End-of-Life Planning and Stigma: Investigating Barriers to Palliative Care, Advance Directives, and Dignified End-of-Life Experiences for Older People Living with HIV within the Familial and Institutional Contexts of Hong Kong

The Hong Kong Aids Prevention Society

Executive Summary

This comprehensive report examines the complex intersection of HIV, aging, and end-of-life care within Hong Kong's unique sociocultural and institutional landscape. As advancements in antiretroviral therapy have transformed HIV from a terminal illness to a chronic condition, a growing population of older adults is living with HIV and facing end-of-life care decisions. People aging with HIV face a double burden encompassing age-related health challenges and HIV-associated complications, compounded by persistent stigma and social isolation (Tamsukhin et al., 2023). In Hong Kong, these challenges are further complicated by cultural values emphasizing filial piety, death taboos, and family-centered decision-making that often subordinate individual autonomy to collective family welfare.

Despite having the world's longest life expectancy, Hong Kong's end-of-life care system remains underdeveloped, particularly for non-cancer populations including those living with HIV (R. Chung et al., 2020). Advance directive completion rates in Hong Kong are extremely low, with only 3% of nursing home residents having completed advance directives compared to 13% in Taiwan (Xu et al., 2021). This report identifies multilayered barriers operating at individual, familial, institutional, and policy levels that impede access to dignified end-of-life care for older people living with HIV. Key findings reveal that stigma operates at multiple intersecting levels—HIV-related stigma, death-related cultural taboos, and ageism—creating compounded vulnerabilities for this population.

The report concludes with evidence-based recommendations for policy reforms, healthcare provider training, community education initiatives, and the development of culturally sensitive palliative care models that honor both individual autonomy and family values through the concept of "relational autonomy."

1. Introduction and Background

1.1 The Aging HIV Population: A Global and Local Context

The landscape of HIV care has undergone a dramatic transformation over the past four decades. Antiretroviral therapy has converted HIV from a fatal diagnosis to a manageable chronic condition, resulting in near-normal life expectancy for individuals with early diagnosis and treatment initiation (Abdo et al., 2020). This medical success has created an unprecedented demographic shift, with an increasing prevalence of older adults living with HIV experiencing multiple comorbidities. People aging with HIV face accelerated aging processes, increased risk of cardiovascular disease, cognitive decline, frailty, and heightened susceptibility to chronic illnesses despite effective ART management (Tamsukhin et al., 2023).

Moreover, those aging with HIV often experience loneliness, social isolation, loss of close friends, and may have estranged relationships with their families, resulting in fractured social networks (Abdo et al., 2020). These psychosocial challenges are amplified by decades of intersecting stigmatized identities in the context of social exclusion, leading to potential psychological challenges including depression, anxiety, and loneliness, all of which may be intensified by the aging process (Tamsukhin et al., 2023). With these more fractured social networks, many people living with HIV may not have a clear proxy to guide healthcare decisions should they become unable to make decisions themselves.

1.2 Hong Kong's Demographic and Healthcare Context

Hong Kong presents a unique context for examining end-of-life care for older adults living with HIV. The city boasts the world's longest life expectancy alongside an ever-escalating demand for long-term care (R. Chung et al., 2020). However, despite this longevity, Hong Kong's end-of-life care infrastructure was characterized as underdeveloped as of 2020, with significant gaps in service provision. A multi-method qualitative study identified

substantial gaps and issues at multiple levels: policy, legal, community, institutional, and interpersonal (R. Chung et al., 2020).

These systemic gaps include a lack of overarching end-of-life care policy framework, ambiguity in the legal basis for mental incapacity, legislative barriers for advance directives, inadequate capacity and resources in the community to administer end-of-life care, inadequate knowledge and training for healthcare providers, inadequate medical-social interface, and cultural factors such as general reluctance and fear of death and dying, as well as interpretations of filial piety that may lengthen patient suffering (R. Chung et al., 2020).

1.3 Advance Care Planning and Advance Directives: Definition and Importance

Advance care planning is a communication process wherein individuals proactively make decisions about their end-of-life care when they are mentally competent. It is highly relevant to older adults with frailty and those living with chronic conditions like HIV because they are more vulnerable to cognitive impairment, disabilities, and death (Wan et al., 2022). ACP encompasses multiple components including the identification of healthcare proxies, documentation of treatment preferences, and discussions about values and goals of care.

Advance directives are legal documents that allow mentally competent individuals to make healthcare decisions about their future condition when they might no longer be able to communicate (C. Chan et al., 2019b). Completion of advance directives or assignment of medical power of attorney ensures that patients' wishes regarding healthcare decision-makers and decisions can be followed most closely in the event that the patient cannot communicate (Abdo et al., 2020). Research has demonstrated that ACP and advance directives improve health outcomes, including reduction in hospitalization at the end of life, increased use of hospice services, and less intensive treatment at the end of life, while also being associated with better patient and family satisfaction and lower surrogate decisional conflict (Abdo et al., 2020).

1.4 Scope and Objectives of This Report

This report examines the multifaceted barriers that older people living with HIV face in accessing palliative care, completing advance directives, and achieving dignified end-of-life experiences within Hong Kong's familial and institutional contexts. The analysis employs a socioecological framework to examine how barriers operate at individual, interpersonal, community, institutional, and policy levels. Particular attention is given to the role of stigma—both HIV-related and death-related—and how cultural values, particularly filial piety and family-centered decision-making, shape end-of-life care experiences.

2. Multilayered Stigma and Its Impact on End-of-Life Care

2.1 Persistent HIV-Related Stigma in Aging Populations

Despite advances in treatment and decades of public health efforts, stigma surrounding HIV remains pervasive and continues to shape the experiences of people living with HIV at the end of life (Tamsukhin et al., 2023). Although HIV stigma has diminished over the years, it still lingers and creates significant barriers to accessing palliative care services. People living with HIV have experienced decades of intersecting stigmatized identities in the context of social isolation, which leads to potential psychological challenges that may be amplified by aging.

The impact of HIV stigma extends beyond individual psychological distress to affect healthcare-seeking behavior and service utilization. Barriers to recruitment into palliative care programs often include misconceptions or stigma related to palliative care itself, with 24% of refusals in one emergency department study attributable to misconceptions about palliative care (Brickey et al., 2022). For older adults living with HIV, this stigma may be compounded by concerns about disclosure in institutional settings and fear of discrimination from healthcare providers and fellow residents in long-term care facilities.

Sexual and gender minority older adults, many of whom are living with HIV, face unique fears related to long-term care entry, including anticipated social isolation, decreased independence, increased vulnerability to LGBT-related stigma, and exposure to unsafe social and physical environments (Kortes-Miller et al., 2018). These fears are particularly

acute for individuals who lived through the early HIV epidemic and may have witnessed significant loss and discrimination.

2.2 Death as Taboo: Cultural Barriers to End-of-Life Discussions

In Chinese societies, including Hong Kong, death and dying remain sensitive subjects often considered taboo, creating substantial barriers to advance care planning discussions (Lu et al., 2025). This cultural reluctance to discuss death manifests at multiple levels. Many participants in research studies felt it would be challenging to discuss advance care planning with elderly family members due to traditional Chinese attitudes towards death as taboo (Chiang et al., 2021). Only 14% of participants in Hong Kong and 18% in Taiwan reported prior occurrence of end-of-life care discussions with family members or health professionals (Xu et al., 2021).

This death taboo operates through several mechanisms. First, there is a widespread belief that discussing death may hasten it or bring bad luck. Second, adult children often refrain from initiating such conversations out of concern for causing psychological distress to aging parents. Third, patients themselves construct family dynamics that include reluctance to talk to family members about their condition, with families being reluctant to accept and believe the reality of the patient's condition (Edmonds et al., 2024). These patterns create an epistemic divide between patients and their families regarding knowledge and understanding of illness.

The implications for older people living with HIV are particularly severe, as the combination of HIV stigma and death taboo creates a double silence. They may be unable to discuss their HIV status openly due to persistent stigma, while simultaneously being unable to engage in advance care planning due to cultural prohibitions around death discussions. This dual barrier significantly impedes their ability to plan for and receive dignified end-of-life care that aligns with their values and preferences.

2.3 Ageism and the Devaluation of Older Adults' Autonomy

Ageism represents a third layer of stigma affecting older adults living with HIV in end-of-life care contexts. The healthcare system and broader society often focus disproportionately on the physical decline associated with aging while undervaluing the mental and emotional

well-being of older adults (Jeste, 2022). This ageism manifests in several ways that directly impact end-of-life care planning and delivery.

Healthcare providers may assume that older adults lack the capacity or interest to engage in advance care planning discussions. This assumption is contradicted by research showing that the majority of older adults prefer taking an active role in decision-making for their end-of-life care, with 58% of Hong Kong respondents preferring an active role, compared to 23.9% preferring a passive role (Nan et al., 2023). However, preference for passive roles was associated with older age groups, suggesting that the oldest-old may face particular challenges in asserting their autonomy.

The intersection of ageism with HIV stigma and marginalized identities creates compounded vulnerabilities. Older adults from marginalized communities—including racial and ethnic minorities, migrants, and lesbian, gay, bisexual, and transgender persons—face multiple stigmas that lead to social exclusion and result in poor healthcare, worse physical and mental health, and reduced longevity (Jeste, 2022). For older people living with HIV who may also belong to sexual and gender minority communities, these intersecting stigmas create substantial barriers to accessing affirming and dignified end-of-life care.

2.4 Intersectionality: Compounded Vulnerabilities

The concept of intersectionality is critical for understanding how multiple marginalized identities interact to create unique experiences of stigma and discrimination. Older adults living with HIV may simultaneously navigate HIV stigma, ageism, stigma related to sexual orientation or gender identity, and in some cases, racial or ethnic minority status. These intersecting stigmas do not simply add together but interact in complex ways to create compounded vulnerabilities.

Research with sexual and gender minority older adults demonstrates how these intersecting stigmas shape end-of-life care experiences and fears. Individuals anticipate discrimination, unsafe environments, and the potential need to conceal their identities in long-term care settings (Menzer, 2025). The lack of inclusive surrogate decision-maker policies

exacerbates these disparities, as many sexual and gender minority older adults do not have legally recognized partners or children to act as decision-makers.

For older people living with HIV in Hong Kong, these intersecting stigmas are further complicated by cultural values that may conflict with Western-oriented healthcare models. The challenge lies in developing care approaches that acknowledge and address these multiple layers of stigma while respecting cultural values and promoting dignity at the end of life.

3. Cultural and Familial Contexts Shaping End-of-Life Care

3.1 Filial Piety and Its Influence on Decision-Making

Filial piety, as a major traditional norm in Chinese culture and families, profoundly affects the attitudes and behaviors of adult children toward their parents and impacts end-of-life decision-making and the quality of death (Ng et al., 2024). This concept, rooted in Confucian philosophy, establishes expectations about how children should treat their elders and shapes family dynamics in ways that can both facilitate and complicate end-of-life care.

In East Asian countries influenced by Confucianism and the concept of filial piety, patient autonomy is consequently subordinate to family values and physician authority (Cheng et al., 2020). This cultural framework means that physicians often disclose a patient's poor prognosis and treatment options to male family members rather than to the patient directly. The dominance of family members and physicians during a patient's end-of-life decision-making is recognized as a cultural feature in Asia.

Research has identified a significant gap between filial piety attitudes and behaviors of Chinese adult children in end-of-life contexts (Ng et al., 2024). Gender, caregiving experience, and death literacy were identified as predictors of filial behaviors toward dying parents. Interestingly, the study found that providing truth disclosure support and offering guidance to young adult children and caregivers of terminally ill fathers were necessary to enhance reciprocal comfort for both adult children and dying parents.

The complexity of filial piety in modern contexts is illustrated by research on DNR decision-making. In Chinese-speaking culture, it is often expected that the eldest son

assumes the role as primary decision-maker (and, 2024). However, this role involves complex emotional experiences including anticipatory feelings of loss and ambivalence. Medical decision-making regarding DNR often leads to conflicts between traditional filial piety concepts and modern ethical considerations, with decision-makers navigating between authoritarian filial piety (based on hierarchy and obedience) and reciprocal filial piety (based on mutual care and emotional bonds).

3.2 Family-Centered Decision-Making Versus Individual Autonomy

The tension between family-centered decision-making and individual autonomy represents one of the central ethical challenges in end-of-life care for older adults in Hong Kong. In all three East Asian regions studied (Japan, Hong Kong SAR, and South Korea), the most preferred decision-maker and person with whom to discuss end-of-life care issues was a family member (Ho et al., 2022). However, more than 70% of participants in each region indicated they would not prefer to leave an advance directive to decide their end-of-life care, highlighting the complexity of decision-making preferences.

Research reveals that older Asians prefer to make their own decisions after consulting others, with family members playing an important role in helping older people plan their preferred end-of-life care arrangements (Ho et al., 2022). This preference reflects a model of “relational autonomy” rather than the Western concept of individual autonomy. The concept of relational autonomy and the collectivism paradigm might be ideally used to assist Asian people, especially older adults, to share their preferences on future care and decision-making with their families and important others (Cheng et al., 2020).

Four key themes emerge regarding family roles in end-of-life communication: conflicts in communication, significance of timing, difficulty in identifying the key person responsible for decisions, and different cultural perspectives on communication (Pun et al., 2023). These findings underscore that participation of family members in end-of-life communication likely leads to improved quality of life and death for patients, but also creates challenges when family members’ perspectives conflict with patient wishes or when communication breaks down.

3.3 Family Dynamics and Communication Challenges

The actual dynamics of family communication about end-of-life care reveal significant complexities beyond idealized models of family-centered decision-making. Patients construct family dynamics in ways that reflect ambivalence and communication barriers. Three key patterns have been documented: patients expressed reluctance to talk to family members about their condition; patients talked about their families as being reluctant to accept and believe the reality of their condition; and patients reported an epistemic divide between themselves and their family regarding knowledge and understanding of illness (Edmonds et al., 2024).

These communication challenges are compounded by generational and gender dynamics. Among family caregivers in advance care planning interventions, family members recognized their need for information to be prepared as caregivers, and many reported that interventions improved their knowledge and attitude toward ACP and created stronger desire to sign advance directives (Wang et al., 2025). However, only 26.5% of study participants had engaged in advance care planning conversations, suggesting that knowledge alone is insufficient to overcome communication barriers.

The role of cognitive and emotional barriers is significant. Barriers to ACP identified in qualitative research with seriously ill Chinese patients and families included limited patient participation in autonomous decision-making, cognitive and emotional barriers to discussion, lack of readiness and awareness for early discussion, and unprepared healthcare professionals and healthcare systems (Cheung et al., 2020). These findings highlight that participations of seriously ill patients, family caregivers, and healthcare workers in ACP initiation are all lacking.

3.4 Culturally Appropriate Models: Relational Autonomy in Practice

Addressing the tension between individual autonomy and family-centered care requires culturally appropriate models that honor both values. The concept of relational autonomy offers a framework for understanding how autonomy can be exercised within relationships rather than in isolation from them. This approach recognizes that for many Asian patients,

decision-making is inherently relational, with the self understood in connection to family and community rather than as an isolated individual.

Healthcare professionals in Asian societies should make continuous efforts to communicate patient status to patients and their family members to ensure family involvement in decision-making processes (Chiang et al., 2021). This requires moving beyond the Western model of ACP, which places strong emphasis on individual autonomy, to develop approaches that can be directly applied to family-centric Asian contexts. Such approaches should target managing expectations during prognosis disclosure and facilitating patients' fulfillment of familial roles while making end-of-life decisions (Pun et al., 2023).

Practical implementation of relational autonomy involves several key elements. First, healthcare providers must recognize and validate the importance of family involvement while also ensuring that the patient's voice is heard and respected. Second, communication strategies should be adapted to allow for family discussions while protecting patient confidentiality and autonomy. Third, advance care planning processes should be flexible enough to accommodate varying levels of family involvement based on patient preferences.

Research suggests that helping families understand and support planned care and advance directives is a strategy for maximizing family compliance with the care (Ho et al., 2022). This requires educating both patients and families about the purpose and benefits of advance care planning, addressing cultural concerns and misconceptions, and providing support for difficult conversations about death and dying within the cultural context of filial piety and family harmony.

4. Barriers to Palliative Care and Advance Directives

4.1 Individual-Level Barriers: Knowledge, Attitudes, and Awareness

Individual-level barriers to advance care planning and palliative care access operate through multiple mechanisms, including limited knowledge, negative attitudes, and low awareness of available services. In Hong Kong, only 17% of community-dwelling older adults indicated willingness to use advance care planning even after it was explained to

them (Yu, 2022). This remarkably low acceptance rate reflects deeper issues beyond mere lack of information.

Knowledge deficits manifest in several ways. The vast majority (78.3%) of respondents in one Beijing study had not heard of advance care planning, and only 39.4% preferred to document an advance care plan even after learning about it (N. Zhang et al., 2015). In Hong Kong, only 0.5% of the general population had made an advance directive, though 80.2% of those who had heard about advance directives expressed intentions to make or had already made one (C. Chan et al., 2019a). This gap between awareness and action suggests that knowledge alone is insufficient to drive behavior change.

Attitudes toward advance care planning are shaped by multiple factors including perceived barriers, sociocultural influences, and personal experiences. More perceived barriers were associated with lower odds of ACP conversations, while sociocultural factors including more years in the United States and English language proficiency among Chinese American populations were positively associated with ACP conversations (P. Zhang et al., 2023). Among older adults with frailty who did not complete advance directives after ACP conversations, three themes emerged: refraining from discussing end-of-life care, remaining in the here and now, and relinquishing responsibility over end-of-life care decision-making (Wan et al., 2022).

Readiness for advance care planning varies significantly with age and living arrangements. Preference for passive roles in decision-making was weakly associated with age and more common among those living alone or in care homes compared to those living with family (Nan et al., 2023). This suggests that social isolation and living circumstances significantly influence older adults' sense of agency in end-of-life planning. For older people living with HIV, who often experience fractured social networks and may lack clear proxies for healthcare decisions, these individual-level barriers are particularly acute.

4.2 Healthcare System Barriers: Provider Knowledge and Training Gaps

Healthcare system barriers significantly impede access to quality palliative care and advance care planning for older adults, including those living with HIV. A critical barrier is the lack of adequate knowledge, confidence, and training among healthcare professionals

regarding advance care planning and end-of-life care. Training has been found effective in improving healthcare professionals' knowledge, confidence, and skills in conducting ACP, yet the association between training experience and actual practice in clinical settings has not been well demonstrated (H. Y. L. Chan et al., 2020).

Studies reveal that approximately half of healthcare professionals have received ACP-related training, with those who received training reporting significantly more positive attitudes toward ACP relevance, willingness, and confidence compared to those without training (H. Y. L. Chan et al., 2020). However, healthcare professionals who received only didactic training format showed lower levels of ACP readiness compared to those who participated in blended mode learning. This suggests that the quality and format of training significantly influence preparedness to engage in advance care planning discussions.

Unprepared healthcare professionals and healthcare systems represent a major barrier to ACP initiation (Cheung et al., 2020). Healthcare providers may lack skills in facilitating difficult conversations about death and dying, particularly in cultural contexts where such discussions are taboo. They may also lack understanding of cultural values such as filial piety and how these influence family dynamics and decision-making patterns. Furthermore, time constraints, heavy workloads, and lack of institutional support for ACP discussions create practical barriers to implementation even among willing providers.

The challenges are particularly acute for palliative care provision to specific populations. Nurses' knowledge of advance directives varies significantly across countries, with nurses in Hong Kong reporting lower knowledge and experience compared to counterparts in the United States (MichalItzhaki, 2016). While older nurses and those with more professional experience felt more confident managing patients' symptoms at end-of-life, overall levels of confidence and comfort in dealing with end-of-life care varied considerably, highlighting the need for enhanced education and training.

4.3 Institutional Barriers: Policy Gaps and Resource Constraints

Institutional barriers operate at multiple levels to impede access to palliative care and advance care planning. At the policy level, Hong Kong lacks an overarching end-of-life care policy framework, creating ambiguity in legal bases for mental incapacity and

legislative barriers for advance directives (R. Chung et al., 2020). These policy gaps result in inconsistent implementation of end-of-life care services across different settings and populations.

Resource constraints significantly affect the quality and accessibility of palliative care services. Inadequate capacity, resources, and support exist in the community to administer end-of-life care effectively (R. Chung et al., 2020). Healthcare and social care sectors lack adequate knowledge, training, and resources specifically for end-of-life care. The medical-social interface remains inadequate, creating fragmentation in care delivery and leaving many patients and families without coordinated support.

Service gaps are particularly pronounced for non-cancer populations. While Hong Kong has relatively good palliative care service coverage for patients who died of cancer and end-stage renal failure, significant service gaps exist among the aging population with non-malignant life-limiting illnesses (Chan, 2018). This gap likely affects older people living with HIV, who may have complex medical needs but not fit traditional criteria for palliative care referral.

Institutional barriers also include rigid clinic policies, disrespectful service providers, stock-outs of supplies, and distance to health facilities (Matima et al., 2018). These practical barriers compound other obstacles and disproportionately affect marginalized populations. For older adults living with HIV, navigating complex healthcare systems while managing stigma and potentially limited social support creates substantial challenges to accessing needed services.

4.4 Societal and Community-Level Barriers

Societal and community-level barriers reflect broader cultural norms, social structures, and public awareness regarding end-of-life care. General reluctance and fear of death and dying pervade Hong Kong society (R. Chung et al., 2020). This cultural taboo around death extends beyond individual attitudes to shape community norms and social expectations, making it difficult for individuals and families to openly discuss and plan for end-of-life care.

Stigma at the community level creates additional barriers for people living with HIV. While HIV stigma has diminished over the years, it still lingers and manifests in discrimination, social isolation, and reluctance to disclose HIV status (Tamsukhin et al., 2023). This stigma may be particularly acute in residential care settings, where older adults living with HIV may fear discrimination from staff and other residents if their HIV status becomes known.

The interpretation of cultural values can create barriers even as they provide potential support. The cultural interpretation of filial piety may lengthen the suffering of dying patients when adult children feel obligated to pursue all possible life-extending treatments regardless of patient preferences or quality of life considerations (R. Chung et al., 2020). This dynamic can conflict with palliative care principles of comfort and dignity, creating tension between cultural expectations and patient-centered care.

Community-level barriers also include inadequate public education about palliative care, advance care planning, and death literacy. Low death literacy among the general population contributes to avoidance of end-of-life discussions and planning (Ng et al., 2024). Strengthening factual and community knowledge of death is necessary to enhance comfort with end-of-life planning and care. Community-based interventions that engage volunteers and social workers have shown promise in promoting advance care planning and improving quality of life for older adults (Lu et al., 2025).

Table 1: Multilevel Barriers to Advance Care Planning and Palliative Care for Older Adults Living with HIV in Hong Kong

Level	Barrier Category	Specific Barriers	Evidence Source	**Individual**	Knowledge & Awareness
- Low awareness of ACP (78.3% never heard of ACP)- Limited	(C. Chan et al., 2019a; N. Zhang et al., 2015)	Attitudes & Beliefs	- Perception that discussing death brings bad luck- “Too early” mentality	(Vilpert et al., 2018; Wan et al., 2022)	Psychological

Level	Barrier Category	Specific Barriers	Evidence Source	**Individual**	Knowledge & Awareness
understanding of palliative care- Misconceptions about purpose and timing			(32.9%)- "Won't need it" belief (30.1%)- Preference for "here and now"		
- Fear of death and dying- Anxiety about HIV disclosure- Depression and social isolation	(Tamsukhin et al., 2023)	**Interpersonal/Family**	Communication	- Reluctance to discuss with family (only 14-18% had discussions) - Family members' reluctance to accept reality- Epistemic divide between patient and family	(Edmonds et al., 2024; Xu et al., 2021)
Decision-making	- Conflict between autonomy and filial piety- Unclear decision-maker roles- Fear of burdening family	(and, 2024; Cheung et al., 2020)	**Healthcare System**	Provider Factors	- Inadequate training (only 50% received ACP training)- Low confidence in facilitating discussions- Time constraints and workload
(H. Y. L. Chan et al., 2020;	Service Delivery	- Inadequate medical-social	(Chan, 2018; R.	**Institutional**	Policy

Level	Barrier Category	Specific Barriers	Evidence Source	**Individual**	Knowledge & Awareness
Cheung et al., 2020)		interface- Fragmented care coordination - Limited palliative care for non-cancer conditions	Chung et al., 2020)		
- Lack of overarching EOL care policy- Ambiguous legal basis for mental incapacity- Legislative barriers for advance directives	(R. Chung et al., 2020)	Resources	- Inadequate community capacity- Limited funding and staffing- Geographic access barriers	(R. Chung et al., 2020)	**Societal/Cultural**
Stigma	- Persistent HIV stigma- Death as taboo- Ageism- LGBT+ discrimination	(Lu et al., 2025; Menzer, 2025; Tamsukhin et al., 2023)	Cultural Values	- Filial piety may prolong suffering- Family harmony prioritized over autonomy- Collectivist orientation	(Cheng et al., 2020; R. Chung et al., 2020)

5. Institutional Contexts and Healthcare Delivery

5.1 Residential Care Homes: Challenges and Opportunities

Residential care homes represent a critical site for end-of-life care delivery in Hong Kong, yet significant challenges exist in providing adequate palliative care and supporting advance care planning in these settings. The proportion of hospital deaths has declined while the proportion of nursing home deaths has increased, underscoring the importance of improving end-of-life care provisions in residential settings (Xu et al., 2021).

Research conducted in Hong Kong residential care homes reveals both challenges and opportunities for advance care planning. A quasi-experimental study examining ACP groups developed by social workers found that the intervention enhanced participants' awareness of advance directives, increased willingness to complete them, and improved communication with family members about advance directives (W. C. Chan & Yu, 2021). However, advance directive completion rates remained extremely low even after intervention, with only 3% of Hong Kong nursing home residents having completed advance directives compared to 13% in Taiwan.

The effectiveness of interventions in residential care settings depends on multiple factors. A nurse-led motivational interviewing ACP intervention for family caregivers of nursing home residents demonstrated feasibility and effectiveness, with significant increases in ACP knowledge, confidence, and stages of change for ACP activity (Wang et al., 2025). Family members recognized their need for ACP information and reported that interventions improved their knowledge, attitudes, and desire to sign advance directives. These findings support the vital role of nurses in preparing family caregivers for end-of-life care decision-making.

However, significant barriers persist in residential care settings. Three themes identified among frail older adults who did not complete advance directives after ACP conversations included: refraining from discussing end-of-life care, remaining in the here and now, and relinquishing responsibility over end-of-life care decision-making (Wan et al., 2022). Participation in ACP conversations might improve if current care plans are integrated to increase patients' motivation and if support is provided to family members in their role as surrogate decision-makers.

5.2 Hospital Settings and Acute Care Transitions

Hospital settings present unique challenges and opportunities for advance care planning and palliative care integration, particularly during acute care transitions. End-of-life practices in Hong Kong intensive care units reveal that life-sustaining treatment limitations are common, occurring in 83% of deaths, with shared decision-making between ICU physicians and families being the predominant model (Joynt et al., 2024). Only 6% of

patients retained decision-making capacity at the end of life, highlighting the critical importance of advance care planning before acute deterioration.

The primary medical reasons for life-sustaining treatment limitation were unresponsiveness to maximal therapy and multiorgan failure, with the patient's best interest being the most important consideration for decision-making (Joynt et al., 2024). However, loss of decision-making capacity is common at the end of life, underscoring that patients should be encouraged to communicate end-of-life treatment preferences to family members or surrogates, or through advance directives, well before acute illness strikes.

Structured advance care planning programs in hospital settings have demonstrated positive impacts. A structured ACP program for patients with advanced malignancies and end-stage organ failure achieved high concordance rates for patients' wishes on quality of life (95%), end-of-life care (100%), and funeral arrangements (100%) (Chan et al., 2020). The ACP group also had lower mean acute admissions and shorter length of stay in the last three months of life compared to non-ACP groups, demonstrating both clinical and economic benefits.

Emergency department settings provide opportunities for initiating palliative care discussions, though significant barriers exist. Patients with advanced illnesses often refuse to participate in palliative care research due to the severity of their illness, mode of care delivery, and misconceptions about palliative care (Brickey et al., 2022). Robust training programs are crucial to overcome these misconceptions and educate patients and providers about the role of palliative care in acute care settings.

5.3 Specialized Palliative Care Services and Integration Models

The integration of palliative care into comprehensive healthcare delivery remains a critical challenge in Hong Kong. Specialized palliative care involves complex and specialized support from teams with specific training in palliative care, while primary palliative care represents basic, integrated support provided by non-specialists as part of routine care (Tamsukhin et al., 2023). Both models are necessary to meet the diverse needs of aging populations, including those living with HIV.

Evidence for the benefit of early palliative care is emerging for structured palliative care services. The PAL-HF randomized controlled trial demonstrated that interdisciplinary palliative care yields greater benefits in quality of life, anxiety, depression, and spiritual well-being compared with usual care alone for heart failure patients (Lo, 2019). Similar models could benefit older adults living with HIV who face complex medical needs and multiple comorbidities.

A multidisciplinary neuro-palliative care model evaluated in Hong Kong demonstrated significant benefits for motor neuron disease patients, including higher rates of advance medical directive completion (46.94% vs 4.76%), better care coordination, improved service delivery, and possibly better survival (W. K. V. Chung et al., 2025). This model illustrates how structured, multidisciplinary approaches can overcome barriers to advance care planning and improve patient-centered outcomes.

Key components for delivery of palliative and end-of-life care in care home settings, identified through a modified Delphi study, include structure and process of care across seven domains: policy and infrastructure, education, assessment, symptom management, communication, care for dying patients, and family support (H. Chan et al., 2022). These components provide a framework for developing comprehensive palliative care services in various institutional settings.

5.4 Community-Based Services and Continuity of Care

Community-based end-of-life care services play a vital role in enabling older adults to age and die in place according to their preferences. An integrated community end-of-life support team (ICEST) model in Hong Kong demonstrated effectiveness in reducing caregiving strain, depression, and worries about patients among family caregivers while improving agreement about care planning and perceived external support (Chow et al., 2024). This model was particularly beneficial for both spousal and adult child caregivers, though each group faced different challenges.

The Community Care Plan (CCP) pilot project in Hong Kong, employing multidisciplinary collaborative services including ACP professionals, nursing teams, social workers, and community volunteers, showed significant improvements in community sense, ACP

knowledge, conversations about end-of-life care, and readiness for ACP engagement (Lu et al., 2025). Following an 8-month pilot, 63 older adults showed enhanced ACP knowledge and increased readiness for discussing medical treatment at end-of-life with doctors and signing advanced directives. Community volunteers also reported improvements in quality of life and increased comfort initiating end-of-life conversations.

However, community-based services face challenges including limited funding, volunteer availability, geographic access barriers, and integration with formal healthcare systems. The effectiveness of community services depends on strong linkages between hospital, clinic, and home-based services, as well as provision of support that includes socioeconomic assistance (Herce et al., 2014). For older adults living with HIV, community-based services must also address HIV-related stigma and create safe, affirming environments for disclosure and support.

Continuity of care across settings remains a critical challenge. The integrated care model requires coordination between palliative teams and specialists managing underlying conditions (Lo, 2019). Fragmentation in care delivery leaves many patients and families without coordinated support, particularly during transitions between settings. Developing comprehensive care pathways that ensure continuity from community to hospital to residential care settings is essential for improving end-of-life care quality.

6. Synthesis and Integrated Framework

6.1 The Socioecological Model Applied to End-of-Life Care

The socioecological model provides a comprehensive framework for understanding how barriers to dignified end-of-life care for older people living with HIV operate at multiple, nested levels. Applying this model to the Hong Kong context reveals how individual, interpersonal, institutional, community, and policy factors interact to create complex challenges that require multilevel interventions (R. Chung et al., 2020).

At the individual level, older people living with HIV face unique challenges stemming from the intersection of age-related vulnerabilities, HIV-related health complications, and psychosocial factors including stigma, social isolation, and fractured social networks (Tamsukhin et al., 2023). These individual factors interact with interpersonal dynamics

shaped by cultural values of filial piety and family-centered decision-making, creating tension between individual autonomy and collective family welfare (Cheng et al., 2020).

The institutional level encompasses both the healthcare delivery system and residential care settings, each with their own barriers including inadequate training, resource constraints, and fragmented care coordination (R. Chung et al., 2020). These institutional factors are embedded within broader community and societal contexts characterized by death taboos, HIV stigma, and cultural interpretations of filial piety that may prolong suffering (R. Chung et al., 2020).

At the policy level, the lack of overarching end-of-life care policy framework, ambiguity in legal bases for mental incapacity, and legislative barriers for advance directives create systemic obstacles to accessing dignified end-of-life care (R. Chung et al., 2020). These multilevel barriers do not operate independently but interact in complex ways, with barriers at one level reinforcing and amplifying barriers at other levels.

6.2 Intersecting Stigmas: A Compounded Vulnerability Framework

Understanding how multiple stigmas intersect to create compounded vulnerabilities is essential for developing effective interventions for older people living with HIV. The intersection of HIV stigma, death-related cultural taboos, and ageism creates unique challenges that cannot be addressed by targeting any single stigma in isolation. Sexual and gender minority older adults living with HIV face additional layers of stigma related to sexual orientation or gender identity (Menzer, 2025).

These intersecting stigmas operate through multiple mechanisms. HIV stigma continues to affect healthcare-seeking behavior, disclosure decisions, and social support networks even decades after diagnosis (Tamsukhin et al., 2023). Death-related taboos create barriers to advance care planning discussions and prevent open communication about end-of-life preferences (Lu et al., 2025). Ageism devalues older adults' autonomy and contributes to assumptions about their capacity or interest in decision-making (Jeste, 2022).

The compounded effect of these stigmas is particularly evident in institutional settings, where older adults living with HIV may fear discrimination if their HIV status is disclosed, while simultaneously being unable to engage in advance care planning due to cultural

taboos and assumptions about older adults' decision-making capacity. For sexual and gender minority older adults, fears about having to return to the closet in long-term care settings compound these vulnerabilities (Kortes-Miller et al., 2018).

Addressing intersecting stigmas requires interventions that acknowledge the complexity of individuals' identities and experiences. Trauma-informed, intersectional approaches that consider the simultaneous interactions between different social categories (race, ethnicity, gender, class, sexuality, age, ability) are necessary to avoid excluding individuals who carry the greatest burden of illness (Shimmin et al., 2017). Such approaches must be integrated into patient engagement strategies, research designs, and service delivery models.

6.3 Relational Autonomy as a Bridge Between Cultures

The concept of relational autonomy offers a promising framework for bridging Western bioethical principles emphasizing individual autonomy with Asian cultural values emphasizing family and collective welfare. Unlike Western notions of autonomy that see the individual as an isolated decision-maker, relational autonomy recognizes that individuals make decisions within networks of relationships and that autonomy can be exercised through relationships rather than in opposition to them (Cheng et al., 2020).

In the context of end-of-life care in Hong Kong, relational autonomy provides a way to honor both patient preferences and family involvement. Rather than forcing a choice between individual autonomy and family-centered decision-making, this approach recognizes that for many older adults, making decisions in consultation with family members is itself an expression of autonomy. The key is ensuring that the patient's voice remains central even as family members participate in discussions and decision-making.

Implementing relational autonomy in practice requires several shifts in healthcare delivery. First, healthcare providers must move beyond viewing family involvement as necessarily problematic or as evidence of the patient's lack of autonomy. Second, communication strategies must be adapted to facilitate family discussions while ensuring that the patient's preferences are elicited and respected. Third, advance care planning processes must be

flexible enough to accommodate varying levels of family involvement based on individual patient preferences and family dynamics.

Research demonstrates that older Asians prefer to make their own decisions after consulting others, with family members playing an important role in helping older people plan their preferred end-of-life care arrangements (Ho et al., 2022). This pattern of decision-making reflects relational autonomy in action. Healthcare systems and policies must be adapted to support this model rather than imposing Western frameworks that may conflict with patients' cultural values and preferences.

6.4 Integrating Palliative Care for HIV: A Lifespan Approach

The integration of palliative care into HIV care requires a lifespan approach that recognizes the unique needs of older adults aging with HIV. Palliative care for this population must address not only physical symptom management but also emotional well-being, advance care planning, and decision-making that resonates with patients' values and goals (Tamsukhin et al., 2023). This integrated approach leads to improved patient outcomes and higher quality of care.

The challenges of providing palliative care to people aging with HIV include recognition and management of accelerated aging processes, multiple comorbidities, complex medication regimens, and persistent stigma (Tamsukhin et al., 2023). Addressing these emotional and social needs is as crucial as managing physical health. Healthcare providers must be trained to understand the unique trajectory of HIV in older adults and how it differs from younger populations and from other chronic conditions.

Early integration of palliative care principles into HIV care, similar to models developed for cancer and heart failure, shows promise for improving quality of life and reducing unnecessary hospitalizations (Lo, 2019). However, misconceptions about palliative care—including beliefs that it is only for the imminently dying or that it means giving up on treatment—create barriers to referral and acceptance (Brickey et al., 2022). Education of both healthcare providers and patients about the complementary nature of palliative care and disease-directed treatment is essential.

A lifespan approach to palliative care in HIV also requires attention to unique psychosocial needs. People aging with HIV often experience loneliness, social isolation, loss of close friends, and estranged family relationships (Abdo et al., 2020). With fractured social networks, many may not have clear proxies for healthcare decisions. Palli teams must proactively work to identify potential healthcare proxies, facilitate family reconciliation where possible, and support the development of advance directives that clearly designate decision-makers from families of choice, including partners, close friends, or community members.

7. Recommendations and Future Directions

7.1 Policy-Level Recommendations

Hong Kong urgently requires development of a comprehensive end-of-life care policy framework that addresses the identified gaps at multiple levels (R. Chung et al., 2020). This framework should include clear legislation regarding advance directives, clarification of legal bases for mental incapacity, and standardized protocols for surrogate decision-making that are inclusive of diverse family structures. Policies should explicitly recognize relational autonomy and accommodate family-centered decision-making while protecting individual patient preferences (Cheng et al., 2020).

Legislative reforms must address barriers specific to marginalized populations, including older adults living with HIV and sexual and gender minority individuals. Surrogate decision-maker policies should be more inclusive of families of choice rather than defaulting exclusively to biological family members (Menzer, 2025). Government support for community-based palliative care initiatives, including funding for training programs and service delivery, is essential to expand access beyond institutional settings (Lu et al., 2025).

7.2 Healthcare System and Provider Training

Comprehensive training programs for healthcare professionals must address both technical competencies in advance care planning and cultural competencies for working with diverse populations (H. Y. L. Chan et al., 2020). Training should employ blended learning approaches rather than didactic formats alone, and should specifically address how to

navigate conversations about death in cultures where such discussions are taboo. Healthcare providers need skills to facilitate family-inclusive discussions while ensuring patient voices remain central (Pun et al., 2023).

Systematic integration of palliative care education into medical and nursing curricula, with specific modules on caring for older adults with chronic conditions including HIV, is necessary to build workforce capacity (Tamsukhin et al., 2023). Multidisciplinary team approaches that integrate social workers, nurses, physicians, and community volunteers have demonstrated effectiveness and should be expanded (Chow et al., 2024).

7.3 Community Education and Stigma Reduction

Public education campaigns must address death literacy, reduce HIV-related stigma, and promote understanding of advance care planning benefits (Ng et al., 2024). Community-based interventions engaging volunteers and leveraging existing social networks show promise for normalizing end-of-life discussions (Lu et al., 2025). Education efforts should be culturally tailored to address specific concerns within Chinese communities while respecting traditional values.

Peer support programs and community conversations that create safe spaces for discussing death, dying, and HIV can help reduce multiple layers of stigma. These initiatives should target both older adults and their adult children to facilitate intergenerational dialogue about end-of-life preferences within the framework of filial piety (and, 2024).

7.4 Research Priorities

Future research must examine the specific experiences and needs of older people living with HIV in Hong Kong's end-of-life care system. Longitudinal studies tracking advance care planning engagement, palliative care utilization, and end-of-life outcomes are needed to identify effective interventions. Research should employ intersectional frameworks that acknowledge how HIV status, age, sexual orientation, gender identity, and other social identities interact to shape experiences (Shimmin et al., 2017).

Comparative effectiveness research evaluating different models of palliative care integration for older adults with HIV, including community-based, hospital-based, and

hybrid models, would inform service development. Qualitative research exploring how relational autonomy operates in practice within Hong Kong families can guide development of culturally appropriate advance care planning protocols.

8. Conclusion

This comprehensive report has examined the multifaceted barriers that older people living with HIV face in accessing dignified end-of-life care within Hong Kong's unique familial and institutional contexts. The analysis reveals that these barriers operate at multiple nested levels—individual, interpersonal, institutional, community, and policy—and are compounded by intersecting stigmas related to HIV, death, age, and marginalized identities. Cultural values, particularly filial piety and family-centered decision-making, create both challenges and opportunities for advance care planning when balanced with respect for individual autonomy through frameworks of relational autonomy (Cheng et al., 2020).

Addressing these complex challenges requires coordinated action across multiple sectors. Policy reforms must establish comprehensive end-of-life care frameworks while respecting cultural values. Healthcare systems must invest in provider training and develop integrated palliative care models tailored to the needs of aging populations with chronic conditions. Communities must engage in education to reduce stigma and increase death literacy. Families need support to navigate difficult conversations about end-of-life preferences within cultural contexts that have historically avoided such discussions.

The path forward requires acknowledging that Western models of autonomy and advance care planning cannot simply be transplanted into Hong Kong's context without adaptation. Instead, culturally sensitive approaches that honor both individual preferences and family relationships—operationalized through relational autonomy—offer the most promising direction for ensuring that older people living with HIV can access palliative care, complete advance directives, and experience dignified deaths that align with their values and goals. With concerted effort across policy, practice, and community levels, Hong Kong can develop an end-of-life care system that serves all its aging residents with dignity and compassion.

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