Public Health Imperative of the 21st Century: Innovations in Palliative Care Systems, Services, and Supports to Improve Health and Well-Being of Older Americans

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A primary aim of federal aging and health policy must be promoting innovations in palliative care systems, services, and supports that improve the experience of growing old in America. Older adults must contend today with increasing burden over the life course often as the result of life-limiting chronic pain and chronic illnesses as well as social and economic factors beyond their control. These burdens are frequently shared with unpaid family caregivers who provide significant uncompensated medical care and social support to their loved ones. Enjoyment of the highest attainable standard of physical and mental health, recognized as a fundamental human right under international law, remains a goal for all older adults and encompasses the right to palliative care. For many older Americans, especially vulnerable subgroups who face health and pain disparities, however, this goal remains elusive. A public health strategy for implementing palliative care policy interventions will help to build age-friendly environments, assure the availability and accessibility of palliative systems of care, essential medicines, and an adequate generalist-level workforce, and sustain diffusion of innovation across all levels of health and social provision. The 2015 White
The 2015 White House Conference on Aging marks the 50th anniversary of the enactment of Medicare, Medicaid, and the Older Americans Act. This anniversary affords a fruitful opportunity to refocus the national agenda on the growing and urgent health, social, and economic development and security needs of older Americans, especially vulnerable subgroup members including older women, racial and ethnic minorities, and older adults living with serious or chronic illness and disabling conditions (Institute of Medicine [IOM], 2011; IOM, 2014). In the nearly half-century since President Lyndon B. Johnson signed these groundbreaking acts into law in 1965, no comprehensive national long-term care policy has been enacted in the United States. In light of U.S. aging demographics and the social and economic burdens imposed by illness chronicity, the need for National Public Health Policy focusing on palliative care is urgent in this second decade of the 21st century as government faces heightened challenges in addressing the vast unmet needs of older adults. States must also develop appropriate policy interventions that respond to the needs of older adults for long-term services and supports (Kaye, 2014). Both federal and state policy must align innovations in palliative care with the ecology of growing old in America—living with chronic pain and chronic illness.

Ecology of Growing Old in America: Chronic Pain and Chronic Illness

Chronic illness and chronic pain are the old age afflictions of the 21st century but are also major problems that affect the public’s health. Older adults in the United States are experiencing high chronic illness burden and unacceptably high levels of pain that go untreated or undertreated (IOM, 2011). Known prevalence of persistent untreated or undertreated pain among older adults is 48%–83% across care settings (IOM, 2011; Maxwell et al., 2008). There is also a high prevalence of multimorbidity or multiple chronic illnesses among older adults (Diederichs, Berger, & Bartels, 2011; Freid, Bernstein, & Bush, 2012). The National Center for Chronic Disease Prevention and Health Promotion (2011) reports that about 50% of older adults have more than one chronic illness. Recent studies show a positive association between pain and chronic illness, and pain and multimorbidity (Morrisey, Viola, & Shi, 2014). In the United States, the nursing home population is characterized by high prevalence of both multimorbidity and pain (Hadjistavropoulos et al., 2007; Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008); however, evidence of high prevalence and under treatment of pain in older adults exists in all care settings including hospitals (Gianni et al., 2010), home care (Maxwell et al., 2008), and hospice (Morrisey, 2012). Multimorbidity is high among older adults with chronic conditions such as heart disease, kidney disease, gastrointestinal disorders, diabetes, dementia, and arthritis contributing to illness burden.

There is a robust body of evidence demonstrating that pain among older adults has physical, emotional, social, cultural, and spiritual dimensions and may be heightened or relieved by the social environment. Social determinants such as neighborhood, food insecurity, economic resources, and education may influence or even change pain experience (Atlas & Skinner, 2010). Persistent pain can limit older adults’ opportunities to achieve quality health and function (Arnstain & Herr, 2013; Hadjistavropoulos et al., 2007; Herr, 2011; IOM, 2011) and unrelieved suffering.

Assessment and measurement of pain in older adults are multidimensional and complex and also present serious challenges. For example, recent research on assessment of pain suggests that in light of the complexity of the pain experience in older adults, a single pain intensity tool may be inadequate for capturing the older adult patient’s whole experience and may also have limited clinical utility in certain populations of seriously ill older adults (van Dijk, Kappen, van Wijck, Kalkman, & Schuurmans, 2012; Wood, Nicholas, Blyth, Asghari, & Gibson, 2010). More clinically aligned patient assessments are being developed that focus on pain impact and tolerability and involve guided conversations with the patient about his or her pain experience as part of clinical encounters (Donaldson & Chapman, 2013; Hadjistavropoulos et al., 2007; Herr et al., 2010).

Pain is therefore both a clinical and public health concern for older adults and requires the interface of policy with clinical practice (Hadjistavropoulos et al., 2009). The Gerontological Society of America (2014) in its report, “From Policy to Practice: An interdisciplinary look at the potential of policy to improve the health of an aging America. Focus on Pain,” identifies interdisciplinary and collaborative approaches to pain as a promising step toward integration of care.

Call for a “Palliative Turn”: A Unified Public Health Response to Human Rights for Older Americans and Their Caregivers

Consistent with the components of the right to health that demand an adequate response to the needs of older adults, an urgent call for a broad-based “palliative turn” in aging and
health policy is necessary. This approach contemplates infusing palliative care across whole health and social systems and providing generalist palliative training to all primary care workers, including physicians, nurses, social workers, and other professionals, as well as aides and facilities workers (Quill & Abernethy, 2013). Building up the generalist-level workforce and expanding public health capacity by developing a workforce of primary care practitioners, as well as health coaches and lay community health workers, trained to provide basic care may offer promise in light of workforce shortages. This approach to workforce development, originating in the developing countries, has been described as “reverse innovation” (Bartels & Naslund, 2013) because it challenges the goals of professionalization as they have evolved over the last century. A central premise of reverse innovation is that community health workers and lay counselors embedded in the community may work effectively with indigenous and diverse peoples, including older adults (Bartels & Naslund, 2013), as it is likely they will understand the community’s social practices and be able to communicate better with community members. The assessment of problems and design of policy responses to problems at the population and community levels distinctively characterize public health (Lee, 2012).

Key Components of Palliative Care
Palliative care has been defined as specialized medical care which aims to provide optimal care for seriously ill persons and their caregivers; to improve both quality of care and quality of life; to align treatment with patients’ goals of care, preferences, and values; and to assure the value of the care provided (Center to Advance Palliative Care [CAPC], 2014). The three principal components of palliative care have been identified as advance care planning, improved communication and care coordination, and relief of pain and suffering. In its most recent report and palliative care toolkit, the CAPC (2014) frames palliative care as follows: “Palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain and stress of a serious illness—whatever the diagnosis” (p. 6). The CAPC report enumerates the key features of palliative care:

- Focuses on the relief of pain, symptoms, and stress of a serious illness.
- Palliative care providers work alongside a patient’s other providers, delivering treatment concurrently with disease directed therapies.
- Eligibility depends on symptom burden, functional dependencies, family and social support needs, and requirements for clear information about options and what to expect.
- Earlier use ensures better quality of care and minimizes the need for crisis care (p. 6).

Importantly, the report also expands the scope of palliative care to encompass essential clinical supportive care, more specifically, family caregiver support and practical and social supports (2014). The latter are described as addressing “practical and social issues (such as literacy, language barriers, access to food, transportation and safe housing, and mental and behavioral health issues) that may undermine effective care” (CAPC, 2014, p. 10). Building on these definitions and framings, it is proposed that for the purposes of aging and health policy formulation, palliative care be more broadly reconceptualized as “specialized medical and socially-directed supportive care.” Within this framework of rebalanced medical and social services (Lynn, 2005), the connections among theory, research, policy, and practice will be more visible and will help to inform design of the most effective and efficient care systems and approaches for older adults.

The recommendations made by the American Public Health Association (APHA, 2013) in its 2013 palliative care policy reflect a commitment to the necessary investments that will make possible a transformation in systems of care. The APHA calls for investments in education and training to develop a generalist-level palliative care workforce; expanding palliative systems of care; and making palliative care an essential health benefit and a condition of payment to all payers.

Older Adults and Human Rights
The goals of the civil and patients’ rights movements in 20th-century America that promoted individual autonomy in making personal health care decisions have had only a modest impact on improving older adults’ health and well-being outcomes or increasing the concordance of older adults’ health outcomes with their values and preferences. Americans’ liberty and economic interests have influenced the development of the legal and ethical consensus in end-of-life and more broadly, health care decision making. The social ecology that supports aging Americans in serious illness and at life’s end, however, is rooted in a more fundamental ground and “palliative ethic of care” (Fins, 2006).

The palliative approach to care and care ethics is concerned primarily with moral relationships, the ethical encounter between the caregiver and care recipient, and a moral obligation to provide empathic, relational care in the diverse social and cultural contexts of relationship and community (Byock, 2002; Morrissey, 2015; Reinhard, Levine, & Samis, 2012, 2014; Zoloth-Dorfman, 1993). Arthur Kleinman (2012) has described well these moral dimensions of the caregiving experience. Increasingly, it is being recognized that a singular focus on prescriptive rules and regulations and individual rights, severed from understanding of older adults’ life-worlds, constitutes an impoverished policy response to the complexity involved in the encounter with suffering older adults. Rather,
the complexity, uncertainty, and even conflict often faced by seriously ill older adults and their family caregivers and health professionals call for deep reflection on older adults’ first-person experience, as well as social practices and assumptions about care. Attunement to the older adult as other and the other’s moral demand for care (Levinas, 1969) must inform more humanistic and diverse approaches to negotiating decision conflict, and creating palliative environments that are age-friendly and hospitable to engagement of older adults and their caregivers with health professionals in processes of mutual recognition and vulnerability (Benjamin, 2004), open communication and healing.

A goal of all developing and developed nations is the enjoyment of the highest attainable standard of physical and mental health (United Nations, 1946) for all its members—including all older adults. This goal is embedded in fundamental human rights frameworks recognized under well-established international law (Gostin, 2014; United Nations, 2008). However, for many older Americans who may be confronted with health and pain disparities (IOM, 2011; Meghani et al., 2012), the attainment of this standard of health and well-being remains largely elusive. Vulnerable older adults struggling with illness and disability burden frequently encounter multiple barriers that impede access to adequate health. Systems barriers include legal and regulatory constraints, negative professional attitudes toward older adults and aging services, inadequate geriatric and palliative care education and training for primary care practitioners and direct care workers, less than robust public understanding of older adults’ needs, and limitations on financing and reimbursement. As a matter of public health, policy makers must address growing chronic disease and associated chronic pain prevalence among older adult populations (blinded). Chronic disease and chronic pain are often accompanied by the presence of suffering, disabling conditions, and social and economic factors beyond older adults’ control such as geography, marginal income or poverty, low educational attainment, language barriers, and bureaucratic human service systems (IOM, 2011; Meghani et al., 2012; Reinhard et al., 2012, 2014). Often these burdens are shared by family caregivers who provide significant social support through informal systems of care, yet are faced with increasingly challenging and complex medical and nursing tasks in caring for their loved ones in the absence of adequate financial and emotional support themselves (Reinhard et al., 2012, 2014). Older adults and their caregivers from diverse backgrounds and communities face multiple threats ranging from food and income insecurity to health, housing and other social and economic disadvantages.

In the 1990’s, the late Jonathan Mann (Mann et al., 1999; Gostin, 2014) was among the first to explain this relationship by making explicit that an adverse impact on health directly impacts human rights such as rights to life, human dignity, freedom of movement, food, water, housing and shelter, right to work, and right to political participation. Similarly, adverse impacts on human rights may impact health and access to health services. Mann (Mann et al., 1994) recognized that health itself is a human right. The right to health and human rights are intimately related and interdependent. This relationship is formally recognized in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESR, 1966) and the Universal Declaration of Human Rights (United Nations, 1948).

In 2000, an authoritative understanding of the right to health was established when the United Nations Committee on Economic, Social and Cultural Rights, working in close collaboration with the World Health Organization (WHO) and many others, adopted General Comment No. 14, recognizing the right to health as the highest attainable standard of health (United Nations, 2000). As spelled out in the Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Hunt, 2007), the right to health, which is broader than “health care,” is understood as, “a right to an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible to all” (p. 2). The right to health is twofold: it requires assurance of an effective health system accessible to all as described in the foregoing sentence; but it also requires assurance of freedom and the right to be free from interference such as torture, nonconsensual medical treatment, and experimentation.

A Right to Palliative Care

There is growing recognition that the right to health encompasses a right to palliative care as a human right. According to the Global Palliative Care Atlas (Connor & Sepulveda, 2014), while there is no express reference to palliative care in the ICESR general comment, the comment explicates the normative content of the right to health, specifying the core obligations of all signatory nations without regard to their resources: “These obligations include access to health facilities, provision of goods and services on a non-discriminatory basis, the provision of essential medicines as defined by the WHO, and the adoption and implementation of a public health strategy” (Connor & Sepulveda, 2014, p. 9). Therefore, all states are obligated to operationalize the right to health under international law, even in the absence of a constitutional right to health care as in the United States (United Nations, 2008). The International
Association for the Study of Pain (2010) recently approved the Montreal Declaration, a policy statement that explicitly recognizes and declares that the right to pain management is a fundamental human right, with the United States and over 40 countries signatories.

For older women and men, the relationship between and interdependence of the right to health and human rights are compelling. Older adults may be agents for development—social, economic, and cultural—even in their later years. Protecting, respecting, and fulfilling (United Nations, 2008) older adults’ right to health, and right to palliative care and pain management, within the full spectrum of human rights will be essential to assure their opportunity for development, agency, and freedom in this century.

Health Reform in the 21st Century and the Affordable Care Act
The 21st century health reform movement, which followed several less successful attempts to craft major health legislation earlier in U.S. history, resulted in the enactment of the Patient Protection and Affordable Care Act (2010), more commonly known as the “Affordable Care Act” (ACA). The explicit aims of the ACA were to expand coverage, reduce costs, and improve the public’s health. The ACA has made investments in public health and implementation of a public health strategy a priority. However, while there has been some progress toward these goals, they will be fully realized only if there is accountability for the health and well-being of older adults. The transformations of the Medicare and Medicaid payment systems driven by the ACA to reduce unnecessary fragmentation in the delivery of care and improve care coordination and transitions must be paralleled by commensurate changes in the dominant biomedical paradigm of care. U.S. policy must also support the growth of palliative systems of care that encompass both medical and practical, social supports, and services (CAPC, 2014).

A long-held assumption that the spheres of health and social provision are separate must be jettisoned and replaced by a radically progressive vision for integrated care. The ACA takes incremental steps toward such integration. Federal policy planning and development for multicultural and multiracial older adult populations must build on these steps in aligning care, treatment, and social provision with older adults’ life goals. A public health strategy for influencing policy will help to sustain a movement toward integration of health and social services and assure the availability and accessibility of palliative systems of care, essential medicines, professional and lay education and training, and diffusion of innovation across all levels of health and social provision. The 2015 White House Conference on Aging must make these realignments a policy priority, and establish the social and economic conditions that will enable the effective and efficient delivery of palliative care through public health interventions and innovations, and the building of age-friendly environments accessible to all community members. This approach to policy making will have high impact in multiple domains—broadening social provision and reducing dependency, transforming the relationship of older adults to their caregivers, and improving the relief of pain and suffering and quality of life for older women and older men.

Public Health Strategy for Palliative Care
The WHO has adopted a public health strategy for palliative care, which has been enhanced by Stjernswärd, Foley, and Ferris (2007). This enhanced public health strategy identifies policy development and implementation, drug availability and affordability, and education and training of providers as key components of palliative care. The U.N. Committee on Economic, Social and Cultural Rights reports that it is critical to provide “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity” (CESCR, General Comment 14, para. 25; Connor & Sepulveda, 2014, p. 9). Access to essential medicines, as defined by the WHO and its public health strategy for palliative care, is part of the minimum core content of “the right to the highest attainable standard of health.” Fourteen palliative care medications are currently on the WHO Essential Drug List. Importantly, the U.N. Special Rapporteur on torture has stated that, “denying access to pain relief can amount to inhuman and degrading treatment” (Connor & Sepulveda, 2014, p. 9). Pain that goes untreated or undertreated has been as a form of elder abuse (Bergman v. Eden Medical Center, H205732-1. Cal. Sup. Ct. 2001) that has gone virtually unrecognized and unacknowledged by health care providers and professionals.

Infusing the Public Health Perspective into Aging and Health Policy
The adoption of public health as both an approach and structure within which to formulate and implement aging and health policy is not new. For some time, state and local health departments have been developing agendas that prioritize monitoring of health issues that affect older Americans such as chronic disease and chronic pain. The APHA has called for state and local departments of health to take certain action steps to improve population and gerontological health and well-being. More specifically, among the recommendations are developing public health agency accreditation processes; promoting effective pain care and pain management by removing barriers to essential medicines; establishing clinical guidance for the appropriate medical use of opioid and nonopioid analgesics in diverse...
patient populations; evaluating policy responses that aim to alleviate intolerable and intractable forms of suffering, with appropriate safeguards to protect against diversion and abuse; and improving coordination across the continuum of care to reduce detrimental care transitions that result in adverse outcomes seriously ill individuals (APHA, 2013).

**Conclusion**

The implications of these explorations for aging and health policy making, informed by scientific and clinical evidence, point to the need to support a shift that is already under way from a dominant biomedical paradigm and toward relational and contextual paradigms of care that rebalance medical care and social services and supports. Palliative approaches to care that integrate good medical and supportive care hold promise for transforming the way care is delivered through the building of environments that are age-friendly and hospitable to growing old, advancing equitable access to care, eliminating health and pain disparities (Meghani et al., 2012), and promoting healing and flourishing through solidarity (Painsack & Buyx, 2011). This is the imperative for 21st century aging and health policy and should provide a blueprint for the work of the 2015 White House Conference on Aging.

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