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International Continence Society white paper on ethical considerations in older adults with urinary incontinence

Anne M. Suskind MD, MS, FACS, FPMRS[1] | **Tiina Vaittinen PhD**[2] | **William Gibson MD**[3] | **Sakineh Hajebrahimi MD**[4] | **Joan Ostaszkiewicz RN**[5] | **Nina Davis MD**[6] | **Tamara Dickinson RN**[7] | **Martha Spencer MD**[8] | **Adrian Wagg MD**[3]

[1]Department of Urology, University of California, San Francisco, California, USA
[2]Department of Social Sciences, Tampere University, Tampere, Finland
[3]Division of Geriatric Medicine, University of Alberta, Edmonton, Alberta, Canada
[4]Departments of Urology and Family Medicine, Research Center for Evidence-Based Medicine, Tabriz University of Medical Sciences, Tabriz, Iran
[5]National Ageing Research Institute, Parkville, Australia
[6]Department of Urology, University of Oregon Health Sciences, Portland, Oregon, USA
[7]Department of Radiation Oncology, University of Texas Southwestern Medical Center, Dallas, Texas, USA
[8]Department of Medicine, The University of British Columbia, Vancouver, British Columbia, Canada

Correspondence
Anne M. Suskind, MD, MS, FACS, FPMRS, Department of Urology, University of California, 400 Parnassus Ave, Box 0738, San Francisco, CA 94143, USA.
Email: Anne.Suskind@ucsf.edu

Abstract

Urinary incontinence is a common problem among older adults that is often complicated by many nuanced ethical considerations. Unfortunately, there is a lack of guidance for healthcare professionals on how to navigate such concerns. This International Continence Society white paper aims to provide healthcare professionals with an ethical framework to promote best care practices in the care of older adults with urinary incontinence.

KEYWORDS

dementia, elderly, frailty, geriatrics, goals of care, multimorbidity

1 | INTRODUCTION

Urinary incontinence (UI) is common among older adults, occurring in 30%–40% of women and men over the age of 65 and in 60%–70% living in long-term care facilities.[1,2] Alongside other multi-aetiological conditions such as delirium, falls, dementia, and weight loss, UI is considered to be a geriatric syndrome.[3] As the proportion of older adults in the population continues to grow, the absolute number of older adults with UI will also greatly increase. Importantly, caring for these older adults is no longer just about prolonging life, but it is also about ensuring that these later years are healthy, meaningful, and dignified.[4] *Ageism*, defined as a process of systemic stereotyping of and discrimination against people because of their age,[5] is both common and unethical, and can be a major challenge to older adults in achieving these meaningful and important goals. Unfortunately, however, there is little guidance for healthcare professionals on how to best ethically care for older adults with UI in the face of these, and other, challenges.

Some examples of ethical considerations specific to caring for older adults with UI include *how to best deliver care that reflects the dignity of the individual*, *how to* *manage urinary incontinence in an individual living with dementia who cannot express their own preferences,* and, if at all, *how should age factor into treatment options presented to the patient*.

Fortunately, several ethical frameworks that can help guide this discussion exist and will be further discussed and applied herein. Among them are the Four Ethical Principles and the Ethics of Care Model. The Four Ethical Principles can aid in the moral decision-making process and includes (1) autonomy (the moral right to self-determination concerning one's own health care), (2) beneficence (acting in a way to benefit someone other than oneself), (3) nonmaleficence (doing no harm), and (4) justice (the extent to which healthcare is delivered in an equitable fashion).[6] The Ethics of Care model is another tool that can be used to help guide moral decision-making. It is a context-bound ethics model where moral practices are grounded on the recognition of the needs of particular persons. It recognizes the importance of personal relationships, paying particular attention to the attributes of compassion, sympathy/empathy, and a sincere concern for caring for others.[7–9] These frameworks serve as a starting point for this document.

The purpose of this International Continence Society white paper is to provide guidance in addressing some of the ethical dilemmas that arise in caring for older adults with UI, taking into account the various perspectives of the patient, the caregiver, and the healthcare professional (inclusive of physicians, nurses, physiotherapists, and other types of care aides). This paper does not provide definitive solutions to ethical problems, as many of these issues are nuanced and individualized beyond the ability of a formal document to adequately address them. As ethical dilemmas are always context-bound, we will begin the paper by revisiting the varying contexts and cultural considerations wherein continence care is provided for older adults. Thereafter, we propose the following guiding principles to help healthcare professionals provide ethical care for older adults with UI:

- Health systems should create environments that support ethical continence care
- All older adults should be treated with dignity
- The healthcare team should elicit the patient's own goals of care
- Advanced communication should be employed in intimate continence care interactions with older adults
- Treatment should be aligned with goals of care
- The healthcare team should consider the potential burden of the treatment that they recommend in the setting of multimorbidity, frailty, physical, and cognitive impairments

These statements serve as a starting point to raise awareness of the important ethical issues associated with the care of older adults with UI. While this paper focuses specifically on UI, these same guiding principles will also apply to other lower urinary tract disorders in this population.

1.1 | The contexts of care for older adults

The Ethics of Care is an approach to moral thinking that was originally developed in moral psychology and political philosophy,[8–11] but which has been also addressed in nursing philosophy and theoretical medicine.[12–14] It is grounded on the argument that practices of care give rise to moral thinking that is specifically suited to meeting the needs of others. This approach complements justice-based ethical guidelines, where the aim is to treat everyone equally, often through universal guidelines for justice.[12] Ethics of Care emphasizes that justice and ethical conduct take more than just following a set of rules. In this approach, ethics is about *responding caringly to the needs of particular persons in the specific contexts where the needs emerge*. Thus, to provide ethical guidance for continence care for older adults, we first must briefly elaborate the different contexts where this care takes place.

Depending on the country-specific system of health and social care, the contexts of care for older adults can be divided roughly into two distinct settings: (1) institutionalized settings of care (including clinics, hospitals, and nursing homes) and (2) home-based health and social care, provided by care professionals in the clients' own homes, by family members, or by care assistants who may not have official healthcare qualifications. In many societies, older adults with heavy care needs live in nursing homes or serviced housing, where they have access to professional nurses' and caregivers' help at all times. These resources are increasingly limited, however, in formerly strong welfare systems, where access to 24/7 care services has become restricted.[15] Institutionalized care is also not a universally accepted solution to coordinate care for older adults. In many societies, older adults age at home, being cared for by other, usually female members of the family. Additionally, paid domestic help may also be utilized. Thus, on the global scale, the majority of older adults with UI problems live at home, depending on family members or other informal caregivers, which may or may not be complemented with services provided by health professionals working in community care.

All of this places limitations on what continence care experts can do to improve the care for older adults with

UI: while most day-to-day continence care for older adults is provided by personal care workers and nurses providing intimate care, the most up-to-date specialist knowledge of treatments and forms of incontinence is often found in the clinic and in hospitals. When older adults with incontinence problems do not have access to such specialists, their continence issues may not be adequately treated or mitigated. Simultaneously, the continence experts working in the clinic may not always have a realistic picture of practices of intimate continence care, or the set of skills that the caregivers in those contexts require when seeking to meet the needs of their clients competently, compassionately, and with dignity. We will return to this in a subsequent section. However, our recommendations are mainly directed towards healthcare professionals who care for older adults. This would mean, first, that those working in the clinic or hospitals comprehend the day-to-day realities in which most continence care for older adults is provided. Second, it would mean that those providing intimate care in the clients' homes, or in nursing homes, be provided with knowledge of continence issues as part of their training in elder care.

The geographical context of care matters, too. While the rapid aging of demographics is also a reality in low- and middle-income countries (LMICs), a number of stressors are more common in these parts of the world, including poor housing, lack of access to standard toilets, poor access to medical services, limited digital facilities, lack of appropriate medications, poor hospital care, and insufficient security and social support. Medical education is lacking in continence care for professionals and caregivers, and there are limited educational resources translated into local languages. Furthermore, while the lack of sanitation and inadequate waste management make safe disposal of continence products difficult in LMICs, the products may remain entirely inaccessible to large segments of these populations. This applies both to absorbent products and to safe catheter care. Studies show, for instance, that catheter insertion, indication and monitoring are lacking in many health centers in LMIC contexts.[16]

There are thus several societal issues that need to be considered to support ethical continence care in the context of LMICs.[4] Furthermore, like in high-income countries (HICs), in LMICs, knowledge of incontinence tends to be low among the general population, and remains a gendered taboo that is not discussed. There may also be specific cultural constraints to discussing urine and fecal leakage. In Islamic law, for instance, urine is considered "Najis" (ritually unclean), meaning that if one's garments are contaminated with urine, one will be limited in doing daily rituals and in participating in social activities such as going to the mosque. Non-Muslim communities have similar social limitations. Across societies, many still believe that UI is an inevitable part of aging, and this belief is easily entangled with derogatory forms of ageism. In many languages, there may still not be an adequate translation for the clinical term "incontinence,"[17] making the problem difficult to address in ways that are comprehensible to older adults.

While various inequalities and inequities shape continence care for older adults globally, the same applies to inequalities and inequities within societies. In HICs, older adults living in poverty may have difficulties in accessing adequate and safe continence care, treatments, and products. Medical illiteracy may affect the possibilities to access care, as well as language skills among migrant populations. While individual healthcare professionals may not be able to influence these inequalities in their day-to-day work, it is important that they are aware of these different contexts in which their older patients need care, and thereby the patients' social determinants of health. In the following section, we turn to the socioeconomic structures, which shape the space for ethical interaction among health professionals.

Section 1 Summary

- Care for older adults takes place in institutionalized settings and in people's own homes. Globally, the majority of older adults with continence problems live at home, depending on family members or other informal caregivers for help.
- Many older adults do not have access to specialist care.
- A number of stressors in low- and middle-income countries, including poor housing, limited access to standard toilets, poor access to medical services, lack of appropriate medications, poor hospital care, and insufficient security and social support, may make continence care more complicated.

2 | HEALTH SYSTEMS SHOULD CREATE ENVIRONMENTS THAT SUPPORT ETHICAL CONTINENCE CARE

The concept of *socioeconomic structures*, generically used in the social and political sciences, refers to the ways in which different social, political, and economic factors *shape and constrain, or influence, individual or group action*.[18–20] Whilst some structural conditions can hinder health professionals from ethical interaction, others can facilitate ethical care. In continence care for older adults, this term can refer to the material, temporal, epistemic, and human resources that are available for treating or caring for a patient. For example: *Is there an adequate number of staff members available to meet the needs of the patient? Are training and skills appropriate to meet patient needs, while respecting the patient's dignity? Is there enough time for the caregiver to listen to the patient and understand their individual needs, before making decisions about treatments? Are there adequate diagnostic tools and technologies available? Are there adequate human resources available to assist patients after treatment, for a safe recovery? What social and environmental determinants of health influence the patient's condition, and their possibilities of self-care? Does the health system provide the patient with access to the necessary treatments and care, regardless of their wealth and status in society?*

Accounting for the global inequalities and inequities of health care described above, it is helpful to think of the influence of socioeconomic structures on care through different levels of analysis that overlap and interact (Figure 1).

First, on the *macro-level*, the socioeconomic structures are shaped by the national health system. Here, legislation and policies form a structure that defines the patients' rights to care, while outlining the system of payments. For instance, insurance or out-of-pocket based health systems form very different macro-structures for care provision, compared to the more universal systems of social and health care, where services are tax-funded and generally more accessible. These macro-structures are shaped not only by national policies and jurisdiction, but also internationally. Trade agreements, for instance, may have an impact on treatments and medications that are available in particular contexts.

Second, on the *meso-level*, the institutional context of care sets up its own structures. As noted above, continence care for older adults occurs in different environments: hospital wards, clinics, nursing homes, and households. In each setting, the staff qualifications, skills, as well as staff resources and available technologies, shape the possibilities for ethical action.

Third, as described in more detail in the subsequent sections of this white paper, the ethical interaction between healthcare professionals and their

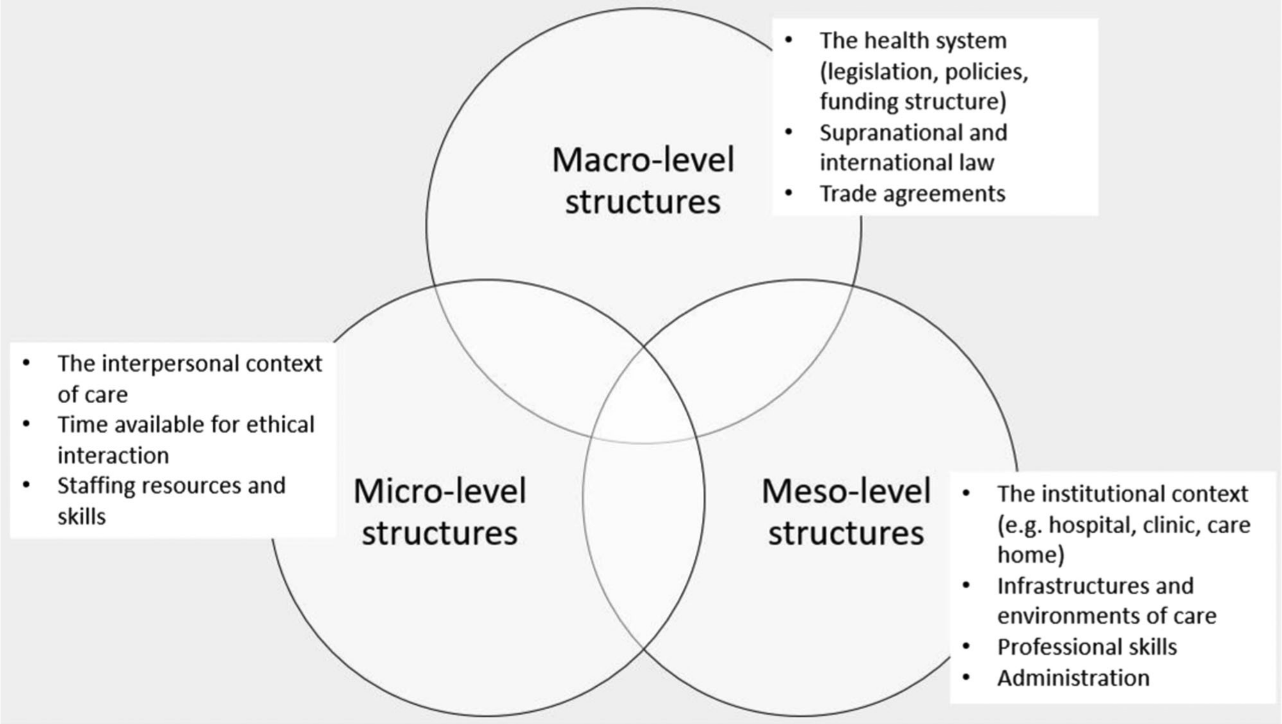

FIGURE 1 Socioeconomic structures: intersecting levels of analysis

older patients always takes place via interpersonal encounters between individual human beings. In this *micro-level,* there are various structural constraints and possibilities at work. A crucial factor is time available for listening and understanding the patients' needs from their own perspective. Temporal constraints and possibilities, however, are often placed at either meso- or macro-levels. An awareness of such structural influences on care *expands the ethical responsibility for good care, from a focus on the actions* of individual healthcare professionals to the administrators making decisions on how resources are allocated on different levels of the healthcare system.

Indeed, on all levels of analysis, socioeconomic structures are political. In the micro-level encounters, politics is present in the inter-personal power relations between the healthcare professionals and their older patients. On the macro- and meso-levels, in turn, there is the day-to-day level of political, administrative, and fiscal decisions regarding the health system, how it operates, and how it is funded. These decisions have a crucial impact on equality and equity in patients' access to care—and, respectively, on the kinds of ethical possibilities that are available to healthcare professionals in their practices of care. Healthcare professionals often struggle to provide care that meets their own ethical standards of work leading to moral distress.[21–23] Such situations require the redesigning of socioeconomic structures, rather than attributing blame to individual healthcare professionals. Indeed, if the socioeconomic structures hinder ethical action for healthcare professionals, it is not only possible, but morally necessary to redesign the structures so that they support ethical interaction in care. In the subsequent sections, we describe what such ethical interaction looks like when caring for older adults with UI in different contexts.

2.1 | Environments that support ethical continence care in older adults

To respond ethically to the continence care needs of older adults in organizational settings, there is a need to address the socioeconomic structures that influence the quality of care. Two quantitative studies highlight the importance of considering organizational structural factors such as staffing. One study analyzed the minimum data set for 46 044 residents in 162 nursing homes in New York State, from June 2006 to July 2007, and survey responses from 7418 workers in the same facilities. The study found that rates of incontinence were significantly lower in homes that had higher rates of staff cohesion, a higher percentage of staff in daily care teams, and a higher percentage of staff with consistent assignments.[24] Similar findings were reported in another study that examined the impact of organizational factors on the quality of incontinence care in Korean long-term care hospitals. This study found that higher Registered Nurse to patient ratios were significantly associated with better resident UI outcomes in long-term care hospitals.[25]

We suggest that structures that support ethical continence care for older adults in organizational settings align with those that privilege the older person's dignity. Based on a concept analysis, dignity-protective continence care' for care-dependent older adults is characterized by: (1) time to deliver care and flexible work practices; (2) staff knowledge and beliefs about incontinence; (3) adequate number of staff as well as staff who are trained; (4) managerial support and leadership; (5) a predictable work environment; (6) regulation that does not constrain caring practices; (7) a health system that ensures an equitable access to adequate and appropriate care and treatment, across the population. These findings can be used as guiding principles in an ethic of care for older adults who require continence care.

<u>Section 2 Summary</u>

- The Ethics of Care framework emphasizes that care must be provided in ways that meet each person's specific needs, within the contexts in which their care is delivered.
- Elder care is primarily home-based or institutional, but the availability of knowledgeable and competent caregivers, educational aids, incontinence products, and infrastructure that supports the delivery of proper continence care vary widely depending on systems of care, geography, and cultural norms.
- Care practices are shaped by the socioeconomic structures in which the care is delivered. This expands the ethical responsibility of good care to include not only the healthcare professionals, but also the policymakers, hospital, and home care administrators.

3 | ALL OLDER ADULTS SHOULD BE TREATED WITH DIGNITY

Whilst the concept of dignity is contested, difficult to define, and difficult to measure, few would argue that UI represents a threat to a person's subjective dignity. Dignity appears as a duty and a right in professional codes in human rights frameworks. Article 1 of the Universal Declaration of Human Rights (UDHR) states "all human beings are born free and equal in dignity and rights."[26] The International Council of Nurses Code of Ethics[27] states "*Inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect*" (p. 1). Thus, dignity is linked to respect, equality and rights.

Leget[28] identifies three versions of dignity:

- *Intrinsic dignity* pertains to the idea that all human beings have inherent dignity that cannot be diminished or taken away as long as the person lives.
- *Subjective dignity* is the experience of one's own dignity tied to self-respect and self-esteem.
- *Social and relational dignity* is based on merit or rank and upon recognition by other people.

The concept of dignity has particular salience for healthcare professionals who have a professional obligation to acknowledge and protect all humans regardless of their agency and autonomy.

However, in recent years, attention has been drawn to the fact that many older adults are not accorded the respect they deserve, particularly if they have cognitive challenges that affect their ability to self-advocate or if they require care in an institution such as a nursing home or hospital. Indeed, details about neglect and abandonment in the form of not being fed, bathed, or toileted during the COVID-19 pandemic are emerging from long-term care homes from multiple countries. In Canada, armed forces found cockroach infestations, short staffing, neglect of residents, and uninfected residents sharing rooms with those who were symptomatic.[29,30] In Spain, Belgium, and Canada, the military was called in to care homes for standards of care collapsed amid reports of lack of personal protective equipment (PPE), staff sickness, and negligence complaints against the management of care homes.[31]

Similarly, a Royal Commission of Aged Care Quality and Safety,[32] investigating the quality and safety of residential and in-home aged care in Australia reported several examples of practices that the Commissioners viewed as violations of older peoples' dignity. They included:

- Using continence containment products as a substitute for toileting
- Rationing the use of incontinence products
- Failing to respond when residents need help to change wet or soiled products
- Failing to respond when residents need help to use the toilet, causing them to experience an episode of incontinence.

Concerns about the quality of continence care in institutions are longstanding and international. Artero-Lopez et al.[33] described the care of hospitalized patients with UI in Spain as therapeutic inertia. The researchers conducted 132 non-participative observations of practice and reviewed 600 medical records and reported a pattern of severely compromised action in the assessment of the pattern of urinary elimination, in actions related to urinary continence, in therapeutic behavior, and in-patient satisfaction.[33] Drawing on an ethnographic study within five hospitals in England and Wales, Boddington and Featherstone[34] claimed the twin assaults on agency of a diagnosis of dementia and of UI threatened patients' personhood. These findings suggest that subjective dignity and the social construction of moral personhood are both threatened and maintained in such a setting. We claim the preservation of dignity should form a guiding principle in ethical care of older adults who require support to either manage or maintain continence.

Given this background and the absence of quantitative data about violations to the dignity of older people who require care, Ostaszkiewicz et al.[35] attempted to clarify the attributes of practice that protect the dignity of people who require support to manage incontinence or to maintain continence. Using a method established by Rogers et al.[36] from 14 empirical studies that met the inclusion criteria, the authors identified 50 antecedents and attributes of continence care practices that protect a person's dignity, that is, dignity-protective continence care. Based on this analysis, dignity-protective continence care is operationalized through practices that promote respect, empathy, trust, privacy, autonomy, and communication.[35] For example, continence care practices that promote autonomy focus on offering a choice and support to make decisions about the gender of caregivers, toileting preferences, and choice of products. Dignity-protective care requires carers to have adequate verbal and non-verbal communication skills. These communication strategies include managing negative emotions, adopting a soft, calm tone, picking up on verbal and nonverbal cues, and using touch appropriately. Respect is conveyed through practices that treat the person as an individual rather than an episode of care, and by taking time. The researchers also identified

23 consequences of undignified continence care that they categorized into three levels of impact (i.e., resident/family member, staff member, and organization).

Whilst the researchers anticipate the domains of respect, empathy, trust, privacy, autonomy, and communication to be universal, a limitation of the concept analysis is the reliance on published research in the English language that does not take account of cultural differences between and within countries and nations. Depending on the class, gender, generation, ethnicity, religion, urban/rural positioning of both the caregiver and care recipient, dignity protective practices are likely to be culturally specific.

Understanding these attributes of dignity-protective continence care could allow caregivers and healthcare professionals to challenge practices that violate dignity, and recognize caring opportunities for protecting the dignity of vulnerable and care-dependent older adults. The researchers plan to use their findings to develop an instrument to evaluate whether continence care is delivered in a way that protects the dignity of care-dependent older people.

Section 3 Summary

- Incontinence represents a threat to an individual's subjective dignity and healthcare professionals have an obligation to respect and maintain this dignity.
- It is imperative to acknowledge and address contexts in which dignity may not be maintained, such as in those who are living with cognitive impairment or older adults with frailty living in institutional care who are unable to advocate for themselves.
- Dignity-protective care requires good verbal and non-verbal communication strategies and treating the person respectfully as an individual and autonomous being.

4 | THE CARE TEAM SHOULD ELICIT THE PATIENT'S OWN GOALS OF CARE

Eliciting the patient's own goals of care is paramount to the ethical treatment of older adults with UI. When it comes to caring for older adults, communicating with cognitively intact patients is not fundamentally different from communicating with younger patients. However, in people living with cognitive impairment, challenges may occur in the patient's ability to understand information, make decisions, and communicate preferences clearly. In this section, we consider how to approach those older adults who may not be able to communicate their own goals of care and to the relationship-centered care (RCC) model as a means of communication.[37] We also address the challenges that arise when the patient and the caregiver have differing experiences or expectations of UI and goals of care.

4.1 | Framework for eliciting goals of care

The process of eliciting the patient's own goals of care starts with understanding their values and how they may be affected by their condition. To learn about an individual's values, the care team must communicate empathically and listen actively to learn and understand, rather than solely acting to solve or "cure" the patient's problem.[38] The care team should ask open-ended questions to facilitate articulation of the patient's own preferences. For example, to understand an individual's dominant care goal, one could ask, "what is most important to you at this point in your life?" To further understand the individual's values, one could ask, "What makes life worth living for you?"[39] Responses to questions such as these can help the care team to better understand the patient's values and preferences and aid in appropriate treatment selection aligned with these goals. Ethical concerns can arise when the person's wishes and available resources and care are misaligned.

4.2 | What happens when the patient is unable to communicate their goals of care

Autonomy, the concept that an individual has agency to choose to undertake or decline a particular medical intervention, is paramount to consider when eliciting an individual's goals of care. However, autonomy in the case of cognitively impaired adults is less clear and may not be binary. These overriding principles are supplemented by the *Four Box* model of medical decision-making, which places medical indications, patient preferences, quality of life, and contextual features on equal footing within the process of finding an agreed plan between the care team and patient.[40]

Many older adults living with cognitive impairment retain the capacity to make decisions regarding their health. Involving others in discussions should always be based on informed consent. When this is not possible, an assessment of capacity should be conducted. In cases when individuals are not able to make decisions regarding their own care (following an assessment of capacity), substitute decision-makers, usually those nominated in a personal directive or similar document, assume the responsibility of being involved in discussions. Substitute decision-makers may also be called "proxy," "surrogate," or "assisted" decision-makers. As substitute decision-makers face difficult decisions between the utility and futility of treatments that impact the wellbeing of persons who are often their loved ones, the position is psychologically demanding. The same applies to decisions regarding continence care. They may feel confused over mixed messages or guilt for the choices they have made, and they may have to negotiate difficult choices with a wider family group, sometimes leading to family disagreements. It is therefore crucially important that the healthcare professionals involved in elucidating choices provide adequate time and support for surrogate decision-makers, that they communicate the choices and their consequences clearly, in plain language, and without medical jargon, and that they are ready to listen empathetically, seeking to understand their concerns.[41]

For those older adults who are unable to retain or understand information, it becomes the responsibility of their surrogate decision-maker working with the treating professionals to establish what course of action is in the person's *best interests*—that is, aligned with what they believe would be consistent with the person's own values and preferences. These discussions can be challenging, particularly when views differ between professionals and surrogates. Here, RCC provides an ethical framework.

4.3 | Relationship-centered care as a means of communicating across differences

Originating from the Pew-Fetzer Task Force on Advancing Psychosocial Health Education,[37,42] RCC seeks to recognize the nature and the quality of relationships as central to healthcare practices and health systems. Going beyond both patient-centered care and the old-fashioned doctor-centered approach, RCC portrays *healthcare delivery as a network of human relationships* that involves the patient, their substitute decision-makers, and health professionals involved in the delivery of care. As Nolan et al.[42] describe, "[in RCC] the interactions between these groups constitute the 'defining force' in health care, as they are the medium for exchanging the information, feelings, and concerns needed for a better understanding of the meaning of illness"—and hence the patient's best interest.

First, RCC requires that the personhood of *all* the participants be considered, including care team members, who need to be aware of their own values, biases, and reactions, and how they shape the healthcare relationships in which they participate.[37] Second, RCC challenges the idea that healthcare professionals should be detached from their emotions to maintain neutrality, and empathizing with the patient is strongly encouraged. Third, RCC recognizes the value of reciprocal influence in care relationships, where the patients and their family members may influence the healthcare professionals. Allowing the patient and the surrogate decision-makers to have an impact on the healthcare professional respects their personhood, and allows for ethically sustainable healthcare praxis. Fourth, RCC maintains, in line with the message of this white paper, that the formation and maintenance of genuine relationships in healthcare are morally valuable.

4.4 | The importance of gaining trust

RCC is likely to improve care delivery through an increased overall commitment to care practices, for as social animals, "humans are more morally committed to those with whom they are in a personal relationship."[37] Similarly, keeping family members regularly updated about continence care as well as other care increases trust in a manner that makes them feel they are involved and respected. It is also imperative not to "talk over" the person living with cognitive impairment, but rather to *include* them in a discussion at a level appropriate for their cognitive and communication ability. Furthermore, RCC reveals that communicating the goals of care is not a singular event between two persons, but part of a wider network of relationships, where each actor's views and experiences, and trust in the system, can influence the patient's wellbeing. Whether making decisions for one's own care, or for someone else as a substitute decision-maker, the patient and their family members, or surrogates, must be able to trust healthcare professionals and the health system as a whole.[41] As RCC emphasizes, trust is gained over time; the ethics of communicating and eliciting goals of care is, therefore, an ongoing process.

"Mixed messages" and contradictory practices can undermine the patient's and their representatives' trust in the system's capacity to understand their best interests. To assess the patient's continence problems holistically, it is important that healthcare professionals communicate clearly within the team, and that all team members appreciate each other's knowledge and professional views.

4.5 | When opinions between the individual and caregiver differ

When individuals living with dementia and their caregivers have different views and opinions regarding their continence care, conflict can arise. A common situation exists when a person with dementia is untroubled by their UI, but the caregiver is quite burdened, for example by purchasing and changing containment products, helping with toileting, doing laundry, or experiencing disturbed sleep. This can lead to an ethical dilemma—to what extent can healthcare professionals force continence care, like washing, that they know is imperative for the person's wellbeing, but which the person aggressively resists? It is known that "intentions associated with determining and agreeing [on] care goals can be ambiguous."[41] There is no prescriptive or "correct" answer here. Open communication between the patient, the caregiver, and the medical team is essential to ensure the best compromise is reached, seeking the least restrictive option that provides acceptable symptom resolution and treatment burden, tailored to the individual is achieved. Fundamentally, the well-being and dignity of the patient are central, as discussed earlier in this publication.

5 | ADVANCED COMMUNICATION SHOULD BE EMPLOYED IN INTIMATE CONTINENCE CARE INTERACTIONS WITH OLDER ADULTS

Most continence care for older adults is provided by family caregivers, nurses, and care aides, who often have direct responsibility for helping dependent persons to use the toilet, clean themselves after an episode of UI, and change and dispose of incontinence products. These intimate care encounters take place in a range of different settings, including people's own homes, nursing homes, and hospitals. They typically occur in private and behind closed doors. For a long time, accounts of care work played down the bodily aspects, including practices of continence care, "emphasizing instead, the social, emotional and interpersonal aspects of the body and its decline."[43] Nursing and biomedical literature still remain curiously silent about how to deliver care to clients who may require assistance to perform basic bodily functions. The literature provides no guidance about the psychological aspects of breaching social norms about touch, how to manage embarrassment, and minimize distress, including distressed behavioral responses. Norton, for instance, has claimed that although there are a small number of specialty texts about fecal incontinence, "prominent nursing texts that devote a whole chapter to elimination, give no guidance, other than outlining the practicalities of changing the incontinent person."[44] This is problematic because a lack of guidance for practice can lead to variations in care that are potentially harmful.

Section 4 Summary

- The healthcare team should strive to elicit the patient's own goals for their care, considering their personal context.
- If upon assessment the patient is deemed not capable of making his/her own medical decisions, a substitute decision-maker is required to determine the treatment plan that best aligns with the patient's goals and values. Surrogate decision-makers may require considerable support in making decisions according to the best interests of the care recipient.
- Trustful, open, relationship-centered care provides a means by which older adult's goals of care can be established and well-being maintained.
- Relationship-centered care takes into account the reciprocal relationships of the patients, the substitute decision-maker, and all members of the health care team.

When the person lives with severe cognitive impairment, such as in advanced dementia, caregivers require advanced knowledge and skills to manage the care interaction in ways that minimize the risk of harm and protect the person's dignity. Given the progressive deterioration in cognition, persons with advanced dementia are often not able to interpret bladder and bowel signals or understand the care provided to them. Due to its transgressive nature, intimate continence care is particularly prone to triggering distress and combative behavior.[45–49] Individuals may interpret touch as an unwelcome sexual advance, an assault on their dignity, or a violation of their body,[50] especially if they have experienced abuse earlier in life.[43,51] People living with dementia are also likely to respond badly to rushed continence care. They may resist care, sometimes non-aggressively,[43,52] but often aggressively. In dementia care, both professional nurses and informal caregivers are regularly exposed to physical and verbal violence, where they may be kicked, hit, bitten, and assaulted verbally, racially, or sometimes sexually.[53–56] Carers' or nurses' education tends not to include systematic training of skills in how to respond caringly in situations where they face aggressive behavior, so that they can provide good care while protecting *both* the aggressively behaving client *and* oneself from the physical harm. Yet, many develop such skills and suitable responses on the job.[57] These skills should be mapped in detail and included in training programs. Despite the risk of being harmed whilst providing continence care, family caregivers, nurses, and nursing assistants have little choice but to engage with the person. They cannot withdraw. Indeed, if family carers are unable to grapple with UI, then their caregiving role is likely to be relinquished.[58]

Section 5 Summary

- When cognitive conditions involve aggressive behavior and resistance to intimate continence care practices, both the caregiver and the care recipient are at risk of harm.
- In intimate continence care for older adults with cognitive impairment, caregivers require advanced knowledge and skills to manage the care interaction in ways that minimize the risk of harm to both the carer and to the care recipient, while also protecting the person's dignity and providing good continence care.
- There is a lack in guidance for practicing communication and interaction with older adults with neurodegenerative conditions. This can lead to variation in care.

The care must be provided, since not doing so would result in neglect of the person's care needs and could result in an uncontrolled, uncontained UI, which in turn could undermine personal dignity, or lead to incontinence-associated dermatitis, and thereby to physical harm. It is in situations like these, caregivers need advanced communication skills, including the ability to adopt both verbal and non-verbal communication. Research on nursing practices has identified several strategies that nurses employ in such circumstances.[59] Vaittinen, for instance, has mapped techniques of "caring self-protection." These are three-pronged practical skills, which caregivers can employ to [1] "protect themselves from the physical violence" of care recipients who behave aggressively, while [2] "simultaneously ensuring they do not hurt them, and that [3] good care is provided regardless of the violent situation."[57] Based on Vaittinen's pilot study, a guideline for these skills can be found in Box 1. To promote ethical practices of intimate continence care for patients who respond behaviorally, there is a need to: (i) acknowledge the inherent complexities of providing this type of care, and (ii) systematically study the often unappreciated skills of "caring self-protection," so they can be systematically mapped, and included in carers' professional training.

6 | TREATMENT SHOULD BE ALIGNED WITH GOALS OF CARE

It is increasingly important that healthcare and treatment decisions be aligned with the patient's goals of care with input from the healthcare professional and the caregivers, where appropriate. Goals of care should be patient-centered, respectful, and culturally competent. Treatment selection should similarly be patient-centered and aligned with the patient's goals of care, with special considerations given to remaining life expectancy, the risk/benefit of the proposed treatment (or lack thereof), and impact on quality of life. Beneficence must always be at the forefront of any discussion safeguarding the patient and always first do no harm.

6.1 | Life expectancy and risk/benefit of intervention

Consideration of remaining life expectancy and how this affects medical decision-making and management is an important component of an ethical discussion between the

Box 1 **Techniques of caring self-protection to minimize distress, combative behavior, and harm during continence care interactions (following Vaittinen 2020)**

- When caring for a client known for aggressive behavior, prepare yourself for the situation in advance. This may mean managing your fears, so the client does not sense your anxiety.
- Seek to understand the lived reality that the *client* occupies: what do they sense in the situation of care, and why? Adjust your verbal and non-verbal communication as well as the care practices to meet *that* reality.
- Account for the entire sensual experience of the situation from the viewpoint of the care recipient: Does the room echo, can something be done about the acoustics? Do reflections from the mirror appear threatening, can they be covered? Is the room cold, or too warm? Would music or singing help to calm down this person? Can something be done about the smells, or "taste" of the situation (e.g., putting a piece of chocolate in the client's mouth)? Pay attention to how the client senses your touch. For example, an intricate modification in the position of your thumb may change the touch on the care recipient's shoulder from threatening to caring: the thumb evenly pressed next to the other fingers may feel gentle, whereas if the thumb is separated from the other fingers it may feel as if someone is grabbing the shoulder in a threatening manner.
- Work in pairs where necessary, but provide the main responsibility for speaking to one carer only. This provides the care recipient space to participate in the interaction, rather than just being worked upon by a team of people. When issues in personal chemistry occur between the carers and the care recipient, changing the carer in the lead may tame aggressions before or once they erupt.
- Consider, what kind of verbal and non-verbal communication best suits the personality of the client in situations of aggression: is it jokes and humor for this person, or rather more professional biomedical language? Or perhaps just stepping back, silently, while letting them get their aggression out? Adjust your tone of voice and speed of speech to the resident's personality: this is particularly important, when they no longer understand the words being spoken. If the client has no words to express their frustration, you may try and verbalize their anxiety, while giving it adequate time to develop—and pass.
- Pay attention to how the client senses your presence. For example, standing next to (and above) the person sitting on the toilet may appear dominant, whereas squatting so the carer's face is on an even level with that of the care recipient, may appear friendly.
- Use clothing to innovatively: If the client is likely to scratch the carers, you may cover their hands with soft mittens. Or, if the care recipient is very reserved, it may help to partly cover them with towels while showering, so the person does not feel naked and exposed.

healthcare professional and the patient, their family, and/or their caregivers.[60] The intervention may likely be altered based on an individual's life expectancy and individuals may choose to undergo less aggressive treatments for their UI.

Patients and their family/caregivers must be fully informed of the risks and benefits of each treatment option and on how they may either improve or possibly impair their quality of life. All aspects should be examined when assessing the risks and benefits of any proposed plan of action, including that of no intervention. Preservation of the patient's autonomy and ethical right to veracity are important aspects of the open communication process of any informed consent as it relates to treatment planning. Older adults may be at greater risk for treatment-related adverse events, such as more frequent drug-related side effects than in younger people (i.e., dry mouth, constipation, and cognitive side effects associated with antimuscarinics; headache, elevated blood pressure, and elevated heart rate associated with beta-3 agonists). For surgical procedures, compared to younger adults, older adults experience higher rates of postoperative complications, longer hospital stays, and a greater likelihood of discharge to institutional facilities rather than to home.[61]

6.2 | Consideration of comorbidities and treatment guidelines

Many other conditions and medications affect urinary function and continence. Urinary function in neurodegenerative conditions, such as Alzheimer's Disease, Multiple Sclerosis, and Parkinson's Disease, are often associated with UI. It is important to consider that a treatment or intervention for UI in the present time may not be as effective in the future if/when the underlying neurodegenerative or other comorbid condition worsens. In these situations, discussion of the invasiveness and/or time commitment required for the intervention is important. Patient-centered goals of care should be repeatedly discussed and updated often.[62]

While clinical guidelines are often helpful, they may be inappropriate for some older adults due to their comorbidities, goals of care, or social circumstances. For example, the American Urological Association (AUA) and the Society of Urodynamics, Female Pelvic Medicine, and Urogenital Reconstruction (SUFU) have published guidelines for the diagnosis and treatment of non-neurogenic overactive bladder. Per these guidelines, individuals are instructed to try treatments for their overactive bladder in sequential order, starting with behavioral therapies, then pharmacologic management, followed by neurostimulation (both sacral and percutaneous) and onabotulinumtoxinA.[63] However, this "one size fits all" model may be inappropriate for use in all older adults due to various special considerations such as frailty, functional and cognitive impairment, coexisting multimorbidity and polypharmacy, and estrogen deficiency.[64]

6.3 | Considerations around testing and evaluation

Ethical use of testing and evaluation in the older population should also be based on goals of care and a shared decision-making process. Overutilization of diagnostic testing and overdiagnosis should be avoided. Favorable risk-benefit analysis and fiduciary responsibility should play a role in the use of diagnostic testing and investigation of older (and all) adults. There should always be a clear clinical question for the use of invasive testing that is aligned with the patient's goals of care. Over-testing and overdiagnosis may lead to anxiety, patient discomfort, and wasted resources, potentially causing harm or burden to the patient.[65]

7 | THE HEALTHCARE TEAM SHOULD CONSIDER THE POTENTIAL BURDEN OF THE TREATMENT THAT THEY RECOMMEND IN THE SETTING OF MULTIMORBIDITY, FRAILTY, PHYSICAL, AND COGNITIVE IMPAIRMENTS

Within the traditional ethical principles of medicine, "first do no harm" holds special significance for many older adults due to the presence of vulnerabilities related to frailty, physical and cognitive impairments. The older adult population requires a thoughtful and holistic approach to the evaluation and management of problems such as UI. In this context, one of the greatest barriers to providing ethically appropriate care to older adults is ageism.

Ageism is defined as "stereotyping, prejudice, or discrimination against individuals on the basis of their age."[66] Recent studies suggest that ageism is becoming more prevalent in medicine and in society in general.[67,68] It is clear that such a pervasive and deep-seated bias will seriously constrain the ability to objectively evaluate and treat older adults. Signs of such inherent bias include disrespect for dignity or autonomy, minimizing the severity of a patient's symptoms, rejecting patient concerns and acting in a patronizing fashion as well as withholding treatments or resources. At its worst, systematic or institutional ageism can result in dehumanization of the affected individuals.[34] Such dehumanization constitutes a form of moral exclusion in which older persons are not afforded the protection of the core bioethical principles leaving them vulnerable to neglect, overt harm, or injustice.[69] It is therefore incumbent upon clinicians responsible for the care of older adults to be sensitive to ageist bias in themselves and others and to recognize the negative attitudes that signal such prejudice.

Section 6 Summary

- While clinical guidelines are often helpful, they may be inappropriate for some older adults due to their comorbidities, goals of care, or social circumstances. Treatment decisions should reflect special considerations of this population.
- Patient-centered goals of care should be repeatedly discussed and updated often and reflect consideration of progressive comorbid conditions.
- Avoid over-testing and overdiagnosis, as these may lead to anxiety, patient discomfort, and wasted resources, potentially causing harm or burden to the patient.
- Beneficence and dignity must always be at the forefront of any discussion safeguarding the patient and to always first do no harm.

There are a number of factors to be considered in shared decision-making that are not so much related to age as they are to a patient's mental and physical capacity. In this context, it is important to recognize the distinction between chronological age and *biological* or *functional* age. Physiological status and mental acuity must be measured by objective means to make an accurate assessment of medical vulnerability.[70] In particular, frailty, the multidimensional syndrome characterized by "decreased homeostatic reserve and [consequent] diminished resistance to stressors due to cumulative declines across multiple physiologic systems that result in vulnerability to adverse outcomes" is increasingly important.[71] Multiple scales measure frailty; the early iterations assess phenotypic frailty[72] or accumulated deficits.[73,74] Later versions, such as the Edmonton Frail Scale[75] and Clinical Frailty Scale[76] are generally easier to apply in routine clinical practice. Although no frailty tools have been developed for predicting outcomes of continence treatments, frailty affects outcomes for many treatments offered to older adults including surgical treatments.[77]

Likewise, cognition is an extremely important factor to consider when evaluating older adults for any medical or surgical therapies. Not only are the cognition screening elements used to evaluate a patient's perioperative risk in all types of surgery,[78] but they also provide diagnostic information and clues to guide management. The recognition of an underlying neurocognitive disorder is key to developing treatment plans for older adults. Impaired cognition predicts a higher risk of delirium with new medications or surgical procedures and relevant decision-making may require a formal surrogate.[79]

Before any clinical encounter with an older adult, practitioners should screen for sensory impairment, particularly in vision and hearing deficits, to ensure that the patient is able to engage in the clinical interaction, this is even more important if cognitive testing is planned. Ensuring that patients are wearing their glasses and hearing aids respects their autonomy and ensures that they are best able to fully participate in decision-making. Healthcare professionals should also consider investing in voice amplifying devices for patients where hearing impairment may affect their participation in the interview and/or cognitive testing.

Appropriate physical, cognitive, and situational assessments and the resultant interventions not only reflect clinicians' professional responsibility to their patients, but also represent an ethical and moral imperative to respect a patient's values and goals of care, and provide the most appropriate, practical, and safe management plans.

There has been a marked rise in the absolute number of older people with multimorbidity.[80] Many medical conditions require a considerable effort in terms of self-management,[81,82] and the average patient spends 86 min per day managing a single condition.[83] Little consideration is given to capacity, ability, or limitations in managing daily care, particularly in the multimorbid patient. Although professionals are often encouraged to understand a patient's perspective, including their values and priorities, the factors underlying these values are poorly understood and often ambiguous, varying with disease diagnosis, the context in which the patient experiences that disease, and the decision at hand.[84] Adding additional workload may lead to diminished self-care, lower adherence to medications, worse treatment outcomes, and additional impairment in quality of life, and even potentially in blame and loss of the therapeutic relationship.

A useful framework when considering these matters in the context of management plans may be that of minimally disruptive medicine (MDM).[85] MDM describes a patient-centered and context-sensitive approach to care that focuses on achieving patient (and here also informed by the care partner) goals for health while imposing the smallest possible treatment burden on their lives. This approach requires a comprehensive view of the context in which the patient exists, and adjusting practice to fit patient needs, expectations, and complicated circumstances. The MDM framework recognizes the pre-existing impact of care upon the patient and care partner and strives to ensure that this is minimized, whilst maximizing healthcare outcomes in accordance with patient/care partner wishes and expectations.

When the burden of caring for any condition outstrips the available capacity to do so, patients may deprioritize care, making treatment failure more likely. This may affect UI more than other conditions, as it is often viewed as "less important" by clinicians and even patients themselves, but which potentially has a greater impact on the quality of daily existence.

To be ethical and effective, the MDM approach must be holistic, sensitive to context, and capable of accounting for and addressing the complex ways in which relevant factors exist and interact: this requires wisdom and empathy on the part of the clinician at multiple levels.

Such an approach may be contrary to modern interventionist medicine,[86] or may fly in the face of fee-for-service based compensation models, but it effectively facilitates legitimate patient partnership and engagement and respects the values and preferences of patients and their care partners. The approach considers ways to acceptably fit health care into patient's lives and achieve the healthcare outcomes that they desire.

The MDM model requires that the care (which is agreed by clinician and patient) is identified and delivered in a timely and safe manner. This approach prioritizes those services which can deliver the most appropriate care, not necessarily the "best" care nor the most invasive. This care requires the participation of a multi-professional team, including the day-to-day caregiver, as noted by the recommendations of the International Consultation.[87] Here, to provide equitable, beneficial care the clinician needs to consider the impact of comorbid conditions which affect the ability of the older adult to successfully toilet and maintain continence, and that also take into account the impact of caring for those conditions when adding in management for UI.

To summarize, when engaging with older adults in shared decision-making around treatment options, it is critical that the assessment and subsequent discussion be based on objective assessment, not merely the patient's age, and take into account the burden of management of other coexisting medical conditions.

8 | CONCLUSIONS

Considering the aging of populations worldwide and the prevalence of UI in older adults, as well as barriers to care including ageism, there is a critical need for defining and promulgating ethical structures to model and guide equitable care for UI globally. This document addresses this imperative by expanding on contemporary ethical frameworks that provide the tools to allow healthcare administrators and medical professionals at all levels to construct and implement beneficent and just policies and protocols governing the care continuum from patient evaluation to treatment to aftercare. These ethical frameworks include the Four Ethical Principles and the Ethics of Care Model, augmented by the philosophies of RCC and MDM, each of which advocates holistic, compassionate, and individualized care that takes into account patient goals of care, thus respecting patient autonomy and preserving patient dignity. Extensive systematic transformation, which is thus being advocated, requires overcoming the inertia that commonly leads to the maintenance of a lower standard of care. This white paper is therefore intended to motivate and enable those who advocate for and effect reform in the delivery of continence care to older adults worldwide.

Section 7 Summary

- Healthcare professionals should be aware of biases related to ageism, which can threaten the dignity and autonomy of certain older individuals.
- Healthcare professionals should be aware that chronological age is a poor predictor of physical and cognitive function, and should consider using objective measures to identify frailty and cognitive impairment.
- Healthcare professionals should take a holistic approach when treating and caring for older adults with urinary incontinence, with a particular emphasis on vulnerabilities such as frailty, impaired cognition, sensory impairment, and multimorbidity.
- Urinary incontinence is seldom the only medical problem that older adults face, therefore, care plans/approaches should be considered using a patient- and context-sensitive model, as exemplified by that of minimally disruptive medicine (MDM).

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

ORCID

Anne M. Suskind https://orcid.org/0000-0002-8437-3861

William Gibson https://orcid.org/0000-0002-3481-6484

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