Feature Article

Reframing continence care in care-dependence

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ABSTRACT

International guidelines promote active investigation and treatment of incontinence; however, these guidelines do not fully accommodate the psychosocial aspects associated with providing continence care, i.e., the caregiving dynamics. The author developed a new framework that aims to support nurses and care workers in their efforts to identify and meet the continence care needs of individuals with complex health conditions who are dependent on another person for assistance to manage incontinence or to maintain continence. The framework is underpinned by two core concepts: ‘dignity’ and ‘care’, and is characterized by a focus on: empathic continence care; personhood in dementia; therapeutic communication; authentic partnership in continence care; acknowledging stigma, social taboos and courtesy stigma; and the need for a foundational continence assessment. This paper describes the Dignity in Continence Care Framework and suggests strategies for its use in the future education of nurses and care workers about continence care.

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Introduction

Nurses and care workers are at the forefront of continence care across all patient groups and in all health and social care settings. The term ‘continence care’ refers to the range of activities that are typically performed by nurses and care workers to assist care dependent individuals to void or defecate, or to maintain continence or manage incontinence. Despite the critical role they play in continence care, the author claims nursing texts give scant attention to incontinence and its management, and existing guidelines are largely written for, and by medical practitioners and do not fully accommodate the psychosocial aspects of the caregiving dynamic.

Within the biomedical literature, urinary incontinence is described as a permanent or reversible symptom/condition caused by physical organic factors such as urological or neurological disorders.1 Loss of bladder or bowel control can occur for many reasons, including intrinsic physiological reasons, as well as socio-cultural or environmental reasons. An ethnographic study conducted in a nursing home attests to the difficulties some nursing home residents experience in their attempts to maintain continence, autonomy and self-care.2 claimed ‘the physical and socio-cultural environment in the nursing home required older residents to overcome greater physical and cognitive challenges to maintain their participation, autonomy, and dignity in toileting, bathing, and dressing than would have been expected had the resident been living at home’ (p. 376).

Guidelines for the management of incontinence in adults emphasize active investigation and treatment of incontinence.3 5 At the same time, it is acknowledged that for certain people, cure (i.e., complete dryness) is unlikely, particularly if they are elderly, frail, institutionalized and have severe cognitive and functional impairment.6 The International Consultation on Incontinence (ICI) guidelines therefore recommend using an ‘alternative paradigm’ to establish goals for the management of incontinence for all ages and all types of urinary incontinence.7

Designed by Fonda and Abrams,6 the ‘alternative paradigm’ identifies four goals of continence care for people with urinary incontinence: (i) independent continence; (ii) controlled incontinence; (iii) contained incontinence, or (iv) incontinence. Independent continence is where a person has never been incontinent or is dry as a result of treatment. Controlled incontinence is dry with an intervention (i.e., medications, behavioral treatments, toileting assistance). Contained incontinence is incontinence that is contained with continence products, and ‘incontinence’ is the least desirable situation whereby incontinence is uncontained and uncontrolled. While the paradigm is an important conceptual tool, the author argues there is a need to equip nurse and care workers with additional information and support to manage the complex...
psychological and sociological aspects of incontinence and care dependence. This information should promote individualized person centered continence care that ensures care dependent people feel safe, respected, and dignified. Specifically, there is a need for equal focus on ‘meeting the goals of care’ and ‘the goals of cure’.

Qualitative research conducted by the author and others indicates nurses and care workers attach very specific meanings to incontinence, which they equate with old age, dependence, and a state of uncleanness and indignity. They act on the basis of this meaning, and therefore invest considerable time and effort in performing carework that centers on cleaning, containing, and concealing incontinence. The author claims that at the heart of their concern is the goal of protecting the care dependent person’s dignity. Not surprisingly, individuals who are care dependent and/or their proxies also place a high value on dignity in continence care. The key dilemma is that nurses’ and care workers’ beliefs about continence care practices that dignify a care dependent person do not necessarily align with those of care dependent person and/or their proxies. This lack of agreement is a source of considerable angst for both parties.

At least three other studies draw attention to divergent views about continence care practices. O’Dell et al. describe a qualitative study in which they sought to understand the views of frail elderly women in residential care related to quality of life, values, and preferences for pelvic floor care. The study was initiated to inform the establishment of a urogynecologic outreach project planned to bring on site care to regional residential facilities. However, interviews with the 25 women who had pelvic floor dysfunction revealed they were resistant to evaluation or interventions, citing risks of discomfort and ineffectiveness. By contrast, they valued comfort, containment, restful sleep, and making do. The findings led to the team abandoning their plans to establish the intervention.

Similar unexpected findings arose in the context of a large survey of 500 nurses, nurse managers and state surveyors in the USA. DuBeau et al. described considerable angst from nurses working in nursing homes after providing them with education about new regulation that emphasized the need for them to assess residents’ incontinence to identify underlying causes, and to select and evaluate treatments, including toileting assistance programs. Indeed, some nurses claimed the new regulations were a ‘violation of residents’ rights’ and that toileting programs and procedures such as pelvic examinations and catheterization for post voiding residual volumes were invasive or intrusive. The researchers noted that some staff were particularly concerned about residents’ dignity.

In the third study, Johnson et al. explored preferences for continence care from groups likely to serve as proxy decision makers for nursing home residents from four long term care facilities and two residential care facilities in Los Angeles. They included 171 family members of incontinent nursing home residents, 66 nursing staff caring for these incontinent residents and 79 older adult residents of care facilities. Each group was asked to indicate their preference between: (i) diapers [continence pads] and indwelling catheters; (ii) diapers and prompted voiding; (iii) diapers and medication; (iv) diapers and electrical stimulation; (v) indwelling catheter and prompted voiding; (vi) indwelling catheter and electrical stimulation; (vii) medication and electrical stimulation. While most respondents indicated a preference for non invasive strategies, such as continence pads and prompted voiding to invasive strategies such as indwelling catheters and electrical stimulation, respondent groups occasionally differed significantly in their preferences. An analysis of open ended responses revealed a preference by older adults for UI treatments that would make them feel dry, be odor free, and simple/easy, not bulky, feel natural, not cause embarrassment, and not result in dependence. Indeed, some family members and older adults considered prompted voiding to be “embarrassing” and were concerned it would foster dependence. By contrast, nurses viewed prompted voiding as “natural” and strongly preferred it to using continence products. Their criteria for choosing a treatment was based on increasing self esteem and avoiding infection.

Notwithstanding differences of options about continence care practices that dignify people who are incontinent or dependent on another person for assistance with bladder and bowel function, the fact that different groups of stakeholders share the goal of dignity is an important finding. The author used this shared understanding to design a new framework that aims to guide continence care for individuals with complex health conditions who are dependent on another person for assistance with bladder and bowel function.

**Aim**

The aim of this paper is to describe the *Dignity in Continence Care Framework*, and to suggest strategies for the future education of nurses and care workers about continence care based on the framework.

**The dignity in continence care framework**

The framework, termed the *Dignity in Continence Care Framework* is underpinned by two core concepts: ‘dignity’ and ‘care’. The framework represents an integration of contemporary biomedical understandings about incontinence with theoretical concepts from the disciplines of nursing, psychology, and sociology. The framework is illustrated in Fig. 1.

**Dignity**

Dignity is the explicit and primary goal of continence care in the *Dignity in Continence Care Framework*. Dignity is a multifaceted and subjective concept. Although the idea of using dignity as a guide to patient care is much contested, it has particular relevance as a guiding concept for continence care for individuals who are care dependent. According to a concept analysis of ‘dignity for older adults,’ “dignity is an inherent characteristic of being human, it can be subjectively felt as an attribute of the self, and is made manifest through behavior that demonstrates respect for self and others. Dignity must be learned, and an individual’s dignity is affected by the treatment received from others.”

The subjectivity of the concept means that practices that dignify one person could represent a violation of dignity to another. For example, people may differ in their opinions about the dignity associated with using pads instead of going to the toilet. Similarly, being assisted to the toilet in a hoist may represent a dignity measure for one person, but not another. Active investigation and interventions that aim to treat incontinence may dignify one person, but violate the dignity of another.

Given this variability, the *Dignity in Continence Care Framework* promotes continence care that is underpinned by the care dependent person’s (or proxy’s) personal beliefs and values about continence care practices that make them feel safe, respected, and dignified. Consistent with this approach, a continence assessment should prompt enquiry about the care dependent person’s (or proxy’s) beliefs, goals and preferences for continence care, and interventions should be based on this information. Moreover, education programs about providing continence care should include reflective discussion about continence care practices that dignify and practices that violate dignity.
The concept of dignity in healthcare is certainly not new. In recent years, governments, professional interest groups, and consumers have taken a greater interest in health care that respects patients’ and residents’ rights to receive timely assistance to use their bladder and bowel in ‘dignified’ ways. For example, campaigns in the UK such as the ‘Dignity in Care’, ‘Behind Closed Doors’ and ‘Do not Forget the Person’, champion patients’ rights to have access to assistance in order to maintain optimal levels of continence. The United Nations described a lack of toilet access in institutional settings such as prisons, detention centers, and psychiatric institutions as a dignity and human rights issue. The concept of dignity can be used to advocate for improved toilet access, including access to timely assistance to go to the toilet.

**Care**

The second central concept in the Dignity in Continence Care Framework is care. While caring is universal, there are nuanced differences in how the concept of caring is understood and applied in nursing and medicine. Caring has a central and demonstrable place in nursing. A review of studies focusing on the concept of caring in nursing reveals over 60 books and thousands of professional articles on the concept of caring in the discipline of nursing. Based on seven such studies, caring in nursing is a content specific interpersonal process which is characterised by the professional knowledge, skills, personal maturity, and interpersonal sensitivity of nurses, which result in the protection, emotional support, and meeting of bio psycho social needs. While caring is also important in medicine, in some medical literature, caring is viewed as problematic in so far as it could distract or mislead from the goal of diagnosis and treatment.

**Adopting an empathic approach**

Empathy is a central characteristic of caring. The Dignity in Continence Care Framework advocates an empathic understanding of the human experience of being incontinent and/or care dependent, and about the human experience of caring for a person with incontinence. Like the term ‘dignity’, the term ‘empathy’ is complex and multidimensional and overlaps conceptually with sympathy, and compassion. Rogers defined empathy as the ability “to perceive the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person” (p. 2). In other words, empathy has a cognitive dimension which allows one to understand another person's inner experience and view the outside world from their perspective, and an affective dimension (compassion) which involves the capacity to enter into and join the feelings of another person. Nurses and care workers have an important role to play in helping people adjust to changes in their bodily function that affect their identity, autonomy, control, and independence. Empathy is required in order to perform this role. Because of the intense emotions surrounding incontinence and care dependence, the author hypothesizes that a lack of empathy could result in a limited capacity to respond effectively and sensitively to a care dependent person's incontinence and may even contribute to a struggle for power and associated distress and combative behaviors.

While there is debate that goes back as far as Plato about whether virtues such as empathy can be learnt, two studies highlight the importance of improving healthcare practitioners’ attitudes and emotions about incontinence in order to improve continence care practices. Henderson and Kashka explored the association between knowledge, attitude, and beliefs about urinary incontinence in 126 nurses. They found a significant relationship between attitude and practice, but not knowledge. Specifically, a more positive attitude toward people with urinary incontinence resulted in more positive practice styles.

Similarly, Karlowicz conducted a pilot study to evaluate the effectiveness of an instrument to measure the impact of an incontinence experiential learning activity. Twenty one senior nursing students were invited to participate in a six hour disability incontinence experiential learning activity where they wore a variety of different disposable incontinence undergarments as part of a rehabilitation nursing course. The researchers reported significant increases in the nursing student's beliefs and attitudes about urinary incontinence, and self reported improvements in their continence care practices following the activity. Thus, the Dignity in Continence Care Framework advocates education for health professionals to develop an empathic understanding about human responses to incontinence and care dependence, and to recognize the effect of these responses on behavior. Ideally, creative teaching strategies should be adopted that target not just knowledge, but also attitudes, beliefs, and emotions.

Simulating the experience of incontinence or listening to a person with incontinence speak about their experience are ways to promote understanding of the range of human responses to
incontinence and care dependence, and to recognize the effect of these responses on the care dependent person, and their own personal responses and behaviors. This understanding may help those involved in care to better understand and respond effectively to a care dependent person’s denial, resistance to care, disengagement, low affect, and attempts to conceal incontinence and self-manage.

Respecting personhood in dementia

The Dignity in Continence Care Framework also advocates care that aims for all people to feel safe and supported. However, achieving this goal of care can be particularly challenging when providing continence care to people who are cognitively impaired. Promoting continence and managing incontinence in people with cognitive impairment can complicated by the progressive loss of their global planning and interpretive skills.25 As the dementia progresses, the person’s efforts to self-manage and thereby conceal incontinence become increasingly difficult. According to a phenomenological study about caregiver coping in dementia:

‘Incontinence within the setting of a dementing illness invariably bears no comparison with that of compos mensis individuals. The nature of “dementia style” incontinence invariably presents as a behavioral problem (the product of a confused mind) that is physically and psychologically draining/demanding on the care giver, especially if other challenging behaviors/attitudes are concurrently present’.25,p.1200

Moreover, as previously indicated, providing continence care to a person who does not understand the nature of the care may trigger distressed behaviors.26,27 There is a gap in existing guidelines and nursing texts about managing the interpersonal aspects of caring for the dementia wanderer, or the concept of ‘a person as an attempt to protect their psychological integrity. While there is a danger that their personhood would be undermined because they would be transformed from a being regarded as a spouse, parent or friend to a “wanderer” or “demented”.

Drawing on the concept of personhood in dementia, the Dignity in Continence Care Framework advocates continence care that is based on a deep respect for the person with a diagnosis of dementia, and to interpret the behaviors of a cognitively impaired person as an attempt to protect their psychological integrity. While there is no known research about the subjective experiences of being cognitively impaired and incontinence or dependent on another person for help with bladder and bowel function, it is highly likely that distressed behaviors during continence care are valid attempts to communicate an unmet need, or to maintain autonomy and privacy. Skilled nurses and care workers advocate getting to “know” the person with dementia, and understanding their idiosyncratic values, beliefs, behaviors and preferences. They also describe being vigilant, and anticipating the cognitively impaired person’s continence care needs. They also use highly developed communication skills in their efforts to ensure the person with dementia feels safe during intimate care. The Dignity in Continence Care Framework promotes education that equips nurses and care workers with the knowledge and skill to provide continence care in a way that acknowledges personhood in dementia.

Communicating therapeutically

The Dignity in Continence Care Framework additionally champions therapeutic communication that aims to build the care dependent person’s resilience, and enhance their physiological and psychological wellbeing. Addressing the continence care needs of another person in a holistic manner requires not only scientific knowledge, such as knowledge of the etiology of incontinence; it also requires the application of highly developed interpersonal and therapeutic communication skills to manage the interpersonal encounter in ways that protect the person’s integrity. Incontinence is a highly stigmatized condition that elicits profound emotions.31 The term ‘stigma’ refers to the attribution of deeply discrediting traits to a person. It was first described by the French sociologist Durkheim,12 and more recently, by the renowned sociologist, Goffman.33 Goffman described stigma as “a process by which the reaction of others spoils normal identity”. Stigma is “characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgment about a person or group ... based on an enduring feature of identity attributable to a health problem”....34,p.4

Loss of bladder or bowel control or loss of autonomy affects a person’s intrinsic sense of self causing a sense of shame and humiliation.35 Individuals with incontinence typically adopt several strategies to conceal their incontinence to manage the stigma associated with incontinence and to avoid compromising their competence in the eyes of others.39-41 Common human responses include: denial, resistance to care, disengagement, low affect, and attempts to conceal incontinence and self-manage. Garcia et al42 hypothesized that stigmatized individuals defended themselves against possible rejection, by withdrawing from the situation, being more vigilant, and, if possible, concealing the stigma. Existing guidelines and nursing texts do not support nurses and care workers in their efforts to help care dependent people adjust to changes in their bodily function that affect their identity, autonomy, control, and independence.

Well intentioned efforts to protect a care dependent person’s feelings by normalizing incontinence may inadvertently convey the impression that their incontinence is insignificant. Similarly, at times to confront a cognitively impaired person with the reality of their incontinence may cause unnecessary distress, and be counterproductive. Communicating therapeutically about incontinence with any person, including people with dementia, involves the demonstration of warmth, compassion and humanity. Humor may also play a role in the interpersonal encounter. If used appropriately, humor can help preserve dignity, even in undignified circumstances and can acknowledge the person and his or her family as individuals’.31,p.40 Future education programs about providing continence care for care dependent people should include role plays that equip students with the knowledge and skills to communicate therapeutically.

Promoting authentic partnership centered continence care

The Dignity in Continence Care Framework also advocates a partnership centered approach to continence care for care dependent people. Partnership centered care acknowledges the interdependencies and reciprocities inherent in caregiving and care receiving, and calls for a relationship of mutual respect, trust and collaboration between the care dependent person, their families, and care staff.44 Although nurses and care workers indicate a high level of support for family involvement in a care dependent person’s continence care, they may differ in their understandings about how best to operationalize this involvement. Education is
required to support their efforts to promote an authentic caregiving partnership approach to continence care, and involve family members in ways that align with their expectations. This education should include reflective exercises that encourage nurses and care workers to examine their own personal beliefs and assumptions about family members’ involvement.

Acknowledging stigma, social taboos, and courtesy stigma

While the Dignity in Continence Care Framework calls for education to promote an empathetic understanding of the personal experience of being incontinent and/or care dependent, it also recognizes the need for an empathetic understanding of the human experience of caring for a person with incontinence. This is because incontinence not only elicits deep seated emotions in the person with the symptom; it is also likely to affect the behavior and responses of others, including the behavior and responses of nurses and care workers. For example, Garcia et al. theorized that non stigmatized individuals engage in considerable emotional labor so that they are not seen by other people as prejudiced toward the person with the stigmatized condition (i.e. incontinence). The researchers contended that the emotional suppression of feelings such as disgust cannot be sustained in an ongoing manner. Hence, on both sides, the stigma cycle creates a lack of safety and trust.

Providing intimate hands on care that includes touching, seeing, and smelling unpleasant body products can however, be extremely difficult for caregivers and care recipients alike. At the same time, some nurses and care workers reject having any negative emotions such as a sense of disgust, and consider it a mark of competence to distance themselves from incontinent and/or care dependent person. According to Upton and Reed whose phenomenological study of spousal caregivers found incontinence not only elicits strong emotions in the person with incontinence, it also recognizes the need for an empathetic understanding of the human experience of caring for a person with incontinence. This is because incontinence not only elicits deep seated emotions in the person with the symptom; it is also likely to affect the behavior and responses of others, including the behavior and responses of nurses and care workers. For example, Garcia et al. theorized that non stigmatized individuals engage in considerable emotional labor so that they are not seen by other people as prejudiced toward the person with the stigmatized condition (i.e. incontinence). The researchers contended that the emotional suppression of feelings such as disgust cannot be sustained in an ongoing manner. Hence, on both sides, the stigma cycle creates a lack of safety and trust.

Conducting a foundational continence assessment

A core feature of the Dignity in Continence Care Framework is the promotion of a foundational continence assessment that can be completed by frontline nurses and care workers. This level of assessment precedes the ICI initial assessment. Notwithstanding the need for patients to be medically assessed, the majority of people who provide day to day continence care do not have the medical training to undertake the level of assessment promoted by existing guidelines. For example, the ICI promotes assessment to identify and manage co existing co morbid conditions which are known to have an impact on continence status or the ability to successfully toileting. It identifies multiple factors that should be assessed, including factors both intrinsic and extrinsic to the lower urinary tract and gastrointestinal tract. The ICI also promotes an initial continence assessment followed by a specialized level of assessment. Both levels of assessment rely on clinicians with advanced clinical knowledge and the associated ability to clinically diagnose the type of incontinence, identify contributing medical causes, prescribe and monitor pharmacological therapy, and determine the person’s suitability for surgery.

While arguably nurses and care workers require education that is informed by biomedical understandings about incontinence, including education about the anatomy and physiology of incontinence, assessment and diagnosis, risk factors, goal setting, prevention and treatment; the goal of a foundational continence assessment is to help those involved in caring for care dependent older people to identify:

- The levels of support the care dependent person requires for optimal continence or to manage incontinence, that is congruent with their (or their proxy’s) preferences, goals for care, and beliefs about dignity
- Bladder and bowel signs and symptoms that warrant further attention
- Socio cultural and environmental factors that contribute to incontinence
- Targeted and individualized continence care

Thus, the Dignity in Continence Care Framework promotes a comprehensive continence assessment that has an equal focus on meeting the goals of cure and the goals of care. Education programs about incontinence are required to equip nurses and care workers with the knowledge and skills to conduct a foundational continence assessment. In order to identify and act
upon bladder and bowel signs and symptoms that warrant further attention, this education should address normal and abnormal bladder/bowel function. Arguably, this education should also address methods to non intrusively collect information about the frequency and severity of a care dependent person’s bladder and bowel symptoms. Consistent with this education, is the need to support nurses and care workers to develop individualized strategies to optimize the care dependent person’s rest/sleep in the context of the person’s concurrent need for continence and skin care. In addition, given the influence of socio-cultural and environmental factors on incontinence, education should also include information about ways to create a social and physical environment that optimizes the person’s autonomy and continence.

Dignity in continence care educational learning outcomes

The intended learning outcomes of an education program based on the Dignity in Continence Care Framework are as follows:

1. To develop an empathic understanding about the range of human emotional responses to incontinence and care dependence, and to recognize the effect of these responses on behaviors.
2. To discuss practices that dignify a care dependent person with continence care needs.
3. To describe a person centered approach to continence care for cognitively impaired care dependent individuals.
4. To demonstrate therapeutic communication strategies that build a care dependent person’s resilience, and promotes their physiological and psychological wellbeing.
5. To describe strategies that promote a partnership centered approach to continence care that affirms the relationship between a care dependent person and their family.
6. To conduct a foundational continence assessment.
7. To describe practices that represent targeted and individualized partnership centered continence care.

Applying the framework to practice

The applicability of the Dignity in Continence Care Framework is in its potential to provide direction and support to nurses and care workers who are directly involved in providing continence care, and to managers and nurse educators who are responsible for ensuring quality nursing care for people who are care dependent. Conventional wisdom connects the quality of continence care, and quality patient outcomes to the quality of the healthcare employee’s knowledge and skill. To apply the framework to practice involves developing an education program that starts with a focus on the human experience of being incontinent, and then progresses in a non judgmental manner to explore and challenge beliefs about continence care practices they believe represent dignified care. The concepts of person and partnership centered continence care should be introduced. The education program should provide nurses and care workers with the knowledge and skills to communicate therapeutically and manage the interpersonal dynamics of the caregiving encounter in ways that build the care dependent person’s resilience, and promotes their physiological and psychological wellbeing. While there are several methods to teach therapeutic communication skills, role playing is one such method. The theoretical framework can also be used to inform education about conducting a foundational continence assessment, that in turn, informs targeted and individualized continence care.

Conclusion

Incontinence is an increasingly prevalent problem for adults, and its impacts are widespread. Within research, policy and practice settings, there is considerable debate about the most appropriate goals of care for care dependent people with incontinence, particularly if they are elderly and require nursing home care. The Dignity in Continence Care Framework presented in this article stems from the author’s qualitative research that explicates tacit social beliefs and values about incontinence in old age and associated human cognitive and behavioral responses. It builds on a large body of biomedical, nursing, psychological and sociological research about incontinence, dignity and care. This new conceptual approach to continence care for care dependent individuals is important and timely as it coincides with the challenge to develop national and international policies and strategies to respond to the increasingly complex care needs and expectations of older citizens who will require skilled nursing care.

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