living under different social, political, economic, and health-care structures, there are also remarkable similarities when it comes to the problems confronting long-term care. Experts in the affluent United States, for example, lament the absence of "a coherent, comprehensive, coherent long-term care public policy" (Levine et al. 2006, 305) and argue that long-term care is "no longer viable" (Miller, Booth, and Mor 2008, 450). From a global or transnational perspective, the same or worse is true. Long-term care planning has not been a priority in most places, or worse, is lacking entirely (WHO 2009). Especially worrisome is that, compared to wealthier countries, low- and middle-income nations will undergo the demographic shift quite quickly, taking on a greater share of aged citizens even as they will continue to contend with the burden of diseases like HIV/AIDS and tuberculosis, and do so with considerably less in the way of resources.

The problems facing the elderly and others who need long-term assistance are innumerable and intersecting, not to mention long-standing. To paint things in broad strokes, they include the following: poor long-range planning; underinvestment and poor conditions in care settings/workplaces; workforce shortages and persistent recruitment and retention problems; a dearth of long-term care specialists (medical, nursing, and other) working in systems typically built for acute care; fragmented care and payment systems; smaller, increasingly dispersed families; and ageist and "ableist" social norms in some cultures that place little value on the lives and well-being of the elderly and disabled, and, as feminist scholars especially have made clear, the lives and well-being of those who care for them.

To consider the plight of the elderly and disabled, indeed, is to consider the plight of family caregivers along with that of paid members of the long-term care force. The evidence tells us that the former often live under weak care regimes, and so tend to lack sufficient social and/or financial support—as well as professional institutional and/or managerial support if they work under weak family-leave policies. They also face quite serious harms to their own health. As neoliberal policies restructure economies and push toward greater informalization and privatization of long-term care in many parts of the world, family members are taking on a greater share of care work. The work of these unpaid caregivers—the vast majority of whom, also, are women—represents "a critical piece of the global health workforce" (Skjold 2007, 16; WHO 2006b).

Employees in long-term care are often among the least respected and worst-paid workers, tend to have few benefits, and at the same time face high rates of occupational injury. A growing number are migrants from the Philippines and India, countries in Africa and the Caribbean, and Eastern Europe who have left fledgling, restructured, shifting economies to find employment in this labor sector abroad. Their countries view them as strategic assets in the effort to reduce debt and poverty, and a rising number cultivate them (through educational institutions, rhetoric, and recruitment strategies) for export. Meanwhile, as governments in affluent countries confront "growing demands and expectations" for affordable, quality long-term care services (OECD 2005, 10, my emphasis), health workers flow from source countries at unprecedented rates seeking employment. These laborers leave home and community, at least in an embodied capacity, but often engage in long-distance care practices, a matter with its own profound ethical implications for them, their families, and their societies. They often lack citizenship in the countries where they are employed and therefore have a limited set of political rights.

Moreover, consensus is that the outflow of health-care labor from low- or middle-income countries to wealthy ones—and long-term care is a major sector for migrants—is helping to deepen global health inequities (Chen et al. 2004; WHO 2006b). The loss of nurses and other care workers is especially troubling, for they are the "backbone" of primary care in developing countries (Lynch, Lethola, and Ford 2008). Policy discussions about long-term care are framed myopically, though, in nationalist terms (OECD 2005; WHO 2009), ignoring global connections and the rapidly growing structure of health workforce interdependence. A recent report explicitly attributes the growing reliance on migrant care workers to inadequate long-term care policy, especially in privileged parts of the world (International Organization for Migration 2010, 7).

Long-term care is shaped by economic, labor, trade, immigration, and health policies established primarily by governments, but now, too, it is influenced by international lending bodies, transnational corporations, and other for-profit entities. The worry is that it's organized in such a way that it creates and sustains injustice against the dependent elderly and those who care for them and, under contemporary global economic and trade policies, weakens the care capacities of low- and middle-income "source" countries and their health systems. Meanwhile, the everyday concerns facing the elderly and their caregivers—from moments of minor moral distress to major moral (and simultaneously perhaps social, psychological, economic, and health-related) traumas—loom.

The need for discussions of why current arrangements in long-term care are wrong and what should be the values on which future action is based is desperate. Analyses and recommendations regarding long-term care that are informed by feminist approaches in this context are essential. Long-term care and long-term labor are highly gendered. As noted above, the elderly, and especially the oldest old, are disproportionately women. Their caregivers, whether family members or paid care-workers, are also disproportionately women. All are engaged in labors of love and/or care that are constructed in terms of ideals of femininity as well as racial and cultural stereotypes, and provided in environments that constrain and can be outright hostile. All are vulnerable to profound injustices (however, asymmetrically so) whose roots are in social and economic structures and processes, many of which are transnational in reach.

This special issue of *IJFAB* aims to help contribute to the ongoing conversations around ethics and policy in aging and long-term care. The essays and commentaries gathered here address a wide range of issues, all with ethical and policy import. Martha Holstein sets the context by elaborating upon the ways in which

the organization and structure of long-term care imperil the elderly and perpetuate gender and class inequalities. Rosemarie Tong makes clear how this happens at a transnational level by bringing the plight of migrant long-term care workers into view. She assesses migrant eldercare worker policies in Italy, Germany, and Sweden against the demands of feminist ethics of care and justice with the aim of identifying the most ethically defensible ones. Eva Feder Kittay takes the focus back to the domestic, at the levels of policy and also persons, with her wideranging essay. She critiques the deflated, defunct CLASS Act, a failed piece of U.S. legislation aimed at improving long-term care. But perhaps Kittay's most important contribution is to explore entirely new territory in the literature: the obligations of care recipients in the context of family caregiving. Her conclusions here raise important questions about the moral requirements of care and of a care ethic. Monique Lanoix draws on Habermas to theorize on the nature and significance of emotional labor in ancillary care, also sometimes called "direct care" or "paraprofessional care," provided, for example, by nurse aides and homecare aides. She suggests that the economic structures in health care that discount it almost entirely have the potential to undermine care and to generate moral distress in care workers, and therefore demand ethical and policy attention. There is also a pragmatic argument: according greater value to the emotional labor that is integral to ancillary care could help to address persistent retention problems in this especially vulnerable sector of the care workforce.

Christine Straehle's paper picks up on the globalization thread and poses a pressing question for feminists and others concerned about care-worker migration. Her inspiring analysis, using the Canadian Live-in Caregiver Program as a case study, centers on the possibility of autonomy under conditions of vulnerability, specifically on exploitation of migrant care workers. The theme of agency under conditions of vulnerability is at the heart of Sheila M. Neysmith and Yanqiu Rachel Zhou's paper, which helps to illuminate the role played by elders who migrate partly to support family members' care needs abroad. Finally, Ariana Kaci and Helene Starks explore the ways in which shifting gender norms can contribute to the "care gap," and in turn generate overlapping ethical challenges for families with long-term care needs.

Two other contributions enrich this special issue. Anna Gotlib's narrative takes up silences in post-caregiving experiences and theorizes on their "liminality." She finds moral resources in poetry, identifying it as means "of opening one's experiences to others, thereby making them, and oneself, less socially, psychologically, and epistemically liminal" (183). In his commentary, Thijs van

den Broek examines a special case of a global phenomenon—the redistribution of care work and its costs in the Netherlands under economic restructuring—and critiques its gendered consequences: social, health-related, professional, and financial. To top things off, we offer book reviews of Maxwell Mehlman's new work, *Transhumanist Dreams and Dystopian Nightmares: The Promise and Peril of Genetic Engineering*, and *Fritz Jahr and the Foundations of Global Bioethics: The Future of Integrative Bioethics*, edited by Amir Muzur and Hans Martin-Sass. There will always be more to consider and say, but we hope the collection here advances thinking and conversation on these urgent issues.

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